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EHDI - LONDON

DIFFICULT CONVERSATIONS: DELIVERING NEWS, CHALLENGING FALSE IDEAS,

AND CONVEYING HARD-TO-DIGEST INFORMATION

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>> For folks sitting in the back, there is still space available up at these front tables. Please join us. And if you read the description of this workshop, you know it is participatory, and we will be engaging, so we hope that you will do that. Several spaces up here. A couple in the middle tables. Please join us.

>> I'm Jane Dwyer, the room monitor for Difficult Conversations. So if the room is too hot, the room is too cold, if you're Goldilocks, let me know and we'll adjust and I will let the presenters introduce themselves.

>> Good morning and welcome! There's more room up front. If you just snuck in, come up here, there's another space up here.

We are really lucky to have a full room today. So we're thrilled about that. Thank you for coming and dedicating your morning to learning about Difficult Conversations.

Let me just tell you a little why we're doing the talk.

Last year at EHDI I did a presentation and number of people came up and said, I really have this questions, how do we talk to patients about this? Or how do we inform families about this?

And after that conversation, after the conference, we pulled together these lovely young ladies and said, I think we need to have a panel or workshop about Difficult Conversations. We're in them often.

As a psychologist, I think... or I thought... you know, I've had a few difficult conversations in my time. I know something about this. But really for this presentation we pulled from the literature and looking at difficult conversations in a number of ways that I hope will be interesting and intriguing for you.

So let's tell you who we are.

So I am Dr. Amy Szarkowski. I'm a psychologist. I work with deaf and hard of hearing children and families and have been doing that for a number of years. I spent some time at Boston Children's Hospital, and more recently have moved to the Children's Center for Communication at the Beverly School for the Deaf. I have a faculty position at Harvard Medical School in the Department of Psychiatry, and I'm involved in training medical emerging healthcare providers around working with individuals with disabilities, part of that including difficult conversations. And bringing some awareness about deaf‑related topics to professionals who are interested in disabilities in general.

And that's a little about me.

>> [ off microphone ]... my name is Jennifer Clark.

Really grateful to be here and thank you for all...

>> NICOLE HUTCHINSON: I'm Nicole Hutchinson and I work in Washington, D.C. and I run the financial program there and am administrator.

>> [ off microphone ]

>> AMY SZARKOWSKI: So all of these young ladies have had opportunities to have difficult conversations. We're going to share some of our own experience, we're going to do role plays in front of you, engaging you in some other activities. We hope this will keep it fun.

We're not getting paid to be here and none of us makes profit and we're not going to try to sell you anything. That's our disclosures.

We do want to find out a little about who you are. We're not going to have 100 people introduce themselves. That takes a little bit of time. At your table you have small cards. On the slide it says "index cards," but where you'll actually find the index cards are on my desk at home, the ones I purchased to be here, so instead you have pieces of paper. We would like each person to write your name, your professional identification. So that could be teacher of the deaf, speech language pathologist, pediatrician, whatever the case might be. Your role as it relates to EHDI. And your conversational style.

Are you a ‑‑ somebody who has to talk things out? A visual learner? Somebody who needs examples? Are you somebody who likes to tell stories? That kind of thing.

And then put number one, number two, number three, favorite dessert, favorite vacation spot, and the hardest part of your job.

Be kind to the people around you, if you don't have a pen and you don't mind sharing, pass it along.

There are pens in the back as well.

Look! Our IT guy is really helpful. He's got some. If you need some, grab a pen from back there.

So, if it's hard to see, I'll reiterate, we want your name, professional identification, what is your role related to EHDI, conversational style, how do you like to converse, how do you like to learn. Number one... favorite dessert.

Two... favorite vacation spot.

Three... hardest part of your job.

Feel free to leave off names. You don't have to put your boss down there. We're talking about generalities here.

Okay. I would like you to pick three people at your table or within your row and share the first four things. Your name, professional identification, world of EHDI, and your conversational style. Talk amongst yourself with three or four people and then we'll move on.

If you need an interpreter, please raise your hand. We have them. They can spread out.

Two... three...

>> If you need assistance, some sign language interpretation, we have three formal interpreters and a couple folks that can help to facilitate communication if it's needed.

>> Don't tell us all of your ones, twos, and threes. Don't tell us all of your ones, twos and threes.

>> AMY SZARKOWSKI: Don't tell us your ones, twos, threes. Make sure you stop here. We're doing name, professional identity, role, and conversation. We're stopping here.

Stop.

>> AMY SZARKOWSKI: Okay, wrapping up...

>> AMY SZARKOWSKI: Okay. Imagine I'm flashing the lights. Flashing lights. We can't, actually, this room doesn't allow. Okay...

Thank you for engaging. That was a test to see how good of a listener/rule follower you are... (chuckling).

We will have opportunities to move around to different tables and share number one, two and three with various people. So it wasn't a waste of time to write that down.

Okay.

Overview of the workshop. Here is what we're going to talk about. A little bit of the rationale. We'll share ideas, we'll be demonstrating strategies. We're going to talk about the limitations just in case you thought you were going to come and get the right answers, we're going the to lower your expectations a little bit. We're going to provide opportunities for people to engage and ask questions and really truly audience participation is expected. You can't learn about conversations without having some, right? So that will be our set‑up for today.

To re‑emphasize that, take a read here.

You laugh, but here is the thing... we often try to get away from difficult conversations. They start to happen and we retreat. So part of our strategy today is to think about how we manage that in a way that is a little bit different.

So Nicole, because she has the best handwriting, has been nominated by our group to be the writer. And at this point we do want to ask, what is one thing that you really would like to gain from this workshop? We're going to keep track of these and make sure we try our best to address them.

So, because we don't have a pass‑around mic, we have one with a cord, it takes a while to get there. If you would like to raise your hand and offer a response, we can make sure we repeat it so it gets on CART and everybody has access to that.

You can be the runner, but how about I also repeat so everybody has access.

So, please raise your hand and share with us one thing you would like to gain from today's workshop. You gave $50 to be here, and you're committing three hours of your time, so there must be something you're hoping to learn. What is it?

In the back...

She is running... I like this... (chuckling).

>> Maximum amount of handouts, websites, stuff to give them they can take home for the 90% of information that I forgot that I told them.

>> AMY SZARKOWSKI: Perfect. Okay. Other hands up?

Keep them raised until we get there. Yes, over here...

>> Helping families move through the process smoothly. You know, at times we have families who just ‑‑ they seem non‑compliant, but I think they have other things happening in their lives that need to be addressed before they can even accept a diagnosis of hearing loss. And so... that would be helpful.

>> AMY SZARKOWSKI: I think intending to how we engage with families, thinking differently about "non‑compliance" and taking into consideration some of the special factors will all hopefully be addressed today.

>> We have a large international population that is growing in Seattle, so conversations with parents who don't speak English as their first language and being able to break down really high level concepts to attainable knowledge.

>> AMY SZARKOWSKI: Great. Up here in front...

>> I'm looking forward to actually two things. One is how to get rid of myths, help people overcome myths. And the other one is help people accept at the beginning their denial, how do we accept.

>> AMY SZARKOWSKI: Okay.

>> We pride ourselves on presenting unbiased information to families, but then sometimes you walk in... I don't know, how to discuss with families when they've been given really biased information, and without ‑‑ while still remaining neutral or still trying to meet their needs. If that makes sense

>> AMY SZARKOWSKI: Without telling them, how biased was that information you've been given! Oh, my goodness!

Over here...

>> Supporting families as they enter the process of transition, if they enter a school system that is making a decision for them and how to get ready for that without it being a battle, but it may be made for them based on where they live.

>> AMY SZARKOWSKI: Yep.

>> Sometimes I know more about the family than they know because I have access to prior medical testing and records, and so sometimes when I'm calling to encourage them to have follow up, they don't need that they needed follow up, so how to introduce this new shocking information that is scary to them and share things that I am not medically trained to ‑‑ that information to give.

>> AMY SZARKOWSKI: Right. Good.

See how good her handwriting is! She was destined to be a teacher. Yes, in the back...

>> AUDIENCE MEMBER: I think the balance between listening to where families are at and calling them to, like, the challenge and to be present for what they can do for their kids.

>> AMY SZARKOWSKI: Yeah. Let's just take a one‑minute break and move things around. We have another chair that has been added up here.

But get your hand ready if you want to be the next person called on (chuckling).

There's one more chair over here.

Did I mention how excited we are that people came to our workshop?

Sometimes you offer these and you think, I hope someone signs up.

Okay... any other thoughts you want to get on board? One thing you want to make sure is addressed today?

We will be using several scenarios as I mentioned, as examples, and some match very well on to this. I also do want you to think slightly, like at the next level, of sometimes scenarios can be a little bit different. But really the content and the ideas behind how we engage in those conversations might be similar.

So while we might not have exactly the same scenarios, we do cover many of them, but also how can you take sort of lessons learned and apply it to the situation that you're thinking of.

Whether you raised your hand and offered an example, or if you're thinking about one, hold on to that. Because as we go through this morning we want to see how well we can apply what we have learned to that particular scenario.

Yes?

>> AUDIENCE MEMBER: One difficulty of conversation ‑‑ difficult conversations is even though ‑‑ how do we include the Deaf community from the very beginning.

>> AMY SZARKOWSKI: Okay. Great.

So, what does the literature say about difficult conversations? So let me tell you what I did. I looked at literature in the field of bioethics. I looked in a field of medicine and delivery of news, oncology, unsurprisingly, has sort of the best models out there.

But it's striking when you've looked at research how are medical professionals taught to deliver bad news, in fact, many of them are not.

In a study from six years ago ‑‑ we did six years ago, training may have changed since then, but in the study from six years ago, more than 60% of physicians reported they had never had formal training on how to deliver bad news.

Which given what their job is is a little bit surprising, right?

So there is an emerging sort of look at this difficult conversations in the field of education, in the fields of medicine, bioethics. So we're drawing on all of those. Also cognitive neuroscience, because that's my bailiwick.

And I like it. So in every talk you hear me, I'll say something about the brain, if even if it's about difficult conversations.

So big takeaways that will be reiterated through the morning. Emotions, theirs, meaning the family's, the patient's, the child's, and ours, influence these interactions in a really big way.

Realness matters. When we talk about difficult conversations, I'm not kidding when I say I'm not going to give you the right answers, because it has to come from you. There are certain ways we can strategize and we know lead to better outcomes in terms of families accepting news, for example, but when you are delivering that news or sharing that news or guiding a process, your realness matters significantly and how well families and those we interact with will receive that news.

So what you say is far less important than how you say it.

Here is another situation where we need a runner. Who wants to be the runner?

Shannon is our runner. What are difficult conversations? What might they look like? Sometimes it's like opening a can of worms. As soon as I put this out there, so who knows where it's going to go.

Sometimes there's a fear of saying too much. How does the family already know and where are my bounds about what I can say?

Sometimes we're providing conflicting information, and, in fact, I would say in our field that might be true more often than we want to admit, that we might be correcting mission information that has been given to others.

Sometimes conversations are planned, so you go into it thinking, this is going to be tough, I'm going to have to tell the family that they thought the child only has hearing loss. Turns out the child has this other condition. That can be planned.

Sometimes it's really not planned where the family takes you by surprise.

They can involve large groups or single people. They can involve people of your same ‑‑ who communicate in the same way as you or who communicate differently. They could be people of the same sort of background or somebody whose background is quite different than yours.

All of these conversations are influenced by perceptions and misperceptions.

Any other generalities you can think about, what do hard conversations look like?

So here we're not talking about specific examples but just talking about what are these things that tie difficult conversations together?

Our writer and our reader are ready. Any other thoughts?

>> AUDIENCE MEMBER: Difficult conversations are usually around investments in the conversation.

>> AMY SZARKOWSKI: Yes, high emotions involved.

Other commonalities among difficult conversations.

>> AUDIENCE MEMBER: I don't mean this in a bad way, but time‑consuming.

>> AMY SZARKOWSKI: Yes, definitely time‑consuming. And the comment here upfront was difficult for who? Like what are we ‑‑ who is it difficult for? Is it difficult for the family or is it difficult for us because we're anxious or worried about it?

Yes?

>> AUDIENCE MEMBER: I would add that rarely are difficult conversations about what is actually happening in the moment only. Like most often difficult conversations are difficult because we're reacting to stories that we've heard or experiences that we've had or experience with societal and institutional issues instead of just what is in front of us.

>> AMY SZARKOWSKI: Perfect. Yes, right up here up front.

>> AUDIENCE MEMBER: Difficult conversations often have unequal representation. And the lack of specific stakeholders represented within the conversation, and that causes a power imbalance or inequality.

>> AMY SZARKOWSKI: I don't want examples right now because we don't want to get specific. We're thinking in terms of generalities. Like what are the common things, if we're thinking approaching or engaging in difficult conversation, what are the big overarching things that can really impact those? Yes?

>> AUDIENCE MEMBER: Facing denial.

>> AMY SZARKOWSKI: Facing denial.

>> AUDIENCE MEMBER: Working with families who are trying to minimize the impact of the diagnosis in their heads.

>> AMY SZARKOWSKI: Yep. Great. Let's do two more. One here and one over there.

>> AUDIENCE MEMBER: Having different cultural perspectives, a different culture you're working with.

>> AMY SZARKOWSKI: Absolutely.

>> AUDIENCE MEMBER: Same. We have another endorsement over there, similar response.

>> AMY SZARKOWSKI: Thank you for that.

So I'll take that one.

It's not really often about what we say. We mentioned that before. In fact, families rarely remember the specific words used. But they can very often tell you, the person told us about our child's hearing loss, his or her name, this was the situation, they were wearing this, here is how it made me feel. But when you ask what was said, sometimes that can be lost. You know this. If you've delivered difficult news, once there is emotion involved and there's that feeling of dread or worry, that a person's ability to process the information that is shared is minimized, right?

So, we need to make sure that those conversations feel okay to the people we're engaging in conversation with. Because the feeling is what they're going to remember.

So, what are the things that impact the perceived ability to communicate information? This is a study that includes some folks listed below there, they're actually from Boston Children's, and they have an Institute for Professional Communication and they do interesting work and studies and research about the ways in which information is delivered.

What influences how people take in or react to difficult conversations, regardless of news shared? Here is the thing... whether I'm telling you, guess what, you have a rash, you're going to need some antibiotics, or guess what... you have a terminal illness and this is really serious, the actual information conveyed ‑‑ so separated from the news delivered, there are commonalities in the way people respond to given news that they would rather not have.

When you communicate and connect with family and they feel that, and we see increases in family satisfaction, so even if I'm delivering the bad news, when I've connected with a person first and they feel they can trust me and that realness factor is there, they feel more satisfied with that interaction.

They show greater understanding, even when it's highly emotionally charged they show more understanding. They're better able to allow the cognitive space to take in information when they feel that they have connected with the person who is giving that information. That's a big deal. One of the people in the back said we give this information and the families don't remember 90% of it. It can be true. Also can be true how much families can retain when we build the connection first.

When families have difficult conversations with people who they feel connected to they talk about feeling able to adjust better and, in fact, they do. Some studies have followed family adjustment to diagnosis. And it is significantly smoother and reported by families to be better when that connection is there with the person giving them the news.

They also rate their quality of care better. So if that's something that your system or your program or your hospital or clinic cares about, that when the people in those difficult conversations connect with folks, they report, you know, this was better. I understand it better. And they have better outcomes.

So, consider the role that you play in difficult conversations. So here is where I put it on you. Because, if we think about the examples... you know, we want to help the families to overcome myths. We want to support families with the tradition. We want to support families from where they are. Your examples, we're focused on them, not on you. Right?

So part of this engaging and difficult conversations is saying "what's my role"?

In fact, you have a big role, and the intersectionality of all the parts of who you are that comprise your make‑up matter. Some of them you can do something about. Some of them you can't. But recognizing what you bring to the table is an important piece.

So, the comment was made about differential power. That's a real thing. The more that you can make people that power differential is decreased while still maintaining a sense of I kind of do know what I'm talk about, that will make them feel more comfortable.

You maybe can't change your ethnic background or your gender or some of those things, but you can be aware of that and how that impacts people.

So, think about these influences, what you bring to the table, and you actually bring them to every single encounter.

It might be the case that you're a pediatric audiologist, so you're used to giving this spiel and you're a specialist and you know what do in the first two sessions, but every family is going to have a different takeaway, even if the information you give is pretty much the same, based on who they are and how that intersects and combines with who you are and what you bring to that table.

So, I would like you to speak to the person or two people next to you. No more than groups of three, because we don't have a ton of time. We're not going to go around the entire table. Share what your origin story is. You can decide what this is. Which of these in your situation are most relevant?

It might be that for some people, sexuality doesn't come up. It might be for somebody working in an LGBTQ+ clinic, that is going to be primary. Can you identify with me?

So the relative value, given to any of these particular factors just will depend on where you are in context.

But... in a paragraph, how do you describe your origin story? What are the factors that you bring to the table that you interact with with most families?

Raise your hand if you need an interpreter or we have communication facilitators who are not formal interpreters, but they can help facilitate the conversation because it's brief, okay?

Any questions?

Okay. If you would like an interpreter or communication facilitator, please raise your hand. You're going to share your origin story with maybe two people at your table.

Okay?

Go!

>> AMY SZARKOWSKI: Okay, one minute.

One minute warning.

>> AMY SZARKOWSKI: Let's bring it back to the center.

>> AMY SZARKOWSKI: All right. So, we can think about... first of all, anything stand out from your origin stories that you would like to share, that either yourself or somebody at your table that you thought "ah, that's really interesting"?

Way in the back.

>> Meet halfway...

[chuckles]

>> AMY SZARKOWSKI: This is like the Price is Right. I came on down!

>> AUDIENCE MEMBER: So I think what we were talking about, Jane and I, to start off with... and I say this to my families, hearing loss and deafness has always been part of my life. This career and doing this was my choice. It's not their choice.

And I think that's a really big piece that, you know, I can go in on a first visit and I can be very happy and very excited and see lots of positives. And I look up and that's not what I see on Mom or Dad, and even now I'm seeing, as an early intervention teacher, more grandparents, raising grandchildren. And so, again, that kind of adds another level of challenge, because that grandma is grieving, going through that process, for not only, you know, the child, but for her daughter or her son.

So, the difficult conversations become more and more difficult.

>> AMY SZARKOWSKI: You raise a good point. I don't think they become easier, I think we can become better at them, but they continue to involve a change, so that makes us stay on our toes as professionals, right?

Other thoughts?

Way up in front... Emily?

>> AUDIENCE MEMBER: I'm a speech and language pathologist and so first of all, when you had the thing about the enter... and also the grandmother of a grandson with unilateral hearing loss, he's just three, so I go in there as the education, and when you just said "the grieving grandmother," that's absolutely right. I feel the guilt, I'm supposed to know something about this, although I didn't ‑‑ my path was different. I didn't work with hearing impaired kids. So it's just... it's difficult for me to just be the grandma. I don't want to be the therapist. But to my daughter... and I also have to say this my son‑in‑law, after Luca was born, he said to my daughter, "Janet, it's your fault Luca has a hearing impairment."

>> AMY SZARKOWSKI: I bet that might have led to a difficult conversation too.

Any other folks from the gallery that wish to share?

>> AUDIENCE MEMBER: I like that comment about how we go into the home we're often happy but the parents are in a different place. I think that's a chance for us to take pause and not have a conversation. Maybe that's us led as much as it is parent‑led and just listening or asking questions and creating that connection and that bond that they know that it's a safe place to have questions and concerns and to share feelings and emotions that we're not really there with information because they're not going to receive it that day anyway.

When you have an ongoing relationship, you have that opportunity. And I think for some of our audiologists or medical professionals, they see these families and have to get all that information out at once. So we really do have an advantage as early interventionists to have an ongoing relationship with families and allow that time for just listening.

>> AMY SZARKOWSKI: Okay, let's do two more. Back there...

>> AUDIENCE MEMBER: Several of us at this table are involved in Hands & Voices as well as I'm an audiologist, and we were talking about difficult conversations not just with families but with other professionals, particularly with Hands & Voices and us trying to be helpful and gain information to families early on, but not making other professionals upset, or there being different camps in your state that believe this bias and that bias. And so there's a lot of difficult conversations that maybe are not emotional but they're very difficult because you don't want to burn any bridges.

>> AMY SZARKOWSKI: Yes, that's a great point. And we're invested in the ‑‑ where we put our stake, right? When you stake your claim and say, this is what I believe or think, then you become more invested in that, and the more you've dug in your heels, it can be harder to say, I'm willing to see another viewpoint or I'm really willing to say, perhaps, maybe, I'm not exactly 100% right.

Okay.

>> AUDIENCE MEMBER: I think my perspective on the timeline and the speed that families move through their journey is really different. Like I have a lot more respect for ‑‑ it's going to be different for every family and be okay with that and not having that urgency as a pediatric audiologist to get it going right now.

>> AMY SZARKOWSKI: Competing demands, right? There is an urgency, and we know about brain development, and less of an urgency if you say, if I just dump it on the family they're not going to get it anyway. But expectations from a program or hospital may say this is what I need to accomplish. I can accomplish that with this family, but this family, they're in a different place. So sometimes that difficult conversation can also be between you and your supervisors or clinic directors where you say, this is what the family needs. And it doesn't exactly fit the mold that our program has established.

So, when we think about the origin story, we're going to talk about this question in particular, but what do you do if you were me?

There was a comment earlier about the power differential in deaf and hard of hearing individuals. I would say that there are some situations in which a deaf person might feel like there's a power differential ‑‑ I'm not the one with the most power.

You might encounter a family, though. Let's say you are the deaf mentor and they say, what would you do? You may have an out‑sized power potential that you might not know you have. They look to you and say, you are a successful Deaf adult. Wow! That's important. A good thing to have. But the power available there too is important. Think about your origin story and how does it influence the following questions? How does it influence me? That's a question a lot of families ask. But the ways you respond will very much depend on your origin story and having that straight. Why should I listen to you? That might be a response. Why should I listen to you? You came into my home and telling me this stuff and I don't want to hear it... why should I listen to you?

The way you tell your story might influence the way they respond that question.

Do your suggestions make sense for me and my family or is it what you prescribe to everybody who is on your caseload? Have you ever worked with a family from the Philippines like me and my family?

Something like that.

From your position of privilege, given that you're the professional in the situation, can you understand where I or my family member is coming from? How do you explain that to families? How do you say, based on my origin story, here is what I do understand and here is what the limits of my knowledge are? Both of those matter. When you both establish yourself as somebody who knows something and you establish and convey that there are limits to what I know, you build trust.

You don't have to be and you should not try to be the person who knows everything. Because they will see through that. Go back to the idea of realness being a major factor how families respond to you. Say here is what I know, here are what my limits are, I will work with you to figure out what other questions you have.

Being a means... what?

Being a female means I respond in this situation. Being a male means what? How do all of the parts of that intersectionality influence what it is that you bring to the table? I think it can be very powerful to have a conversation with families about that.

It's not a hidden ‑‑ it shouldn't be your hidden agenda. Right?

We're coming in to go through session number one in what is prescribed in our program, but, in fact, laying the groundwork for, here is who I am. Let's find out more about who you are.

Managing emotions. How do clinicians and frontline service providers feel during difficult conversations? Looks like there's been research in this area. And here is what people have found.

Anxiety. Sadness. Empathy. Frustration. Insecurity. Those are the themes most prevalent in studies that looked at frontline service providers across a whole bunch of studies. This is a meta‑review that looked at those and said, these are things people feel.

Anxiety and empathy lead the way. Both of those can be good and bad. So, we think of anxiety generally as being bad, right?

Who wants to feel anxiety? Who likes feeling anxious? Anyone?

No!

Why can anxiety be good?

Runner?

How can anxiety be good?

>> AUDIENCE MEMBER: You can create opportunities for urgency but not panic.

>> AMY SZARKOWSKI: I like that. That's a good differential. Urgency but not panic. Good.

>> AUDIENCE MEMBER: It's anticipatory. It can help improve preparedness.

>> AMY SZARKOWSKI: You can be more prepared if you're anxious. If you're going to wing it in a presentation, if you do work in advance, it probably will come together a little bit better.

>> AUDIENCE MEMBER: I think that for me anxiety can be a cue to myself to kind of raise some self‑awareness. Because usually I really care about and am invested in things that make me anxious and also can serve as a way for me to stop and reflect and ask myself, why am I anxious about this? And prepare that way mentally.

>> AMY SZARKOWSKI: Perfect. Both of those, the literature bears out. The idea of making yourself stop ‑‑ the things you do to make yourself less anxious are actually really good for you. And then it helps you take inventory on... does your anxiety tell you, I'm not as prepared as I need to be, I need to do something differently? And it can let you know what matters to you. You know, you might be not typically anxious, but in this particular time you're more so, so why is it this one feels bigger or more important?

Great. Any other thoughts on anxiety and why it's good?

The psychologist in me will tell you if you don't have enough anxiety in your performance, there's an optimal match. It's an inverted U‑shaped curve. The increase in anxiety at some point increases your ability to perform. When you're over‑anxious, your performance also goes down. But that's a pretty well‑known psychological factor you need sufficient anxiety in order to make yourself really engage in that process. So don't feel like you're bad or not good at what you do if you're feeling anxious going into these situations. That is a normal part of this process.

Why can empathy be bad?

Seems like empathy is a good thing, right? We kind of are connecting with families. Why is empathy sometimes bad?

He thinks he's done (chuckling)...

That's sweet.

[chuckles]

>> AUDIENCE MEMBER: Maybe we could keep the microphone...

>> AMY SZARKOWSKI: That's a good idea.

Yeah. Okay.

Thank you. Good feedback.

>> There's a mic right behind you.

>> AUDIENCE MEMBER: Sometimes too much empathy can skew the results of the conversation too and it might be more... [ [ off microphone ]...

>> AMY SZARKOWSKI: Great.

Any other thoughts why it can be negative?

We have another comment up here.

>> AUDIENCE MEMBER: Empathy in the room, you get stuck in that dialogue. Sometimes it doesn't change. It doesn't perceive, there's no progression.

>> AMY SZARKOWSKI: Uh‑huh. We have one more in the back and then you two in front.

>> AUDIENCE MEMBER: So thinking when you're away from that conversation, if you have too much empathy, it takes over and you get too emotionally invested and it takes over your mental health if you're too emotionally invested as a professional working with a family, their story.

>> AMY SZARKOWSKI: Right. Yeah.

>> AUDIENCE MEMBER: [ off microphone ]... empathy, personal involvement, if you want to stay in a situation, for example, the conversation may not go well. You project your own story, your own feelings, you own the story on the family, and so it's not going well.

And I just want to make sure everybody in the room hears that... you know, avoid sharing personal stories. Sometimes, you know, once in a while, they can be important, but in general, the family will feel that your story supersedes theirs and they're not... if you're trying to save the conversation about a difficult issue, for example, you might want to start by saying "other children"... or "other people have experience..." and they feel lost in the shuffle.

>> AMY SZARKOWSKI: Great. Tommy.

>> AUDIENCE MEMBER: So I think for some people they have anxiety often prevents them to be defensive and prevents their understanding of other people's situation, because they need to be understood first in a conversation. And a lack of anxiety or empathy right now, you know, I'm not feeling it right now. We're talking about my baby, this baby, not other people's children.

So if you can raise the anxiety, then discussing other topics.

>> AMY SZARKOWSKI: Great. Thank you all for sharing.

So you have some really good insights into that. People, when they have been surveyed, for example, at the beginning, they think that anxiety is bad and empathy is good in terms of these interactions. But both have this differential impact. And I think it's important to be aware of.

So how do we manage emotions as the clinicians? Again, we're on the you side.

I will point out in the examples some shared, it's interactions with families. We're quick to talk about difficult conversations with respect to how they're going to respond to us. But really being cognizant of, how do we manage our emotions?

So in studies that have looked at how do clinicians do this... so this is clinicians and frontline workers, including people like nurses and social workers and folks like that, we do these things, before, during and after conversations, we prepare. So self‑care. Taking some breaths. We prepare and think about relational things. Some people anticipate what a person will say or we might rehearse something. We try to have an empathetic response, in their shoes, imagining a family's journey. How on a team do we want to make sure we're on the same page? How are we sharing information?

The commonly endorsed thing is identity, we separate emotions and leave problems at work.

That's good in some ways. And not so good in others.

What can happen is that you can feel empathy and then you say, I can't handle this, it's overwhelming, and I stop feeling empathic, right?

So both anxiety and empathy, being the highly endorsed emotions that people feel, can lead to burnout.

When we are not managing those emotions well, again, this is on the "you" side, the "us" side. If we're not doing that we have increased wellbeing, decreased job satisfaction and increased burnout in health‑related occupations is high.

Burnout in EI, also high. Turnover... big problem, right?

Believing that one cannot control one's emotions leads to these things. Reduced self‑esteem, satisfaction with life. Not just job. Life.

Increased depression. And stress.

I would argue that by preparing ourselves for difficult conversations, given how important they are in the work that we all collectively do, we can be taking much better care of ourselves by doing so.

So take a moment, reflect on your ability to manage emotions. Just remember, this is the self‑reflection. Looking at yourself. How do you do this?

And recall a time when your emotions got in the way.

Is this easy for you? Does it just pop up fast?

Question?

>> AUDIENCE MEMBER: [ off microphone ]... Sometimes professionals forget that they're human too. And when they're not able to... when their emotions are crossing the line, they don't have the opportunity, they don't feel they're allowed to cross a line, so they don't call a time‑out and ask for another person to come in and switch places. That's a possibility. You don't have to be the only person all the time. Sometimes you can take a time‑out, if you're overly involved in something emotionally.

Sometimes if there's a balance that is off, you can take a switch to try to equalize that gender discrepancy. Or if there are cultural differences involved, you know, a variety of situations you can... it's not always emotional. We're here for the family, not for ourselves.

>> AMY SZARKOWSKI: Stepping back, because I would argue we have to take care of ourselves or we can't be there for the familiar. So that part matters. Here at this part of the presentation, I'm asking you to focus on you. So can you think of a situation ‑‑ does it pop in your mind where you lost control of your emotions or your emotions got the better of you and you think, I didn't do what I needed to do with that particular family, or I really lost it... you know, I got so frustrated, but I had all this other stuff I was thinking of and it impacted the care I was able to provide. I'm not going to ask you to share these but I'm asking you to reflect and be honest with yourself and say, has that happened?

Have you felt your emotions, either too much anxiety, over‑emphasizing, or any of those in between, have you felt them impact your work?

Raise your hand if you have had that experience.

Okay. In these difficult conversations, continue to reflect on both what you bring to the table and the conversation and the situation in place, okay?

That's our challenge for you.

All right. Because the impact of a caring professional is enormous. Families report their connection with early intervention provider, their connection with the person who‑the SLP who came to their home, those are hugely instrumental in forming the trajectory of the life of this family.

So having a good caring person who can be there and provide the right supports really matters.

We are going to ask for a volunteer who is willing to come up and read and be a participant in this given scenario with Cailin.

It's scripted. You just are to read and act.

>> It's moms, so males in the room, you're off the hook.

You don't have to be a mom, but in the scenario you do. There's a lot of you. Come on, guys!

Anybody?

Thank you very much!

>> AMY SZARKOWSKI: Yay! Volunteers!

So, let's have you move so they can see the scenario.

>> I want to preface this by saying that in real‑life I like to be seated with the family in this scenario, but for the viewing purposes, you are all looking at us standing. What is your name

>> Allison

>> I'm Cailin.

>> Nice to meet you.

>> Thank you for being willing to help me.

All righty.

Mom, you and Cleo did a great job today. We're all finished with the testing. I'm going to go through all the different parts that we completed today and I want you to stop me if you have any questions, okay?

>> Okay.

>> So like I said earlier, the first test we did tells me his ears are nice and healthy on both sides. No evidence of fluid or congestion today, that's positive. The second test is a screening tool that tells me about his inner ear's functioning on both sides. It's kind of like a screening tool.

He didn't pass that screening for either of his ears today. And then the last test I was doing, that measures his brain's response to the sounds while he's sleeping shows me that Cleo has a severe sensorineural hearing loss hearing loss in both ears today

He has a hearing loss? Is that permanent? Are you sure

>> Yes, a severe hearing loss in both ears. The hearing loss is permanent. All the test results today are consistent and show me a severe hearing loss in both ears.

>> How did this happen? Nobody else in our family has hearing loss

>> It's hard to say where the hearing loss is coming from, but we're going to work together and try to figure out more information about what is going on.

She's crying...

[ sniffles ]

>> I know this isn't what you expected today. Tell me what is making you upset.

>> It doesn't make sense. I just want him to be able to hear.

>> I know. I understand and I want you to know that we're going to figure all of this out together. I don't want you to worry. I'm on your team.

He is still the perfect baby you came in here with today. We just know something a little different about him today.

>> Okay.

>> Over the next couple months we're going to work together and try to get more information. But in the meantime, I don't want you to do anything different at home. I want you to keep singing to him, keep talking to him, all of that is super‑important. He knows that you're his mom. He feels you, he knows that you're there, and it's really, really important that you keep doing all of those things.

I want to come up with a plan. This is really overwhelming. And it's a lot of information. So I want you to stop me at any point if you have any questions and if I'm giving you too much information, tell me to stop, okay?

We definitely want to come up with some type of plan. Sometimes people want all of the information today, right now, and sometimes they don't. So like I said, stop me if you have any questions, okay?

>> Okay.

>> I'm happy to give you and Cleo some time together if you want a couple minutes, or no rush, we have plenty of time today. Do you want a couple minutes with just minimum and I'll come back in a few?

>> No, that's okay. I'm ready.

>> So, again, it's a lot of information. I'm going to give you lots of handouts and papers that will highlight the important stuff. Stop me with any questions.

>> Okay.

>> So, first, we always like to confirm a hearing loss diagnosis. I'm really confident what we got today that he has hearing loss in both ears, but we always like to do this test one more time in a couple of weeks just to check and make sure that nothing has changed, nothing has gotten better or worse. We like to confirm everything, okay?

>> Uh‑huh.

>> And then we also have an ear, nose and throat specialist on our team. She specializes in children with permanent hearing loss and I think it would be a good opportunity for you to meet her and try to get more information from her to try to investigate where the hearing loss is coming from.

>> It took two hours to get here today. I work full time. I don't know how I'm going to make time for all of these follow‑up appointments.

>> I completely understand. I'm going to do everything I can to coordinate those appointments force you. We can definitely try to reschedule the repeat of this hearing test and the ear, nose and throat visit on the same day. Would that make things easier?

>> That would be helpful.

>> Okay. Have you gone back to work yet? We can try to figure it out ‑‑ we can try to come up with a time with your maternity leave that you can come back.

>> I actually go back in another six weeks.

>> Okay. That sounds great. I'm going to go ahead and look at the schedule before you leave today. I definitely think that we could schedule both of those things on the same day in the next couple weeks before you have to go to work.

>> That would work best for me. Thank you.

>> Tell me how you're feeling. I know it's a lot of information to digest.

>> I don't know. It is. It's just a lot. I want him to be able to hear me and I don't understand how I'm going to be able to do this or help him. Does this mean he's completely deaf? Like, what do I do?

>> Cleo is not completely deaf. There are different levels of hearing loss. Children who are completely deaf have a profound hearing loss. Cleo has a severe hearing loss, meaning that his hearing is greatly reduced compared to normal, but he's not completely deaf.

>> So what am I supposed to do? Is he ever going to hear my voice?

>> Cleo will likely benefit from wearing hearing aids. Are you familiar with hearing aids at all?

>> Not really. I mean, I know older people use them sometimes, but I don't know anyone who has them. I mean, isn't he too young for hearing aids?

>> We can fit hearing aids on babies Cleo's size and we do it often. A lot of time babies who have a severe hearing loss in both ears and wear hearing aids are able to listen and able to talk. They're able to hear.

>> Can he even wear hearing aids at this age?

>> He can definitely wear hearing aids at this age.

>> And with hearing aids, he'll learn to talk?

>> That's definitely the goal with hearing aids. With use of hearing aids and speech and language services, many children who have a severe hearing loss are able to learn to listen and learn to talk.

>> When would we need to get the hearing aids?

>> The earlier the children with hearing loss get hearing aids and get fit with them, the better. But usually we confirm these results and then we kind of start that hearing aid process in a couple of weeks.

>> Okay.

>> Can I share something personal with you today? Is that okay?

>> Yeah, that would be great.

>> I have a hearing loss in both ears and I wear hearing aids.

>> You do!?

>> Yeah. I got the hearing aids when I was a kid and I've worn them every day since. I became an audiologist because I wanted to be able to help families and help kids like Cleo just like I was helped by my audiologist when I was little.

>> I didn't even notice you had them.

>> Most people don't notice. And they have been just a huge part of my life and my journey, becoming an audiologist. And I just want you to know that I understand you. I understand your baby. And I'm going to be on your team and help you every step of the way.

>> That makes me feel better. Thank you.

>> What other supports do you have in your family? Do you have other family that lives close to you? I know you said it took you two hours to get here today, and that's a long drive. Who lives close to you? What other supports do you have?

>> My sister and parents live close by. My parents take care of my daughter, or take care of my son, too, once I go back to work

>> Would it be possible for any of them to come to any of the follow‑up appointments with you?

>> I could probably get one of my parents to come. And my sister has Mondays, she's off on Mondays, so she can maybe come with us on those days too

>> Okay. I think that would be a really good idea. It's a long drive and a lot of information for you to digest on your own. I think having additional people with you would be really, really helpful.

I'm going to give you all of my contact information today. This is a ton of information. And they are going to have a lot of questions. And it's not your job to answer all of their question. That's my job. So you are going to call me. They are going to call me. Email me with any questions. And I'm going to answer them. You don't have to do that, okay?

>> Okay. I know my parents and sister will have a lot of questions. Hearing loss isn't generally accepted in our culture. We have a really big family and we're all together often. I don't think many of them will even believe that he has a hearing loss or will believe that he would need hearing aids.

>> So, tell me more about that. Do you think that's going to impact your ability to use hearing aids with Cleo?

>> I'll do whatever I need to help my baby, but I'm worried about how my extended family will react and if they'll learn to accept him

>> I think for right now we should focus on getting him set up with all the right people and figuring out what his needs are going to be. This who process is brand‑new for you, but I know that eventually you're going to be the expert on everything that he needs on his hearing and everything he needs to be able to listen and talk, which is your goal. I think that in time you'll be able to explain and share everything with your extended family and hopefully that will help them become more accepting of Cleo's hearing loss.

>> They're all just so excited about him and I just want them to love him and accept him.

>> I think Cleo will be able to teach everyone in your family a lot of important things. I know this is unexpected, but it doesn't have to be bad news. I can definitely help with explaining it to family members and making sure everyone is on the same page. Like I said before, it's my job to answer these questions, not yours. So you're going to call me and email lots and lots in the next couple weeks.

>> Thank you so much.

>> I promise this whole process gets easier and I know for a fact that you are exactly what Cleo needs. He's going to get all the support that he needs and he is very, very lucky to have you as his mom.

>> Thank you. I'm okay. I'm really sad, but we'll just see what happens.

>> I know this isn't what you were expecting today, but I promise, like I said, I'm going to be with you every step of the way and we're going to figure out together. I'm going to call your pediatrician today, if that's okay, and give them the results of the testing. Is that okay?

>> Yeah, that would be fine.

>> Okay. What other questions do you have?

>> I don't think I have any right now, but I'm sure I'll have a lot in the future.

>> Like I said you're going to call me, I'm going to call you in a couple days and follow up on everything and if anybody is in the home with you that we can chat, I'm happy to do that. Right now let's walk up together and get Cleo strapped into his seat and upfront and figure out a time you can come back and see me and the ENT and we'll go from there. Does that sound okay?

>> Sounds great. Thank you so much.

>> Thank you.

>> AMY SZARKOWSKI: Okay. So just some things within this delivering diagnostic information. Some takeaway points. So you probably heard me highlight bad news versus unexpected difference. For parents this is absolutely bad news. Maybe it is, maybe it isn't for some families. Depends on the family you're working with. As an audiologist, for me it's a difference. I have to give this news often. And it's hard every single time, but trying to differentiate that for the families, that bad news, trying to reframe them. Establishing yourself as an expert making yourself relatable. I struggle with this as a young professional. People say, I don't believe you. Or they're coming for a second opinion and they see me and they're like, you're too young to be delivering this news to me. I get that often. So trying to establish yourself as the person that is confident in those results can be a challenge.

And, again, it's something I often deal with, some other people may have that experience as well.

And then embracing the difference in culture and trying to look at that with respect.

It can be hard to role play that scenario because there is lots of different pieces of culture that are just in the room with you and the patient or the family or in the home with you and the patient and family, but just identifying those differences, and allowing them to be present in a space can make a huge difference within delivering that news and allowing a family the space to bring that into them and their child. You may or may not experience that as your culture or identify with that culture, but that doesn't mean that it's not an opportunity for you to receive that information and help that family in that regard.

Thank you. Thank you very much for your participation. I appreciate you.

>> AMY SZARKOWSKI: Thank you. Didn't they do a lovely job? Cailin has a nice manner about her and her way of conveying information. We just want to hit on these take‑homes. So this is sort of analyzing that scenario using the literature in this area.

So the gentle art of delivering bad news, that idea of bad news versus unexpected news.

In this room we review reduced hearing as a positive. It's exciting. You know, a new path, a new journey. We see it differently than some families might at least initially how you frame that conversation, again, influences other families' perceptions, the ways in which you might let them know, this isn't what you expected. And even if this scenario, I saw when Cailin did that, the Mom nodded her head. It isn't our history, so we didn't expect this. Leaving that in the conversation is one takeaway.

Okay, here is, from the literature, they talked about using this pneumonic of SPIKES. This is a good way of conveying information.

Setting. Deliver the news in a quiet, private setting. In the hallway, sometimes people want to nab you and they want you to tell them right now, making sure the setting is conducive to that conversation.

Perception. Finding out, what does the family understand about a given situation is another thing to think about. This scenario was about delivering audiological news, but it can be other things. What is the family's understanding? You talked about the importance of getting a family where they're at. Part is helping to ask questions related to that.

The eye from spikes is an invitation.

Ask permission to share information. Cailin did that. Is it okay if we go ahead with this? And gave family the option of saying "nope, I'm done." Or I need five minutes with my baby to process this. It's a scenario and we didn't want to waste five minutes on the stage, we didn't do that. But asking permission to share information gives power to the person who is receiving it. They can also tell you, give me the basics. Or, tell me worst case scenario first. And then I can go up from there.

Or they can say, I can only handle, like, one thing. Don't tell me the whole story. What is the next step? Don't tell me the whole trajectory.

Family... when you ask for the invitation to share information, you're sharing your power. It's a very strong thing to do in that relationship. And families tend to generally appreciate it.

Knowledge. Provide knowledge in a simple and straightforward way. You have to not exert yourself as the professional in the information that you convey.

It might be the case that you do, as Cailin has to say, yes, I'm old enough on the audiologist. I really am!

[chuckles]

But you don't need to convey knowledge to show that off. Meeting the family in reasonable chunks in ways they can process the information.

Show empathy. Not over‑empathizing, but appropriately acknowledge and responding to emotions and saying things like "It looks like this is hard."

Not assuming that it will be hard for every family because we don't know how they react.

And decisions and what are the next steps.

So this is not only for delivering audiological information, but spikes has been shown across a number of kinds of literature to be a very effective way of giving information.

Any thoughts or questions?

Good?

Okay.

Addressing this idea. I am an expert. Really! Really! I am an expert!

Certainly we've been there. I think it does matter sometimes. When I first started in my job, there was the doctors and Amy. Because Szarkowski is hard to say and hard to spell.

But what that did is set the dynamic in the room that the other individuals seem to have more positional power than did I.

So there were certain situations where I was sort of bigger about that. I'm Dr.  ‑‑ you can call me Dr. Amy. It doesn't have to be Szarkowski, but some context I need to convey I know something about this. But by and large, you establish credibility not by the initials after your name or the title before it but through your credibility and your competence, by really being somebody who knows stuff, by your care, and then your ability to follow through. That is how people establish whether you're an expert or not.

When we sort of see ourselves as the persons who are helping caregivers and families to establish competence we see better improved outcomes.

You know this scenario. The family comes in, you tell them what to do, they don't do it, the child doesn't have the outcomes you want. Rather, when you say "you will become the expert on what your child needs," families appreciate that, and the literature suggests that families then take ownership of needing to become the expert.

The longer that you maintain your position of expertise, the less likely families are to see themselves in that role.

So one of the things that happened in this scenario where Cailin said, you will become the expert. I know this is new now, but I'll share what you know and you're going to be the expert on Cleo. That's the important piece.

We can do hard things. We can.

Second scenario.

So we have a request for the interpreter ‑‑ we have a request for the interpreter to stand next to the person they are interpreting. Yep, we're going to have them come here, so you can see the facial expressions of the person who is acting.

>> Thanks for coming in.

>> Thanks for meeting me today. You know, I really appreciate your time. As the consultant in the situation, I always like to meet with you first, kind of, like, go over the joint planning tool. Just take time.

[ off microphone ]

>> Hold on. We're having issues. Can we...

>> Can you cover the projector...

>> CART...

>> Oops. Sorry.

>> Comes from years of experience.

>> Can you still see the CART/captioning?

>> Thank you. Is that better?

>> Thank you.

>> Hi, Jen. Thank you so much for coming. Good to see you.

>> Thank you! I appreciate you allowing me some time today as the consultant in these situations. I feel like I can get a better idea of how to support you and support the family if you can just kind of give me some background on what is happening with the family, we can go through the joint planning tool together, so that we're on the same page, you know, going into the family's home.

>> Great. So thankful you with here as the specialist in deaf and hard of hearing. I'm seeing the family but I don't have that specialized knowledge. So I really appreciate your time.

So, with this family, we're getting ready for the transition to preschool. We started talking about that. There's still a little time before the meeting is going to happen, but it kind of... [ microphone interference ]... we're struggling to keep the hearing aids on and they kind of seem like they want to wait and see. They're not working on the strategies I'm giving them through the week, so I'm worried about the progress, specifically on the language scores, because we're doing some testing, but the family is more concerned with social development. They want him to have friends and make sure he's adjusted, but not really language, that's kind of what I'm concerned about.

>> Got it. So can you tell me, what have you tried so far?

>> We've given them some of the handouts I had and papers we've given them, resources and that kind of thing, but it doesn't seem to be working with this family.

>> Got it. So we're trying to tie in, you know, what we know in terms of the scores, what the family really sees as their priorities and their values and kind of put it into a nice package to help deliver the child to school.

>> Right.

>> Okay. So tell me a little bit about the adult learning style. Do they like paper? Do they like videos? Do they like talking things out? Do they want you to draw pictures? Tell me about him.

>> Well... [ off microphone ]... I don't think the handouts are a good idea. Dad sits on his phone most of the time, so I wonder if there's technology we could utilize that is a better fit for this family

>> Are they millennials?

>> Absolutely.

>> Okay, yeah, I would just ‑‑ just a guess, you know.

[chuckles]

So here is what I'm thinking. Let me know if it works for you.

Okay, so the Center on Developing Child, it's through Harvard University, they have some nice short videos. So hopefully we can capture Dad's attention for two short minutes, sit down and all of us watch the video together. Maybe Mom... I don't know her adult learning style, but maybe if she likes handouts, I also like the ones from Supporting Success for Children with Hearing loss. They have good ones on brain development. The video in mind specifically is the one on brain architecture. So if we can sit down, learn a little bit about the brain and kind of... I know we feel an urgency, we feel like this neurological development urgency! We need to, like, get them to understand it.

So, watching the video together, kind of talking through it, answering any questions they might have, and then tying that to how, you know, this window of opportunity that we have before he goes to school. It's really kind of nearing the end of our time with him and also just the window of opportunity in general.

So, in terms of his brain development, you know, because the pruning process for the brain is going to be really impacting him. So therefore, you know, in terms of his brain development, how is that going to impact him socially? And because of the language, right? Like you need language to be able to make friends and be able to relate. So we need to be able to convey that. So hopefully we can have a conversation to work through that with him.

>> That video sounds great

>> How do you want to do it? Do you want me to take the lead? Do you want to start the session? Tell me about that

>> I think since you're familiar with the video, I think you could lead through the dis, but if you could be there to watch the video and be part of the discussion, so when you leave, next week if the family has questions, I know where to look for the answers.

>> That sounds good. Thanks again for your time. I will see you there

>> I will send you what we did last week or last month so you have that for information.

>> Good. One thing, can you send me their most recent audiological.

>> Absolutely.

>> Perfect. Thanks.

>> Cool.

>> AMY SZARKOWSKI: So some takeaways from that session... where am I standing so I'm not in the way?

Sorry.

Collaboration. In this field we all come from very different backgrounds and different experiences. So collaborating in that scenario. I was an interventionist seeing the family every week. Jen was consulting with the specialized knowledge. We also want to make sure that consultants or people coming in on a less frequent basis have current information.

So using that joint planning before we're in the home so that when we're in the home we can really maximize the time with the family.

>> So in order to best meet the family where they're at, you need to identify what is important to them. So this particular family was really important to them that their child made friends. So how can I take the information that we have and tie that to what is important to them? In order to get our message across and also be able to answer their questions and feel like they have a plan that they can move forward in helping their child.

>> The last takeaway on this one was adult learning style. We all learn differently. We know our families learn differently this family, Dad did not want handouts. I had a family last week that told me they wanted the handouts. Understanding that and having a variety of resources we can use and provide that, but we have to ask. We have to ask that question. And sometimes the family doesn't know right away, so maybe it has to be revisited later. And maybe it changes.

>> Good job.

There's a lot of talk up there about family‑centered care and I think sometimes we think, well, that means we put the family at the center. What does that really mean? All of these things. This is formal definition of family‑centered care adopted by the American Academy of Pediatrics.

Exploring disease and illness. Understanding the whole person and their context. That's in part what this scenario is really emphasizing.

Developing a therapeutic alliance with patients and their significant others. And sharing power in decision making.

Those are all parts of what we should be doing to provide family‑centered care. I would argue that even in a lot of our ideas around the difficulties we have, it's about exploring the illness and ‑‑ I'm using illness not because I think deafness is illness. I'm using it in the definition of family‑centered care. We're often talking about hearing loss or reduced hearing. What does that mean? But we don't always do the latter three of those pillars of family‑centered care. And I think that that might behoove us to make sure we're doing that well.

When we talk a little bit about family values, how do you know what family's values are? This is a strategy used by and large in social work but increasingly in early intervention. The idea of eco‑maps. If you Google eco‑maps you can find examples out there, printable ones that are free. The structure of an eco‑map puts the family at the center and looks at all of the things that might be contributing to how the family is perceiving them and I think when you have a structure in front of you, it allows you to ask questions in a way that you couldn't otherwise.

If you just say to a parent, "What are your values"? Well, what do you mean? Do I go to church or not? It's going to lead a certain direction. When you have something that is structured, people can put it on the paper and it actually allows people to free themselves to talk more openly.

So things like social services, how do you feel about them?

Let's say you work with a family who is an immigrant family whose immigrant status is questionable. They might say, that terrifies me. Any recommendation that is you give me to go and visit social services is going to put me off.

If you establish at the beginning, that helps to guide your treatment plan, right? If you establish that what really matters to me is extended family, because I live in this area of town where people from my culture all gather and being able to share news about reduced hearing to those individuals is as important as sharing it with my spouse. You're going to learn a lot by putting it on paper, finding a way to focus on that. So we recommend the eco‑map. And there's literature around that. So check it out.

Learning styles. You have heard it ‑‑ we asked you to write down your learning style. It came up in this scenario as well. One of the reasons for that is if you don't match with the family's learning style is, you will be less successful. And there isn't a good or a bad learning style. Sometimes we default to saying, that family is highly educated. This family doesn't seem to value education. So we do that, which is a little bit judgmental. We can instead say, "These particular parents are really hands‑on, and when we model it for them, they're engaged and that's the way they learn best." That should shape how we deliver services. The cold style inventory. Very easy. One of reasons I like this one is it does not seem to be highly valued laden. There are strengths within any of those styles, but, again, tons of free resources about learning styles out there. You can engage families with that conversation. And it really helps them to feel like, oh, you're trying to personalize this. Right?

If I told you I need to see it and then you come the next time with video links and we look at them together, they will feel that you're invested in them, and buy‑in will increase, satisfaction with your services increases and their ability to follow through increases.

So, let's reflect for a minute, how similar is this to what you do or how different? I think we don't have... I want to keep it moving. So I don't think we want to spend a ton of time, but let's reflect and maybe share with the person sitting next to you, are these things that you do or are these different or how might you incorporate one of the strategies that we talked about so far?

So just take three minutes to talk with somebody sitting near you.

And raise your hand if you need an interpreter.

>> AMY SZARKOWSKI: Last minute.

Last minute. We're wrapping up.

>> AMY SZARKOWSKI: All right, come on back.

Okay. I promise we are going to give you a break in a few more slides. I just checked to make sure. Hold on... we know it's a long time to sit.

The question: What would you do if you were me?

Research has looked at this, because it's asked so often, right? What would you do if you were me? One thing to think about is that there are three general purposes behind that question.

One is requesting medical procedural advice. What would you ‑‑ what really should I do?

What is the next step for me in terms of the process here?

Another and more frequent reason for asking that question is because parents are seeking support and validation. They want to feel like, when the choice is put on them, they're making a good choice. So knowing that is actually more important to most parents than "what would you do"... that's important.

And the third one, endorsed of the highest importance is placing the decision making on others so it's not a moral burden.

Remember what I talked about, when a family makes a decision or a person makes a decision, then they become greater invested, right?

our world, let's say a family decides the to go forward with a cochlear implant. Then they don't want to go back. Like even if it's not working, even for this particular child we say, gosh, they're just not making the gains we expected to see, we need to think about alternatives. That family, because they made that decision and it's a high stakes decision, right, they become greater invested in that.

When they reach out, often they want to share that moral responsibility.

They want you as the person there saying, what would you do, to be able to own some of that with them. That's a big responsibility, if you think of it, right?

So, what do people say when they're asked, "What would you do?"

Well, studies that looked at this say that 70% of people that ask that will acknowledge it. They will say, "Yep, it's a difficult question, uh‑huh."

60% of people say "I can't answer that. It's hard to say, I can't answer that for you."

And I would argue many trainings probably tell us to do that. Probably, we're told in different trainings, don't give your answer, because yours is different than someone else's.

Sometimes people will share their values. Well, think about what Colleen's quality of life would be like if you decide to go this direction or if you go that direction.

Sometimes people will ‑‑ I encourage them to think about their values and how that might be influencing the decision they make.

40% focus on medical. They'll avoid the question. Rather than saying what I would do, they focus on giving a piece of medical advice. Which, by the way, doesn't help families. Because they don't say, "Oh, doctor, you've just given me more information! "

They say, "You didn't answer my question"

Emotional support, we're here for you, that's a good response. And 20% say, "It were my child, I would..."

That is the least significant. The thing is we don't want to ignore it because that's not helpful to families. We also don't want to tell them exactly what to do. What we can do, going back to the last one, is to acknowledge, I think there are different reasons people ask that. I wonder for you, if that question comes from a place of needing to know more, is there information I can impart to you, does it feel like having other people be part of this decision would be helpful for you? Or do you just really want to feel like I back you on this? Because I can do any of those as the EI provider working with the family. But if I get ‑‑ open it up and it's a difficult conversation, maybe, but it's a possibility of engaging families where they are and what it is they need.

Rather than saying... uh... changing the topic...

Or saying, "Yep, that's tough. I hear ya."

Not so helpful to families in the long run.

So getting comfortable with others' emotions has really important implications. Some of us trained in sciences, have been told you really need to separate reason and logic from emotions and acting out.

Turns out that we're humans and we need to integrate those better.

When we are comfortable with our own and others' emotions we do these things. This bears out in literature too, we foster better therapeutic alliances and have more positive practice outcomes. That's a big deal. Families follow through more. They stick with treatment or guidance or programs. They're more apt to communication. This isn't me making this up. Literature bears out that says, really, when you intend to emotions, it's good for that therapeutic relationship.

I told you I would talk about brains. Because I like brains.

So cognitive neuroscience tells us that people actually in the room ‑‑ let's say you're delivering ‑‑ you're having a difficult conversation. In that room, when their emotions are being attended to, they make better decisions. Because their emotions aren't blocking the way cognitively for them to think through processes. Cognitively, when you're emotionally charged ‑‑ somebody said this at the beginning, high emotions running high, you're not able to think through things or make good decisions.

Processing of information is suppressed. When we think about families don't always understand what it is we're conveying to them, part of that is because we haven't attended to their emotions. If we flip that, if we help to help families and those we're engaging with feel okay about having emotions and let them know that we too have emotions and that we can deal and interact on the emotional level if that's where they need to go, then they're much better able to process the information and the cognitive pieces we're trying to convey.

Isn't that cool?

But it's kind of an interesting thing that the brain itself doesn't process information until it gets to a place where it's like "I feel safe."

That's on us.

So the more we say families are non‑compliant, they don't follow through, they're not doing these things. When we look at ourselves and say, what are we doing or not doing sufficiently to attend to families' emotions, then we can improve our practice.

Any gems, light bulb moments?

Any thoughts to share at this point?

Got a runner?

>> AUDIENCE MEMBER: So I'm kind of coming from a different place, I'm a parent, not a professional. So just some things that stuck out to me, please don't forget these difficult conversations you're having with parents, we have no training and we're having to go home and tell our families. That's hard.

Secondly, it kind of stood out to me in the first little play or whatever we did, I know I personally would not have been able to have any conversation that happened after you said "your child has a hearing loss." As soon as I heard "deaf"... done. I'm a talker. I did not say one word until I got home.

So keep that in mind, kind of like you said with the non‑compliance. I don't think it's from a place like, oh, well, I know more, I'm not going to listen. We didn't get it. Give us some time.

>> AMY SZARKOWSKI: Yes. Absolutely. Thank you for sharing that.

Let's go right behind you, Emily.

>> AUDIENCE MEMBER: [ off microphone ]

>> AMY SZARKOWSKI: Captioning is not capturing what is being said. Are you still on?

[ The speaker is off microphone ]

>> AMY SZARKOWSKI: Rob, do you want to say it here at this mic?

That's fine.

>> AUDIENCE MEMBER: So what was I saying?

Okay. Thank you.

So, we were talking about LSL, listening and spoken language, and manual communication ASL, and as member of EHDI, I've been coming here for several years now and being part of this conversation, I think that we need to move forward. We are moving forward from those camps. The reason is because we need to focus on the child and not on political agendas. And I say that pretty forcefully. If you feel threatened by that, you need to do an ethnographic interview with yourself about what your biases are and where they come from. Because I am seeing a lot of kids in my clinic who are not... the initial visit, when they're behind, I see frustrated parents who have been given misinformation. And that's what I often have to clean up. It's not a mess, it's an unfortunate situation. I have purely deaf kids because of the lack of resources or because of biased information, they are behind. And so I shared with my table and it struck a nerve, is that I was hoping to come today to talk about this. And I do hope you share... I told my table, and I've never said this publicly, or Tommy a little bit, but I will say this publicly. I am 100% supportive of LSL. I am also 100% supportive of ASL, and the sooner you get on my boat, okay, the sooner these kids are going to be served. And I mean that... because we at EHDI...

[Applause]

... and the reason I have my presentation on Monday is putting the I in EHDI is because we need to move forward. We're finding these kids and figuring out what to do. And if you remain behind cloaked of political agendas, these kids are not going to be served well. The parents are going to be confused. These are difficult conversations that we have to have with ourselves, that we have to have with these families, okay?

And I identify in Cailin's beautiful role play what I would have done differently is I would have stopped before she said the word "hearing aid." Because that's not her role in that initial visit. Her role in that initial visit is to deliver the bad news that the child is deaf or has a hearing loss or her hearing status is different than most people, or however you want to say it. We have to work on our language, so it's gentle. But that's where I would have stopped. Why? Because there's another appointment to talk about options.

The mom, you know, I have parents, I have a whole folder that says everything I just said to you, and tell them, I have a checklist. You're going to start them noticing come back and doing nothing you told them to do. Why? Because you shut off. As soon as I tell you your kid has autism you're done. Even though we have 30 more minutes and give you more information about, I want you to give this diagnostic letter to the school, I want you to tell your family, how are we going to tell your family, I know that probably is going to be on your mind. Have those kinds questions in the beginning. How do I get them to hear? That's how you respond to that situation, is I know it's a very complicated question and I want you to be patient with that. Okay?

So I know I'm making enemies, I know other people disagree with me very strongly in this room, but if you do, I want you to think about why that is, maybe. Because my heart ‑‑ as a deaf child or deaf teenager, when I started to figure out what happened to my identity, I started signing in eighth grade. All those years of oralism and FMs and struggling and all that, assimilating, and my world changed when I started to learn sign. And you saw me signing in the beginning. You know, I have had to learn to trust interpreters. I still don't trust interpreters 100% because I am an articulate dude. I talk, okay?

And interpreters are terrified of voicing for me because they know how articulate I am, okay?

So I try to be gentle on them and I stand up and I let you hear my wonderful Scottish accent.

So anyhow... I just wanted to share that with you. Like, tell me how you want the conversation to go.

If you Hart of the LRS community, share with us fade why you feel that way, and what are we not doing in the conversation that you feel uncomfortable with, please.

Okay?

I want to have those difficult conversations with you.

>> AMY SZARKOWSKI: Okay. We're going to, in the interest of time, move forward.

We're always learning.

So I think it's helpful to think about the gems, what sticks out for you, what can we extrapolate from then, how do we apply them in other contexts.

So we are going to take a break and we thought we would have people move tables, but I think in terms of communication access ‑‑ our room is really full. It's going to be hard to do that. If you're always turning to the person to the right, look to somebody else at your table when we have the next go‑round, okay?

So we're going to have a brief break, and then we're going to use your cards when you come back and reintroduce yourself to somebody new.

[ Break ]

>> Lights are blinking... three... two...

>> AMY SZARKOWSKI: Here we go.

We've be asked whether we'll share the PowerPoints, and absolutely we will. We will post them and give permission for EHDI... I think...

You know how sometimes that doesn't work so well.

At the end.

>> [ off microphone ]

>> AMY SZARKOWSKI: So why don't you wait? He went to the bathroom. You can wait for your comment.

We'll do that.

Okay. We will share the slides and post them on the EHDI site. But, we know that doesn't always work perfectly, so at the end of the presentation, come and get a business card from Jennifer. She will be in charge of mailing them out. We also have resource lists and other things that we want to share with you, so we want to make sure that you get those too. There are several articles I think are great. So if you really want to go into the topic, we can share those. Be sure to do that at the end. Don't feel you have to scramble to write down things. Although if you write down something important to you, it helps your brain remember. I don't think taking notes is bad, but don't feel you have to copy everything.

>> AUDIENCE MEMBER: You just mentioned you have articles. Will she have that as well, or do we need to contact you?

>> She will be our contact person for information and materials.

>> AMY SZARKOWSKI: I'll just say that again so it goes on CART. Jennifer will be our contact person for the slides, the handout, other information from this presentation. So get her card and then we'll send those along. Okay?

Any other housekeeping things?

No?

Okay. We're good. Let's talk a little about therapeutic alliance.

So as a psychologist, one of the things we studied is ‑‑ you look at things like behavioral approaches to counseling versus cognitive approaches versus psychodynamic approaches.

Guess what. Turns out that the relationship that one has with their provider is far more ‑‑ a stronger predicter of their success than whatever it is that the provider does.

To relate to Dr. Nut's comment that the exact approaches we're working with people around are far less important than the ideas and the therapeutic alliance, how they feel about connecting with us.

In fact, in the counseling realm, 50% of therapeutic outcomes and results are attributed to that therapeutic alliance, whereas only about 10% of the outcomes really relating to what it is you're doing.

That's a pretty big thing. So therapeutic alliance is something we should think about. How do we align with the families and caregivers we're working with so we feel like we're on the same page and moving in the right direction?

Another strategy for you to try is the idea of using ‑‑ having parents become detectives. When we ask parents to look for evidence of... something. Look for evidence where your child is really succeeding. Tell me about that. First of all, it's nice to look at that, instead of always reporting the negative. Which some if of our families find themselves in the position of saying, yes, there's delays here. Yes, we don't have the language we expected. Or whatever the case might be. So when we ask them to find positives, that's one strategy. And asking them to be detectives and give examples of what it is that they need.

Families really can engage. This is a very easy approach, but families engage and it gives them something active to do. Right?

Also they're not just reporting to you, my child is doing this, or meeting these milestones, but it actually involves them in the process. So using that idea of having them be detectives.

And what are the barriers? Once you put on your detective hat, you see things in a different way. If you just say to a family, What do you think you're not doing well that is preventing your child from succeeding, that doesn't feel good at all. But if you say, Okay, your child is making progress, what are the barriers? How can we remove the barriers? You might find that people will say, Well, you know, at day care they're not using as much signing is so maybe one of things we do is think about how to implement it in that context it doesn't feel blaming to families, it feels like they're on your same team.

All right, thinking about this...

Lots and lots of families report saying, I don't know, I was talking with the audiologist, they talked about fruit... I got lost, I thought, what is she talking about? Or banana... I don't know, they said banana. All I could think about is banana, why the hell are you talking about a banana when my child has hearing loss? We have to contextualize and say, what does this mean for families when they walk away from that situation? We have families tell us, I know this is weird, what is it you understand from this? Is there any way ‑‑ do you recognize any sort of gaps and can I help to fill them in?

Here comes my level of the brain. Peeking out again.

So, I have done this consistently in my practice for the last several years, but moving away from the conversation of approaches, of using this approach to communication, or this approach, or these modalities. Because when you talk about brain development and you put the onus on parents and say, What is really cool and what is a really big responsibility is, you are facilitating your child's brain development. [ gasp ]

Holy cow! That's a big job, right?

But then we can move away... this way works, this way...

And you can sort of say, what a child needs is access to understandable language that he or she can process. And I don't know yet what that is going to mean for your particular child, how we're going to get there, but your child's brain needs language. Your child's brain also needs social opportunities.

Your child's brain requires social emotional understanding to meet his or her potential. That's really powerful. You don't have to be a brain scientist to talk about brains. At the clinic where I worked for a long type, we all moved in that direction. Our conversations with families talking about brains, it's big. It's cool. Right?

You don't have to know all the answers. You can just say we know this impacts, so let's optimize what is going to be best for your child.

Question? Comment?

Okay.

So, multisensory input is I think something we can all be thinking about. And this is going to sound like a plug. It kind of is.

Sue Gibbons and I have a presentation at EHDI about multisensory, we wrote a paper published last week, about why we need to think about providing visual support even in children who are auditory learners. You know, looking at all of the ways in which input, sensory input is processed in the brain leads to better outcomes.

So that, I think, is one direction that you can go. To make yourself an expert when you need to sort of say, we have think about how your child is developing on a grander scale.

90% of a child's brain development happens before age five. We certainly can't wait for children to get to school to think about growing their brains. We have to do that now.

Nicole, I wonder if you can maybe take this microphone.

We're going to check on the one thing you mentioned wanting to learn. We'll see if we can address this.

>> Is this on?

>> It is on. Hooray!

One thing, I'm going to read it off so we can get it on CART and everyone can hear me, because you can't read this, even though my handwriting is beautiful.

It says...

Resources and handouts...

>> Check, because we're going to make those available and you can contact Jennifer for those

>> How to help families move through the process and not get stuck.

>> Strategies for communicating with multilingual and multicultural families

>> We haven't done that yet but coming up

>> Having families overcome myths.

>> That depends on part how we're presenting them

>> Tackling bias.

>> Stay tuned

>> Supporting families with transition to school

>> Yes

>> How to introduces in, especially if it's difficult. Supporting families where they are now and how do we include the deaf community.

>> Okay. I think supporting families where they are now, I think we addressed that in some ways. I think we have other things to go. But, let's see, we're going to hope you get them covered before the end of today.

>> All right. We're skipping this one, right?

>> No.

>> We're doing this one. Yes. Okay. This is a scenario where the early interventionist, Jen, is seeking advice from her supervisor.

Maybe...

Ready?

>> Yeah.

>> So it's role play, but because of the microphone situation we have to be kind of farther apart. But what we can do is cover this up and...

You got it?

>> Yeah.

>> Good.

>> We thank you for taking the opportunity to meet with me today. I know your schedule is super busy.

So, I'm in a situation where I need your guidance because I don't know how to move forward with this family. At first I felt like, man, this family doesn't have any follow‑through. Like, I don't know what is happening with them. They're not keeping their audiological appointments. They're not following through with early intervention, strategies and things I'm talking about. The kid is only 12 months old, so I have like two more years left with this family and I, like, really need to understand, like, how best to approach them with, you know, intervention.

So the situation that I'm asking specifically about is that through conversations, like I have come to realize that this family's fear of influence outside of their core family is really ‑‑ it's huge. So this family says, you know, their church community and parents are saying no need to worry about intervention because they're praying and, you know, there's going to be miraculous healing. So therefore this early intervention stuff and these appointments, no need to worry about them because God is going to take care of it.

I am Christian, like I grew up Christian and I understand... I understand where they're coming from and biblically where they're coming from, but how do I balance that with providing intervention for them?

>> That's a really great difficult conversation to have. Because religion is one of those things that people report being really difficult and hard ‑‑ it shuts down conversations very frequently.

One of the things I think we can do is to both recognize and honor another person's perspective on religion and to say, here is where I think it differentiates.

So, for example, you might say something like, "I really value that you have all of this hope for your child." And you can reframe things. You know, I share hope with you. Whether you're talking about a Christian family you have similar values or a family who has different religious background than your own, finding sort of those kernels you can share, because there are a lot of commonalities in religion. You know, sharing hope, sharing ideas for wanting the best for the child. And differentiating that and letting the family know, I have a different role. So let's talk a little bit more ‑‑ I'm going to introduce you to the "amen" method which is a strategy we try to employ with this particular family.

>> Thank you.

Raise your hand if you have ever had religion play a role in one of your difficult conversations.

Yes, okay.

So, this is actually found in the literature and it is called " AMEN, an acronym for bridging gaps in faith, hope and medicine.

I certainly have had the opportunity to work with families who are praying for a miracle. That is what they want. They don't necessarily want to mare what I have to say. ‑‑ to hear what I have to say. What do you do affirm. Affirm and validate the family's position.

What most people do is say... uh... and they back out of the conversation and don't touch it. That doesn't help to build therapeutic alliance. What does is affirming that you get that that is important to them. You don't have to agree with it or endorse it, but you understand ‑‑ you acknowledge that, I see this is really important for you. I don't want to dismiss it. Meet them where they are. I join you in being hopeful. Here is finding the same nuggets.

I'm working with a family from Abu Dhabi, and talking about their religion, it may be fairly novel, but when I hear some of the keyed terms they're using, I can say... I relate to that. That piece I can say, I kind of get that and I share that with you.

Educate is this E in AMEN.

Recognize in saying "and" instead of "or." When families feel that opposition, either they have to follow their medical ‑‑ rather than religious ideas or do something that feels to them to be medical, to say it is possible to do both. I both want to recognize that you have this perspective and I want to talk with you about the urgency of language for your child. Both of those can be true.

Saying something like "it's God's role to bring the miracles and my role to provide care. My role is to do the speech language therapy. My role is to be the early interventionist that comes into your home."

Holding space for both. And no mat per what is the end, no matter what, I can be here with you. Recognizing and acknowledging, I may not share your religious perspectives, but I can be here with you and I don't have ‑‑ and I'm not going to be afraid to have those conversations.

Religion, the literature shares with us is the most common things that backs people into a corner and makes them feel like they don't know how to proceed with a difficult conversation. So here is a strategy that seems to work to address that.

AMEN.

When there are family barriers as discussed in Jen's role, there are these barriers, I'm not sure how to get around them. Here is a time to revisit that eco‑map. What does it look like for someone? She described their sphere of influence is huge. Maybe this eco‑map looks different than standard we're used to. This may be a time in understanding cultural differences where we say, help me... it's not your job to educate me. It's my job to help you. But the more I know where you're coming from, the better I can try to fit in the supports with we have available to what it is that you need.

So two things there...

Giving permission for the family to not be responsible for teaching you. Because that can be burdensome. But recognizing that if we are able to identify what really matters to you and the kinds of influences in your life, then we can match that. And this will be much more successful for both of us.

So, looking for a mnemonic for listening skills. The other we talked about SPIKES, conveying information. NURSES is having listening skills, taking it in.

Naming. Label that emotion. Sounds as know... looks as though you're disappointed. Understanding. Acknowledging what the person says and asking questions and following up. Showing respect. Empathy plays a role here as well.

Support. Reassuring of support. Very often families, part of the angst is they feel they have to get it all right away, and when they have a sense there will be continuity of care, if that's the case, that's important to convey.

And explore. Asking where to share more, elaborate, working towards comprehension. Acknowledging that not everybody gets this the first time around or, you know, I'm talking about this, but I studied this for five years, and as a parent, you have all kinds of different experiences that you're bringing to the table.

So it's not a matter of me expecting you to understand everything or you feeling like there's something inherently bad about not being able to, let's just meet in the middle and find out where the gaps are.

We are skipping that for the sake of keeping things going.

Self‑monitoring. It's an important skill in being able to have difficult conversations. I'll just have you read that real quick.

Or not

I feel bad reading to people, but recognizing some people in the back may not be able to read. Self‑monitoring is an ability to attend moment‑by‑moment to our own actions.

Having curiosity to examine the effects of those actions. Curiosity, key word. And willingness to use those observations to improve our behavior and patterns of thinking in the future.

We tend to think we're right. Yeah?

So when you say, suspend that and be curious about, what is the effect of my actions on this family, that's where you can grow.

The more that you do the same thing, the less likely you are to grow in new ways. So being curious is a part of... hmm, difficult conversations, let me be curious about myself, what is my role in that, what can I learn from it.

A word or two about bias. Bias was mentioned at the beginning. How do we address bias or present information in a way that is unbiased?

Here is what I say... we all have bias. And it might be your organization or program's idea that we don't present biased information because we want to give opportunities for families. That's good.

But if we say "I'm unbiased," we're not being very truthful. All of us have a particular bent or a particular bias, and we have to own it.

It might be the case that you say, "I understand you, the family, this is what you really want. I think I'm a little biased in a different direction, so let me pull in another person who can help to address your need."

When you acknowledge bias you also acknowledge some limitations and you can step outside of that. When you say "I'm unbiased," then you share the perception that you can handle any of it. And that might not be true. It might not be true that you're the best person to address every single kind of family in your catchment area, right?

So there's something to be said about that. You don't want ‑‑ there's a difference between bias and prejudice. Bias is saying, I lean this way. Prejudice is when I force that on other people. So you can be biased and say, I don't want to prejudice the situation, but I kind of know that I lean in this direction. And so if that doesn't align with you, let's make sure that we have a mediator or another person or another support person.

Okay?

Ernesto, he's the guy helping us set up the situation this morning.

Okay...

Goal setting with families. What does it typically look like? How should it be done?

I wonder if our panelists have any just quick thoughts about how do we set goals with families?

You see their eyes? Oh, you didn't plan that!

[chuckles]

>> How do you set goals with families? I think that as much as possible making it joy focused and positive. You can set a goal for language that doesn't have to be focusing on a gap. It can be focusing on how to move forward and how to start where the child is at, and really build on that in a positive way.

>> Great.

>> The first question I always ask the families, what are your priorities? Tying back to those values, what do you want from your child? Where do you want to see them when they're three or five or 21? What do you want for them?

>> I like to keep in mind that the goals can change over time. So I often will say to parents, like we're making a decision today and that decision might change. This is our short‑term goal. Maybe we have long‑term goals, but the goals that we are trying to attain may change over time, and the journey to get there can change.

>> Connected to that, I think it's important to set time aside to reflect back on goals that you have set in the past. So if you have set a goal with the family, reminding yourself to bring that goal up again. We talked about this before. This is the goal you set. How are you feeling about your progress? Should we make changes? What are your next goals?

>> AMY SZARKOWSKI: Lovely. Thank you.

It's nice to break it up and not just have me talking to you.

Okay. What if the family isn't doing what you want? Ugh! Darn!

The blame is about judging and looking back. And contribution is about going forward. So I think that could be an interesting re‑frame. What contributes to the family either being able to do something or getting in the way of them doing something that it is that either they have claimed they want or you wish they would do?

Okay. Sometimes difficult conversations involve conflict. So, thinking about conflict, what do both parties do? Typically they avoid difficult conversations. Kudos to you again for being here.

They are sometimes being unapproachable. I don't want to deal with it, so I don't want to make myself busy. Assumptions about roles.

The family disconnected. The family did something like that. We need to be mindful of that. And really that failing to understand how profoundly and different and complex we are in past experiences is really an important way in thinking about the conflict occurs.

Checking on our progress. We still want to make sure ‑‑ we did talk about bias. We're not going to talk exactly about transition, but one of the things I think is important about transition is that families have hopefully built good therapeutic alliance and then they're moving on. So part of what we can do if we're in early intervention, is to help them have a successful transition, to introduce them to people, if that's appropriate, who might be coming in next, to assure them that we are still there, and really to help them feel that they don't need to rely on us, if this relationship is ending because I'm an EI provider and not going to be with them, that I have then my best to transfer those skills they need and develop and foster those skills so that they can manage that.

Any others?

Here might be a good place to talk about how do we include the deaf community. We've talked a little bit about ‑‑ briefly touched on the role of sort of deaf mentors, introducing young people to deaf adults, having the families have opportunities to meet deaf adults who are successful is so impactful. Studies have looked at what matters to families of children who have hearing loss as a particular group, that that often rises to the top, top one, two things that they say had an impact on them was meeting deaf adults. It is our responsibility to make that happen.

One of the things that can be tricky is that idea of story sharing, right?

So we have to be a little bit cautious in that the deaf adult who is sharing their story, it not become about them, right? And that it also needs to be that there are potentials for meeting different kinds of deaf adults that might be like, hey, same. My child has profound hearing loss, likely to be a signer, having somebody in that sphere might be useful. A child with mild/moderate hearing loss who benefits from hearing aids, an oral communicator, it might be they need a different person to align to, although that whole variety of deaf persons certainly can be helpful. So being mindful of that. It doesn't need to be that my child will grow up to be exactly like that deaf adult, but it does help to have representation sort of across lots of different kinds of deaf adults. But seeing individuals who are successful really helps families to feel inspired that their child can do the same.

Are there any other one things that we want to make sure we address? I'm looking...

I think we have. Okay, good.

We do have one more scenario that we're going to share with you, because this idea of an additional challenge is something that we think that many of us encounter.

>> We're going to do this one a little differently. Instead of doing a role play, I'm going to read to you a scenario and then we're going to give you some questions to think about, and then you'll have an opportunity to talk to your elbow partner who are sitting next to you to think this through. We'll structure this a little differently. I'm going to read it out loud so everyone can access it. Tiny font.

It says, raising the possibility of additional challenges. Four‑year, six‑month‑old boy with bilateral cochlear implants. He wore hearing aids until he was implanted at 14 months. He enrolled in early intervention at nine months, started preschool at three years.

He has shown consistent growth in the areas of language and cognition until age 4 but has now plateaued. Parents don't have concerns, but the last IEP reporting period showed minimal growth compared to the previous reports.

He is receiving weekly itinerant services from teacher of the deaf and school‑based therapy as well as clinical speech therapy outside of school.

Think to yourself, what are some more things you would want to know? And here are some questions for you.

>> So when brainstorming here, some of the first ones we came up with:

Does the family or other professionals have any concerns?

Is there additional testing that can or should be done?

Are there family factors that impact their understanding of the child's strengths and needs?

So... Nicole and I are both educators by training. Turn to your elbow partner, the person that you're bumping elbows with and talk about your perspective and maybe try and answer some of these questions or other questions you might have.

If you need an interpreter, wave your hand.

You have three minutes.

>> Testing, testing.

With a different mic.

Thank you, CART. We appreciate you.

:‑)

>> AMY SZARKOWSKI: One minute. One minute left.

Everybody coming back. Wrapping up your conversations.

Some of the takeaways from a situation like this, we need to make sure that the family feels valued. Amy will talk more about that later.

Also, exploring the family story and have the parents identify the child's strengths and needs, asking the parents what their perspective is. That's where you start.

And then we talked a little about this in some of the other ones, but framing the conversation in terms of development instead of diagnosis.

>> And just remembering that even though difficult conversations are difficult, the point of conflict can be understanding. So you understand that you each are coming to the table with a different perspective, a different view on things, different experiences, but the point is that you understand each other. So challenge yourself, step into that uncomfortable place with the purpose being understanding.

>> We included a scenario about raising the possibility of additional challenges because that's a legit and real experience for many people. And we can't shy away from it. Here is what I hear far too often. I didn't feel like it was in my wheelhouse. It was beyond my expertise. You know, I'm an audiologist. I can't tell a family I think they have autism. No, you cannot. And don't. But...

You can say, "here is what I'm seeing in terms of development, let's make sure we get lots of eyes on this. Let's make sure we have somebody who knows about development who can help us inform about this decision."

You can't give a diagnosis that you're unqualified to give, and you shouldn't. But very much we want to be able to raise questions with families. Because too often, if people ‑‑ if everybody on the team says "it's not me," then who is going to do that?

I will, again, as a psychologist say, this happens a lot in the social‑emotional realm. Many EI teams, if you have a social worker, their job might need to connect to services. If you have a psychologist in an EI team, it's a problem very often. There's something big happening that warrantied a psychologist. Instead people say, I can't do that, I'm a PT. I'm an OT, I can't talk to families about the emotional stuff. But if nobody does, then it doesn't get addressed. So we have to get comfortable with raising the idea that there might be something happening even if it's not... I don't know the answer, but something that we need to attend to. And that's where the idea of focusing on development can be quite helpful.

Also, deaf kids... people say, well, maybe I do know autism but I don't know autism/deaf, so... and then they arrive at the door of the developmental pediatrician who says, now the child is four. We've lost a window. That is really valuable and important. So that's on us to be thinking in terms of development.

Whether you are the PT, OT, speech or whatever your role might be with that family, having some ideas about typical development and where this child might be a little bit different is just an important question to raise.

So feeling valued. One of the strategies for thinking about how do you connect in terms of conflict is this mnemonic of being valued. So validating. I understand where you're coming from. Asking open ended questions so that you can get more information about where another person is coming from.

Listen. Just don't think about how you're going to counter‑argue. Actually listen. And then also test what are your assumptions going into that. That might look like... huh, my first gut reaction is to sort of defend what I've done. But I'm really trying to step back and hear you.

Just owning that can be really powerful for the person you're conversing with.

What are the uncovered interests? Here is the situation where very often what is being said isn't really what is on the table. And so we sometimes will analyze and really think about what is it that the person said and their tone. But if we, you know, know that even in oral communicators, about 80% of what is being communicated is non‑verbal, then we need to be mindful of the fact that what is said might not be where the message is really being conveyed. So be thinking on different levels.

Exploring options. Usually there's not a right or wrong, one or the other. Very often there are combinations of things. And the more that we are open to saying, I wonder if that could be part of the plan, and we might also add this... that can really help to get family's buy‑in.

And focus on deciding together when that is possible. Even saying upfront, like, I don't want to make the decision, and I don't want you to make a decision that I'm forced to live with, let's see if we can come to common ground that feels okay to both of us. Again, it's not the words that you have to copy and repeat verbatim. It's that idea of making space between, right?

In conflicted conversations, people hold their ground. Where how do you make a space between where both can be at least partially right?

When you do that, people feel respected. They walk away from the conversation, even if they have quote/unquote lost, they don't feel like they have lost their dignity or their respect from their communication partner. That's important.

Exploring other people's stories. We had you do this at the beginning. We had you talk about your story, what is your background?

Sometimes you can say "things are heated, I wonder if we can take a step back, breathe, and see if I can understand more about where you're coming from."

So you get that ‑‑ that might be a chance where you explain your origin story and you find out somebody else's.

People almost never change without first feeling understood. This, in psychology, comes up again and again and again.

I don't have to be right as long as I feel like I've been heard, right? As long as I feel like people have understood where I'm coming from, then I can be more open and more flexible.

So if we're focused on quick delivery of information or moving through a process, we're not going to do that, but that is what will get us the buy‑in we need to really collaborate with families.

We all make up stories about our lives. Right?

So the origin story, I made that up. I might have included important pieces so that I think you will think you're important and I might have left out something else that I think you might judge me on that, right? Our stories are fluid. And so recognizing that both for ourselves and others, that the story they tell us might be one way they want to present at a given time.

That has implications for needing to go back and row tell stories. Sometimes people find out they're working with a family for a year and they didn't know this really valuable information, and they feel betrayed. Instead you think, the family didn't feel comfortable enough to share that important information at that time. I wonder what I might do differently, might have done differently to help them feel comfortable and I wonder what the implications of that are going forward.

Holding it in a space of curiosity is very different than... They didn't even tell me! How am I supposed to work with the family if I don't know this key information?

Well, there's probably a reason, and all of us own our stories.

So, in terms of getting to another perspective, here are strategies. Tell me about the growth that you see. That feels very different, again, to a mom than "have you seen any progress?"

"Are you seeing anything?"

Tell me about what is happening. That growth might be things that you didn't expect.

You know, this week when we were in the bath, I was blowing bubbles, and blew bubbles back and it was fun. We had this exchange. We went back and forth six times.

You might be thinking... Okay, but I'm looking for words, I'm looking for signs.

No, but the family just shared they had an experience of back‑and‑forth reciprocal attention with their child, and that is big. And that opens a gateway to talk about that, right?

Have you ever experienced a feeling when you see your child playing with cousins, other kids on the playground, something different is happening with him? That might be a way to get at concerns parents have without say "What are your concerns?"

Sometimes when the parent has to say what the concerns are and put that in words or signs, then that's scary. But if you contextualize it, it's a really good strategy for difficult conversations.

So let's imagine... you know, you just told me that last week your son Lucas and you went to a birthday party. When you were watching Lucas at the birthday party, what stood out? That might be a way to open a conversation about the family's concerns without saying "What are you concerned about?"

And actually might get you more accurate information because the family might not be using the same terminology that you as an early interventionist are using. They might not say, They don't have reciprocal eye contact.

They might not say "They're not good at turn‑taking in groups of three or more."

They're not going to say that. They're going to describe in the context of what they saw. Have them tell a story which makes them feel confident. Anybody can tell a story about their own kid. Framing it that way, it reduces the power differential.

Show curiosity about the child's development. Terminology really matters. We talk about delays. We talk about deficits. That frames a conversation in a way that doesn't feel very good. Let's talk about the child's development. Even children who are quote/unquote delayed are developing. We can talk about that in that context.

I already told you don't diagnose...... I'm just saying.

Baseline testing can be valuable. Sometimes families say, I don't know if it's worth referring for an evaluation to PT. I'm not a specialist in motor, so I don't know if ‑‑ it looks to me like the child might have challenges in that area, but I don't know.

If you frame it as a baseline, that's okay. When you frame it as "I'm really concerned," it has to be a big enough concern to get a referral, then that's not so good. But the more you know about a child's development, that's really good information.

Let's say you referred for a PT eval and it turned out to be the child is doing okay. They're a little bit behind, just a little bit, like low end of average range.

Okay, what does that mean? That means parents can do something about that. Right? That's good information. Now we can take them to the park and encourage them to walk on the balance beam thing and parents can see growth. Great!

Not a waste of time. Not a problem.

You've also shown you're attending to that, particularly if they told it in a story that makes it ‑‑ you know they've had a concern, right?

So baseline testing, good. Not a bad thing. Doesn't have to be big, bad scary before you refer for an assessment.

We're not going to have you change your tables, but I would like you for a second to share your number ones, twos and threes. You talked about what is your favorite dessert. What is your favorite vacation spot? And what is something hard about your job?

Share that with your elbow partner or somebody else at your table.

One minute.

It's a quick one. Quick and dirty.

>> Lights flashing!

Okay, let's bring it back.

To the group.

All right. So, something that is really important in adult learning is that you actually have to apply new knowledge to knowledge that you already have.

Adults learn differently than children who actually take in more things. But adults you need to say, here is what I know, here is this new information, how do I tie it?

So this is not a conversation. This is an opportunity for you to write down in a sentence or two a piece of information that you have learned, tying it to what you know.

This is going to be a take‑home. The reason it matters is that we're spending three hours together ‑‑ that's a lot of time ‑‑ and you might say, there was stuff and I don't remember it all. That's okay. What is key? Write it down. Take a minute and write down your sentence or two, taking new information, how does it apply?

>> Okay. Here we go...

So...

Actually, let me just do this.

So I'm going to share with you several different mnemonics, such as SPIKES, VALUES, some are applications. Some you need to listen and some you need to convey information and sometimes a conflict or challenge. Hopefully these are things you can incorporate in thinking for how to approach those different kinds of difficult conversations.

We are getting close to the end. There has been some research about what are certain competencies for people who are good at difficult conversations, what do they do? We have two slides discussing competencies. Here they are.

One is having a sense of confidence and self‑efficacy in challenging situations.

Hopefully you can leave today feeling a little more confident about that.

Number two... having the capacity for reflective self‑awareness. That self‑monitoring piece and knowing what you bring to the table, the intersectionality, the who you are and what that brings to your conversations is important.

The third one, validating relational capacities, recognizing what that relationship is. I think that includes the power differentials. It includes the ideas that, you know, if I'm a person who has authority over you in some way, then that will influence your outcomes.

And also recognize, I, too, am a parent. Or I, too, came to this because of this reason. Or I, also, am really passionate about this line of work.

The capacity to empathically but not over‑empathically step into the shoes of others. So appreciating where it is they're coming from without over‑identifying or making sure there is a boundary, that is really ‑‑ this is the time to deal with their stuff, not the time to deal with my stuff.

Those are the top four. Remaining competencies are willingness to share that moral burden of decision make. What works with families, when they say, what would you do? It's when you say, I want to be part of this decision with you. I can own my bias. I can talk about what research says and we kind of as a field know to lead to better outcomes, but let's make sure we're in this together. When parents and families feel you're in it with them, then that trust is there.

Tolerance of imperfection, ambiguity and vulnerability. We don't like that much but hopefully we can get better at it.

Understanding context. This has come up in several of your examples and in our portrayal of things, that context matters. Making sure the place is quiet or you're in a place you're optimizing the family's level of comfort to have difficult conversations. Or, you know, your difficult conversation might be with a colleague or supervisor. And then how do you take that into context and make sure that we're mindful of that?

Here they mention authenticity. That relates to therapeutic alliance. Remember, that's the thing we say 50% of outcome is related to how well the people you're interacting with relate to you and feel supported by you.

And the last enhanced experience of professional integrity, I want to get better at this. I'm committed to doing this work. I'm feeling this important, my job is important and I really enjoy working with and supporting families.

So across a number of professions, when we see people have these competencies, these are the people who do really well in difficult conversations and the people they're conversing with feel supported by them.

Okay.

Three things you can do differently. Hmm...

We aren't going to ask you ‑‑ all three of you, but let's do a runner and see if we can throw out a couple things. What will you do differently being more mindful of this Difficult Conversations?

Hands up.

Look, our runners are ready.

>> AUDIENCE MEMBER: I say I like the idea of giving the parents a couple minutes. I usually go get the information at the end...

>> We can't hear you. Speak into it.

>> AUDIENCE MEMBER: Sorry, as an audiologist, I should know better.

That you give the parents a few minutes to process. Typically I get a whole packet of information to send them home with. At the end of the session, I'll now do differently is give them five minutes to grab all that information that I send them home with and give them just, you know, three or five minutes, process, cry, talk about it with each other, and then maybe bank some questions for me and then walk back in the door and maybe can address that.

>> AMY SZARKOWSKI: Thank you.

>> AUDIENCE MEMBER: I find that I often do ask what progress have you seen this week, or what are your concerns, and I like the way that you've re‑framed that to kind of use stories throughout the week and put it into the context to get more accurate information. It's often a deer in the headlights look, and I think that's why. Thank you.

>> AMY SZARKOWSKI: Great. I think thinking about what you take home matters, because it helps solidify learning in your brain and more likely to benefit from the workshop. So, good.

We have a comment here.

I'm going to come to the front.

>> AUDIENCE MEMBER: For me, as a deaf professional, and as a deaf parent and a deaf adult and a deaf community member, this is important for me as an individual. Why I take things... I sometimes can become defensive, but I know it's not healthy. And it's not good... it's not a good boundary through my professional role, as my various roles as a parent, a member of the community, I have different roles and all these different hats I wear, they tend to become confused. So sometimes my challenge is my takeaway when I leave today will be what I can do when a topic comes up in an audience, I can have a chance to defend the comment and make sure that ‑‑ like for when Rob made the comment he made earlier today, specific to being ‑‑ Tommy might be upset about it. I think we need to make that conversation easier and not painful, so the audience hears they're already nervous about it when they leave. That's not a great feeling. We need to put all of those roles together.

So, I wanted to address that while we were here. Maybe address that comment that came up earlier. I don't want to leave without saying something about it and let everybody stew about it. I want that to be something we can still be talking about while we're in the discussion about difficult conversations.

This may be difficult, and when we call out somebody and then leave, I don't feel that's right. So I feel like we need to talk about it while all in the room together. I challenged myself to do that and bring that forward before I sit down.

>> AMY SZARKOWSKI: Okay. And so...

We do have two minutes. We have two minutes left. Do you want to comment?

Two things. I want to both honor your request and make sure that we do that, and I want to make sure that we are wrapping up...

>> AUDIENCE MEMBER: Yeah, I want help handling that, how to do things differently, how can I do things differently is what I'm looking for.

>> AMY SZARKOWSKI: So let's say, for example, if we use this example, we might say, this is a difficult conversation, or I've felt challenged by something, I wonder if we can find space to talk about that, I wonder if we can be open and honest with the ways that we're both approaching a particular situation.

We might say, first I want to understand a little bit more about where you're coming from. I myself felt defensive. And I want to sort of jump in. But I kind of know that I need to understand more about where it is that you're coming from before I can have my own reaction.

So, first, let's sort of clear the air. Let's think about... like, what brings you to your stance?

And let me hear and ask questions about that, let me make sure I get it. And then allow myself a chance to say what it is I'm thinking. But don't lead with the emotions. Don't lead with the "I'm defensive" or "that made me mad." Get to, what is the meat of that, what is main message we need to convey? And in this difficult conversation say, "I have many hats," that can be part of that. And I bring to this a lifetime experience of... whatever.

And so I find myself approaching it in a certain way. But I need to own that and know that that's me, that that's my reaction. And so rather than leading with that, I need to sort of own it and then say, how do I leave it and meet you where you are?

I think those are all parts of that puzzle.

So I think that that conversation can happen and should happen. And hopefully move that piece forward.

Okay, because we have two minutes left, we're going to bring it back to the whole group. We'll remain available for questions that any of you might have, and we want to thank you so much for your participation.

And these are our email contacts. Feel free to contact any of us. We're happy to share our thoughts and process. As we mentioned, Jennifer Clark is the one that has cards. She's going to be the contact for spreading information and getting that out there, the slides and resources.

We do have reference sheets available. They're not all on here. We just want to say thank you so much for coming and participating and having this conversation.

So... yes?

>> Please make sure you give me your evaluations at the door or you can access the Identify app and evaluate on that.

Thank you!