Increasing Confidence in Counseling Pediatric Patients and Their Families

Presenter: Michael Hoffman, PhD

Welcome back to Doctor Michael Hoffman. Today Doctor Hoffman is going to be presenting increasing confidence in counseling pediatric patients and their families. If you'd like to learn more about Doctor Hoffman and his pediatric and psychology background, you can read his bio on the course registration page, but I'll hand the mic over to you. Doctor Hoffman great. Thank you so much.

Hi everyone. I appreciate the opportunity to be here and present. Hopefully we can make it a interesting next hour for you to kick off a good weekend. And thank you for everyone for giving me the opportunity to come back. As Christy mentioned, you can put questions in the Q and A as we're going.

I will do my best to multitask and try and catch them and respond to them in real time if I can, so don't feel the need to have to hold on to them until the very end.

Disclosures I'm currently employed by the Children's Hospital of Philadelphia. I work within the center of childhood communication there, so I get a salary from the hospital and I did receive an honorarium for this presentation, but no other significant disclosures to report.

And we won't be talking about any specific content or products in that way.

So what we're hoping over the course of the next hour is we'll go through a lot of different things. I crammed a fair bit in this presentation to really give you a good primer on different things that hopefully will increase your confidence. But the main areas that we're going to touch on is explaining some strategies and tools to really be able to improve your communication with patients and family, to make them feel like they've got a higher level of buy in and understanding, discussing ways in which cultural considerations and multicultural identity may be impacting comfort and communicating with families and counseling with them. Certainly as a psychologist, I think that is

crucial to be considering and thinking about culture and people as cultural beings when we're trying to figure out how to best support and counsel our families, and then to identify some specific standardized tools for measuring psychosocial functioning. This is not going to be a full, comprehensive, exhaustive discussion around standardized tools for screening.

That in and of itself could be a multi part series, but I did want to briefly touch on that and throw out some ideas and hopefully leave folks with a few ideas of ways and they can do some more research if you're interested. So more specifically, I'll tell you a little bit about who I am, and then we'll go into those communication strategies, cultural considerations, and then the psychosocial tools. And hopefully at the end we have some time for some q and a, so you can go to the website if you do want to learn more about me, but I'll just run over it real quickly as well. So who am I? Well, start off with a little bit about my personal background.

So I'm a deaf adult. I have a hearing aid on one ear and I have a cochlear implant on my other. So I was diagnosed hand with connection 26 as part of a genetic study years ago. So that's the cause of my hearing loss, which is non syndromic. I have bilateral moderately severe profound hearing loss and so I was fortunate to be caught pretty early, diagnosed at five months, and then received my hearing aids at six months.

So for most of my life I was bilaterally aided and then I got an implant at 28 when I was actually in grad school. So all that is to say, I have a lot of experience working as a patient within different medical systems that may be pediatric hospitals, university training clinics, private practices, adult care. And so that certainly colors the way that I view and work with the families that I see professionally. I have my PhD in clinical psychology, so I attended the University of Miami. While I was there, my specialty was in pediatric health psychology, meaning children who have medical complexity or chronic illnesses and diseases.

My clinical training at Miami spanned across a lot of different areas, different pediatric populations, providing integrated behavioral health services that included audiology and otolaryngology clinics, inpatient consult, craniofacial, what else was there? Plastics, diabetes, endocrinology, you name it. So I got experience in a lot of different ways after that. I did my internship and my fellowship at Nemours Children's Health in Delaware for six years. I stayed on his four years as faculty, and then following that, actually pretty recently, within the last year, I went to Children's Hospital of Philadelphia.

Pretty cool for me because I was actually a patient at chop when I was a kid, and so there's a nice full circle moment in that way. I say all that to say that I have a lot of experience and background as an individual and as a professional. I'm working with individuals who are deaf and hard of hearing, and I've seen people with all different types of experiences come from all different walks of life. And I think it really, really is an honor to be in that position to work with families as they're navigating this, and it means a lot to me.

So in thinking about doing this talk and going over this presentation, one of the areas that we were trying to figure out what would be helpful, what would be useful to people was thinking about counseling. I know anecdotally, when I've spoken to a lot of other audiologists out there and folks I've worked with over the years, they'll say, yeah, we had a course in grad school, one course, then it was helpful, but I really wish we had more. That's a pretty common refrain that often comes through from a lot of the different people that I've talked to. And what was interesting, and I have to give Christy credit for this, is she found this article that came out not too long ago, and it's a worthwhile read if you want to check it out. There's a lot of other points in there aside from what I'm highlighting here, but it asked audiologists about their competence level, how comfortable they feel in counseling families.

And they had 350 pediatric audiologists across the US. 75% felt counseling is very or extremely important. Great. The vast majority of you are like, yes, this is worthwhile. We need to be comfortable, and we need to learn how to counsel the other 25% in the sample who didn't feel it was very, extremely important.

I would like to have a conversation with you. But what's also interesting is, despite having three quarters of the folks say that they think counseling is extremely important, 75% of the respondents in the survey also acknowledge either a moderate or greater challenge in knowing how to assess psychosocial challenges and having time to address those needs. So not only are people saying it's really important, they're also acknowledging that there's a lot of barriers and a lot of challenges in doing this. Whether it's feeling comfortable, whether it's feeling you have the competency, or having just the time and the space. So that was sort of the backbone or the impetus for today's presentation, because it's another reminder of if you are feeling like you are not that comfortable or feel like your counseling skills are a work in progress, congratulations.

You are like most of your other colleagues in the field, the vast majority of people are saying they want more. And I think you deserve to be commended for trying to seek out that training.

So, without further ado, let's dive a little bit into talking about communication strategies to improve counseling for therapeutic alignment. The way that I tend to approach this section is I try to be very concrete and very specific in giving you strategies and skills that I think you can walk away with and literally take into clinic on Monday. Or maybe for those of you who are on the west coast this afternoon, the first thing that I start with may seem kind of painfully obvious, but I think it's really important is to just remember to be a person and establish rapport with the families that you see. A lot of times, you

know, we're in the middle of, it's busy, we're running back and forth, we've got a lot of patients on our schedule, we got this, that, and the other thing going on, and our mind is moving a million miles an hour because we don't have a ton of time to breathe in the course of the day. But, you know, take a moment, talk to the families, introduce yourself, and make eye contact, say hello.

The number of times I can think of doctors or nurses who come out and they're like, Mister Hoffman, come on back. And they're not even, you know, they look so miserable to be there, right? They don't even bother to look at me or greet me because they're just kind of mowing through their day, right? And so when I greet families, from the second I walk out there, right, making eye contact, introducing myself, making discussion outside of your medical scope, say, hey, how's your day going? How was it getting here?

How are you doing? You know, in Philadelphia, sometimes I like to talk about local sports because that's a pretty big thing in the area. But asking families something about just who they are and how their day is going outside of the medical visit immediately establishes a sense of rapport or comfort where they're like, hey, that guy is pretty nice, super easy, very quick, can have a pretty high payoff, but we often, sometimes can forget to do that, or it can be pretty easy to cast that to the side when we're caught up in the flow of our day. But when I actually get to working with patients and having them in my room as a psychologist, I think one of the single most important things that you can do is to normalize what the patient or what the family is experiencing. If you are getting training in counseling or social work or as a psychologist, this is like 101.

The first thing that you will hear most of your supervisors and most of your attendings talk about. They will say that normalizing is one of the most powerful tools that we have at our disposals to support families. And it really makes sense because patients and

families, when they come in, right, they're coming to the hospital, they're not like, yay, I'm super excited to be here or wherever the clinic may be, right? They're dealing with a challenge or a difference that may be going on for themselves or for their kid. And so in the course of that families have lots of questions or angst about it.

They're often wondering, hey, are these challenges that we're experiencing? Are they unique to me? Are these unique to my kid? You know, what exactly is going to happen? What's going on?

And so when you normalize and you say something like, you know, yeah, that's what we hear from a lot of kids. That's what we hear from a lot of families. It really results in families feeling a little bit more comfortable, takes the edge off of them a little bit, and then oftentimes we'll lead into them sort of disclosing whatever anxiety or discomfort that they might feel and then opens the door for further conversation. So when you're like, all right, normalizing sounds great. How do we actually do that?

So here's just some examples, some stems of a sentence that you might say, yeah, a lot of children will say that in the lunchroom at school. It's really hard for them to hear. Or a lot of children say they find it very overwhelming in the cafeteria. Yeah. Many others frequently tell me that the FM system, they really don't like that.

They don't like having to go up and hand it to their teachers and explain it to their teachers or if they have to go explain it to a substitute. Is that what it's like for you? Yeah. Given the history of hearing loss or given your history of what you've experienced, I would expect that that feels pretty stressful or pretty overwhelming for you. That makes total sense to me.

Or this is a very common experience among other parents of children with cochlear implants. Trying to make the decision about whether or not you're going to pursue

implants can be really, really tough. So all of those ways, I am just normalizing and validating what a parent or a caregiver or a patient tells me. And when I do that, it can really result in making them feel like they're being heard, and it can lead to more conversation.

Tied to normalizing will also be something that we call reflective language. In other words, it's a really, really good counseling strategy or counseling skill to think a little bit about, how am I showing my patients that I'm listening to them? If you are, this is true in psychology, I would say it's probably true in most medical fields that when you are first becoming a therapist and you are learning how to sit there and counsel families or support patients or work with them in the room, it's noisy in your brain because you are so worried about what is the next thing you are going to say or the next point that you're going to make. And that worry doesn't always allow you to sit and be present to hear what the patient or the family is saying. As you get more comfortable over time, we're able to sit there and listen to what families tell us and then respond in the moment, in real time to what they're saying.

Reflective language is a part of that, how we're showing patients that we're actually hearing them. And so how that actually works would be saying something like, if I'm understanding you correctly, you're telling me that you find the hearing needs really uncomfortable. It sounds like you wear them at school. We usually take them off when you get home. What I'm hearing is you really like them.

You feel like they're working pretty well for you. I get the sense that maybe there's some other things that could be going on. So based on what you're telling me, it feels as though there are some parts about your hearing aids you really like, some parts you really don't. Or I get the sense that based on what you're sharing as a family, you're struggling quite a bit with accepting this diagnosis with reflective language. If you listen

in the way that we talk, I'm using what's called a downturn at the end of that as opposed to an upturn.

Upturns would be, hey, do you want to go get some ice cream? When I say ice cream, right, that's an upturn I'm indicating in my vocal tone. That's a question that I'm expecting to respond. If you say, hey, I want to get some ice cream, and then I get, so I would like to get some ice cream, too. That's a downturn at the end of that.

So there's a difference in the way that you set it up as a question versus just a reflection. When you use reflective language, what's also really cool about it is one of two things are going to happen. You are either going to pretty accurately encapsulate what the family is saying and how they're feeling, which, of course, then they're going to be like, yeah, wow, like, Doctor Hoffman nailed it. He totally gets it right. Or if this might be aware, what happens if I reflect and it's not accurate.

Well, the way that we set this up, if you look at all these stems, is that I am giving you as a patient the space and the place to say, no, actually, it's more like this, because if I turn around to you and I say, if I'm understanding you correctly, A, B and C, the door is open there for you to come back and reinforce me. So either a, I'm going to nail it, or b, I'm putting it back to you to be able to give me more information so I can reprogram myself and redirect myself, and then hopefully I've got it on the next pass. So reflective language and normalizing are two of the single best and biggest skills you can use when you're counseling families to really make them feel like they're being heard and being understood.

Paired with this sort of the inverse, you could say, would be what I like to call avoid being the finger wagger. We are all aware of the finger wagger. It is like, programmed into our DNA. What I mean by this is most often our desire as clinicians, as healthcare professionals is I've got a lot of information, I've got training, I've got knowledge, and I

want to share that knowledge or information with you. And it sort of comes across in this form of, this is why you should do what I'm telling you to do.

And think about this for a second. It's totally common practice. If I go to the dentist, I know every six months when I go to the dentist, they're going to go, hey, Mike, have you been flossing? Do you floss twice a day? Do you brush twice?

Twice a day? You know, all that stuff? Yeah. That's not new information that they're giving me. I understand that I'm supposed to be flossing.

That is not going to make me turn around and start all of a sudden doing something different where I floss twice a day every day. Or, for instance, if I go to my PCP for my annual check in, and I may already know I need to lose a little bit of weight or maybe not drink as much. And that information that he's giving me when he turns around and wags his finger in my face, or she does, is not going to make me have some sort of epiphany of, oh, my gosh, I didn't realize that the doctor is right in this context in the environment that we're talking about. If you take a family and you say, hey, your kid really needs to be wearing their hearing aids all the time, 24/7 while they're awake, most families know and understand that concept. Me getting in a face and kind of wagging my finger and shaming them is only going to make them feel a little bit more defensive.

All of this is sort of that last point that I have down there about how there's a ton of research that says that when we give people information, that information in and of itself does not drive change, does not make differences. I would be willing to bet that intuitively, every person who is on this call has had this experience where we are with a family and we're talking to them and we're giving them information. We're, quote unquote, counseling them, and we're telling them all the things that they should be

doing different. And you can see it. You can feel that shift, that vibe where the family is just not really paying attention.

They're sort of glazed over. Look, they're waiting for you to stop talking, and you have that sort of reaction inside where we're like, hey, I know this family's not going to do what I'm saying, but I'm just going to get through the spiel anyways. We've all had that moment where we get frustrated when we feel like families aren't going to do what we tell them. And the reason information in and of itself doesn't drive behavior change. And so being able to connect with them, understand where they're coming from, really reflect how they're feeling, and then move more towards problem solving, that's a good path.

If we get in this place where I'm on one side telling you what to do and you're on the other side receiving that or arguing against why you haven't done that, that's not going to work very well. So always try and be mindful or be aware when you're becoming the finger Wagner. I remember getting in people's faces and kind of giving them the business, because if you find yourself in that position, it's probably not going to work very well for you.

Yeah. Frozen for a second there. All right, so another way to kind of carry what I was just saying forward is to think about reactions, to lecturing. What are some of the reactions we've experienced when we're telling families, hey, you need to do what I say. We're providing lots of education.

We can see them becoming defensive. We can see them becoming closed off. We can see them sort of pivot into justifying or trying to explain what their current views and behaviors are. You can see them starting to feel misunderstood. And so the converse of that, the way that we would counter that is to what I would call roll with resistance.

So in other words, when we are with a family and we can feel that moment at the counseling session where you're just kind of telling them what to do, and you can see them not really receiving it. You got to ask, how can I roll with this resistance? Don't go on an autopilot where you're just sort of finishing your spiel. So you get out of the room, pause, call it out. Hey, I can see like, you're feeling a little frustrated right now, or, you know, I want to be honest.

I know you and I have had this conversation many times. I know this information I'm not giving you is new. Would you mind telling me just what's going through your head? Or can you just tell me, like, how you're feeling right now? See if you can find a middle ground, see if there's some sort of compromisee to be had.

I promisee that dialogue and that conversation, when you can pause and call out some of that resistance, is going to feel way more productive and helpful than just sort of going through your spiel and moving on to the next patient.

So you may also be wondering, well, okay, but, Mike, obviously there's going to be some times where I need to counsel or sometimes where I need to be able to provide some information to families, right? Like, I've got a lot of education. I've got a lot of knowledge. I've got a lot of training that's worthwhile. I want to reflect that.

Absolutely. So here's my sort of Jedi mind tricks of how to do that. One is asking for permission. When we provide information asking for permission to get more buy in from them, it can generate more buy in. I'm sorry.

For instance, the way you do that is to say, is it for you if I tell you about some of the different options for hearing some of the different devices we have, is it all right if I share with you the three different CI companies that might be options for your kid? All of you might pause for a second, think about what it's like for you when you go into the

hospital, when you go into your own doctor's visits, when you go to your own dentist, whomever it may be, it can be a little dehumanizing. We're getting poked. We're getting prodded. We're getting tested.

We're getting told what to do for kids. And for a lot of families, there's not a great sense of control over what is happening in those moments and what's happening in the course of their visit. So if we pause and we say, hey, is it okay if I tell you more about it's all right if we do this, we're giving them a little bit more of that control back. We're giving them a sense that they have some say in what's happening in their experiences. And in that way, we're avoiding making these patients and these parents feel like everything is being dictated to them.

And you might be thinking, all right, I'll take your word for it. But what if they say no? Well, great, that's super rare. Very rarely will someone turn around and go, no, you can't tell me about that. And if they do, they say, hey, no, I don't really want to discuss that.

Guess what? They probably weren't ready to receive that information and really ready to have that conversation anyways. They weren't likely to retain it. If they do say that they're willing to have the conversation, great. And what really makes that Jedi mind trick fun is that if I tell you, you can tell me about something.

If I give you that permission, well, darn it, I just committed to that. I just said, sure, yeah, you can tell me more. And so now I've got to pay attention. I've actually got to listen to what you have to say. So either you're going to get this person to commit to hearing more of what you have to say and what you have to tell them, or they're going to tell you that they're not quite ready to receive that information, and maybe you just have to give them a little space to breathe.

Another question that sometimes comes up, especially for me as a pediatric psychologist and someone who works in the world of pediatrics, is sort of, what are the guiding principles or the rules for communicating with kids? I'm sure all of us have had those moments where we've seen parents who are really struggling or grappling with, how do I talk to my kid about whatever is going on from a medical perspective, whether it's audiology or syndrome, hearing loss, whatever it may be, right. Here are some rules that I think are pretty tried and true. If a kid is old enough to ask a question, they're old enough to receive the answer. What is really important about that is once a kid asks a question, that means that they are already thinking about it, they're already kicking that idea, chewing around on it in their brain.

And so if you sort of dismiss that or if you say, hey, we're not going to talk about that, well, then we don't have the opportunity to sort of guide them and shape them in the way that they understand that issue, whether that's, hey, you know, why do I have these hearing aids and nobody else does? Or why did this happen? Or why did that happen? When they ask the question, they're already got the awareness to think about it. And so don't brush them off.

Don't dismiss that. Be open and be honest with kids. They have really good baloney meters. Kids may not always be able to tell exactly, hey, this is what you're not being truthful with me on, but they can tell when something is not feeling entirely truthful. Also, you want to match where they are developmentally.

Things could be simplified. They could be pretty broad. They could be short and sweet. So match your kid where they are. Be open and honest.

The reason that I also think it's super important is if we don't talk with our kids about things that are going on, if we just try to avoid the discussion, who knows where they will land? Who has any idea? So there are lots of examples where kids just kind of

settle on really weird and funny explanations of things where if we're talking about teens and tweens, they're going to go online, they're going to go on the Internet, they're going to ask their friends, they're going to do research. So as a caregiver, when these questions come up, or when situations come up, having the opportunity to sit with your kid and really shape that discussion and mold that conversation or mold their understanding, you want to keep that powerful, not give that away or give that opportunity. So, same for you as clinicians when you're counseling families and families are asking you, how do I talk to my kids about it?

Here's some rules, here's some guiding principles that they can use and really empower those caregivers to feel like, hey, you're the one who's going to help shape the way that they think and understand about their deafness or whatever it may be.

So just as a reminder, we're not just treating the medical diagnosis, we're treating the whole family. We're treating the whole patient. And so we're going to make the patient and family feel as if we're there for them, acknowledge their whole existence.

So this is the next section on engaging patients and behavior change. This is a super quick and dirty primer. This is not exhaustive at all, but I really love this concept. This is called the stages of change model from prochaska and D. Clemente.

First published on and researched in the late eighties, in the early eighties. It has five or six stages of change from what's called pre contemplation, meaning I'm not thinking about changing a behavior at all to contemplation where I'm aware of a problem. I'm starting to think about it, chewing on it, but I haven't really made any sort of plans or concrete action steps. Preparation is now okay. I know this is a problem.

I know this is a behavior I want to change. I'm going to start to take some thinking about some steps to change it. I have some idea. Maybe I'm going to do it pretty soon. Action stage would be I've actually put some behavior change into action.

I'm doing it. Maintenance is usually about two years. You maintain that behavior and then of course there can be histories of relapse or falling back into old patterns of behavior. And then you sort of start over again and spiral upward. The reason that I'm referencing this is because for most of the families that we counsel who are difficult families, I shouldn't say difficult families, but difficult situations, or we feel like we're struggling with them, thinking about where they are in the stages of change, are they not even acknowledging that this is an issue?

Are they thinking about it? Have they made any intention to change? Are they actually trying to make changes? Can be really helpful to meet that family where they are. If you are trying to push a family into action, but they're still in contemplation and they haven't taken any steps to actually prepare for action, it's not going to go over quite as well.

So I encourage you to read more about that. Tied to that is actually another piece of psychology that I'm a huge fan of, which is called motivational interviewing. You do not need to be an expert psychologist or licensed mental health professional to do motivational interviewing. But the idea behind it is how to elicit change and elicit behavior change in patients. Word counseling, families.

Ultimately, what we're trying to do is get them to start new patterns and start new motivations. And so super quickly the way this works would be, hey, you know, on a scale of one to ten, tell me how much you like your hearing aids. And they might say, I might say something like really extreme. Like a one is like absolutely horrible. I totally want to throw them in the trash can and burn them.

And the ten is like, I love my hearing aids, or the absolute bee's knees. Where are you on a scale of one to ten? Kiddo might say, well, I'm like a three or four and I'm trying to get this kid to wear their devices more. I might say, okay, well, help me understand why are you a three or four and not say, a one. What makes you a three or four when I do that?

When you're using something like motivational interviewing. Now, instead of me talking at the kid to try and get them to understand why I think they should wear it, I'm getting them to say, well, the reason I'm a three or four and not a one is because I do like the Bluetooth. And I mean, I know they help me hear my teacher. Sometimes you're getting them talking about the positive reason. They're the ones who are now explaining the benefits of using their devices.

It can also include things like, what makes you think you need a change? A big one can also be, why do you think your parents care so much? Why do you think your parents want you to make a change? Or what do you think will happen if we don't make a change? The whole idea behind change talk or behind motivational interviewing is that most people have some ambivalence around a decision.

They're not always totally for or totally against that decision. And can I get you as a patient talking about a behavior change that you might want to make and you talking more, not me talking at you.

Thank you for our first person who put a question in the chat. All right, so Lisa said, for families in denial of hearing loss diagnosis and challenge the reliability of your test results every step of the way, any suggestions on how to counsel the family? That's a really good question. So in that situation, if I've got a family who is really kind of just not there yet in terms of accepting and understanding the hearing loss diagnosis, I

think what happens a lot of times, hey, let me bust out the audiogram, right? Let me show you my audio and let me walk you through this, or I'm going to put you in the booth and let, like, you sit there and watch while I'm doing this testing and notice how your kid didn't turn his head.

So we get into that position of really trying to, like, put the evidence in front of their face or show them where we got to the decision making that we did. And again, that sort of falls into that pattern of, like, I'm giving you all the information and you just need to take the information I'm giving you. What I would probably try to do more of is just pause and I would say, you know, I appreciate you coming back. I know that you've come for a few appointments, and I know it's been hard in being here. I'm sure coming to this visit is not easy for you.

I know that I can tell when you and I meet, maybe it seems like sometimes you get emotional when we're discussing the potential of hearing loss. Can you just tell me what's going through your mind or tell me kind of what your thoughts are? I would say, are there things that you feel like I can go over or help you understand better? Another one that I'm a big fan of is like, can you. I say this to families all the time.

I can see what's in the medical chart, and I can see what other providers have told you. But can you sort of walk me through what your understanding of everything is or kind of, you know, where things might be a little unclear for you? Maybe I can help explain, but I think a big piece is just like, you know, I know this would be really hard. Can you tell me, just, like, what would this mean if your kid did have hearing loss or a hearing difference? Like, how would that change things for you?

So I think really just trying to sidestep putting all the information to prove that they've got hearing loss in their face and more just trying to get information of, like, where are you coming from? How are you feeling? Like, what does this mean to you? If they do

have hearing loss, what is sort of the barrier that's getting in the way for you of being ready to take that next step into devices? And that might include a little bit more of understanding their background or their culture?

Great question. Hard to be super detailed without knowing a specific case of a family, but I think avoiding some of the. Let me just talk at you as to why my results are valid and more. Tell me where you are. Ask questions, figure out where they're coming from, and then ask what this would mean for them and kind of what might be helpful for them to hear from you.

Ask questions before you go into that.

Thank you for that. Great question. All right. And I would consider an absolutely beautiful segue into our next section, which is talking about cultural humility and culturally competent care.

So maybe I'm being a psychologist again and getting back up on my soapbox. We are all cultural beings, right? As humans, we have. Culture is a part of us. And when we are counseling families, we have to acknowledge the role that culture plays.

And the human experience is diverse. Our counseling cannot be one size fits all. You have to be flexible and willing and able to adapt your counseling to the family that's in front of you. And you have to be willing to kind of think about and consider how their culture and their previous experiences and their previous identities are coming into the room. An analogy I really like is ignoring the role of culture in your counseling or working with families is like ignoring the water when you're in the pool.

It's all around you. And so if you don't recognize that or acknowledge that, it's going to be pretty tough.

So. All right, that's cool, Mike, but how does culture actually show up in the room? Well, certainly in the language that we use, the verbiage, you hear lots of dialogue even now talking about modeling first person language or modeling disease specific language. Right. There's a whole debate about deaf versus hearing, loss versus disability, autistic person versus person with autism.

All of those things are reflected in culture and identity. There is also tons of research regarding racial and ethnic inequities in healthcare. Sadly, in the US, there's a large, large, large amount of disparity that can exist for black families, latin families, families of color, compared to white families. I am not going to go over all of that here. But if you do not ask yourself and think about how am I actively addressing some of the racial inequities that we know exist in our healthcare system, you're missing a really big opportunity.

You've got to acknowledge barriers for care. You've got to call out and recognize differential handling of patients. You might have to think about and recognize families that have a history of medical mistrust, who don't trust the system. When we're talking about that last patient and saying that they sort of were in denial at every step of the way, is there medical mistrust? Like, are there things where for you, in the history of coming to the hospital, have been really harmful for you?

Is there a history of medical trauma? And then thinking about even amongst ourselves in the team, right. Statements of frustration from one provider to the other about families, all of that culture, that identity, and some of these racial inequities are all intertwined. And so I really encourage you to try and think about that as you're counseling families and supporting families.

Tied into that is the concept of intersectionality. I didn't do this earlier, but here's your little question number four. Teaser. But according to the Oxford Dictionary, intersectionality refers to the interconnected nature of social categorizations, such as race, class, gender, regarded as creating overlapping and interdependent systems of discrimination or disadvantage. This term is credited to Doctor Kimberly Crenshaw.

Back in 1989, she's sought to be the one who first came up with this. Intersectionality also refers to how we are navigating one's own diversity and figuring out how to express that with clarity and confidence in different settings. So that might be environments like home, school, church, synagogue, the mosque, the cultural and the geographic communities that we live in. Right. So I was giving the example earlier of living in the Philadelphia area.

Over here, one of the most common hellos and goodbyes, especially during the football season, would be go birds. That's a cultural kind of phenomenon that happens in the Delaware Valley, just associating as an Eagles fan and then certainly codeswitching. So people change their behaviors, the way that they dress, the speech, the language, their mannerisms, to conform to a different cultural norm other than their sort of authentic selves in different settings. For instance, if I am on a presentation, talking to colleagues in a professional capacity, I am being Doctor Hoffman. That is really different than when I am going to be playing with my two daughters later, after school.

Thats very different than when I go to the gym. It is very different than when I am with my friends. Im sort of acting different in the way that I speak, certainly in the way that I dress, certainly my mannerisms in all of these different settings, depending where I am, we kind of switch.

Here's a really good graphic from Doctor Crenshaw that I'm a big fan of. That kind of depicts intersectionality as having all of these different areas, whether it's race, ethnicity, gender identity, class, language, religion, ability, disability, sexuality, mental health, age, education, attractiveness, whoever may be. So when you're looking at all of these different identities, they're constantly overlapping. And so when we're thinking about deafness in particular, that is one piece or one identity that a family may be grappling with and trying to figure out. Right.

But their view and their experience of deafness is very much tied into all the other identities that those families have. I can think of an example of a family I met with this past week who, they were immigrants from Sudan, and they were Muslim. And so the way that they view and understand deafness through their culture is going to be very different than, say, a white family who was born and raised in south Jersey. I had another patient earlier this week with a new diagnosis of hearing loss, and the mom is actually a medical resident from Morocco. And she was saying to me that when I first found out about my son's hearing loss, I was devastated.

Because when I think of deafness in Morocco, most of those kids do not have access to services or hearing aids, and so they end up either being nonverbal or signing or having some pretty significant language differences. And so for her, a lot of that grief that she was experiencing was tied up in our culture.

Another piece that sort of goes into all this intersectionality is thinking about power and privilege. I love this depiction. So if I prop myself up an example, I am, yes, I am a person who is deaf. I am a person who has experienced hearing loss my whole life. But I also am a white, cisgendered, heterosexual male.

I come from an upper middle class family. We had access to resources. We had a car, transportation. And so for me, my experience of being a deaf person is pretty privileged

because despite my disability, most of all of those other identities I hold are closer in proximity to power. For people who have disability or deafness, they may also be experiencing a lot of other marginalized identities that are tied up in their deafness.

So when we're running into conflicts or challenges with families, when we're trying to figure out how to counsel them, or we feel like they're just not quite meeting me where I want them to be, one of the questions might be thinking about, you know, hey, what are some of the other identities this family might hold? And is it possible that some of the challenges I'm experiencing are tied up in.

So, hopefully I don't have to keep belaboring this, but culture matters. We should always try to consider the intersectionality between multicultural identity and someone's experience of their illness or their disability. And we know for a fact that white, well resourced families experience hospitalizations, medical treatment, and illness very differently than those families or individuals of color who have less resources. And so I again, I say, if you are not thinking about asking yourself questions of how can I actively challenge or dismantle some of the inequities that exist in our healthcare system in the US, then you're really not doing anything to dispel the status quo. And I really hope that we can start to think more about how we can do that.

So to be a little bit more specific, let's shift to deaf identity formation. And here's your little teaser for question number three. They are out of order three and four. But I thought it would be worthwhile to also touch briefly on deaf identity and kind of how that works. What's super fascinating to me is that identity transmission tends to happen via three routes.

There's vertical transmission, which is from caregivers to offspring, right. My parents or whomever is raising me is teaching me about an identity that I'm going to have, say, my religion. My understanding of my religion mostly is shaped by the cultural tradition

and experiences my parents and my grandparents. There's horizontal transmission, which we get from our peers, people of the same age, and then oblique transmission, which would be from other adults and other institutions. So you either get it vertically from your own family, from those above you, horizontally from peers and friends, or obliquely from adults and institutions.

95% of deaf kids are born in typically hearing families. We know this. You don't need to hear me. Go over that again. But that means that the most common form of cultural transmission of what it means to be deaf is not happening from our caregivers or from our grandparents.

For most families, that identity about what it means to be deaf is coming from that oblique or horizontal transmission from other peers or other adults, teachers of the deaf, audiologists, slts, social media, schools of the deaf. And so at the same time as kids and families are navigating what it means to be deaf, they're trying to get that information from other sources. And I think caregivers in particular are also trying to figure out their own identity of what it means to be parents of a deaf child. For families, particularly if you have a family that's really struggling and accepting a diagnosis, I would be willing to bet that part of that is accepting this idea that, yeah, I am also now the parent of a deaf child, and I have no idea what that means, and I need to figure out how to define that, and I need to shift whatever potential thoughts or expectations I had in my. My brain to accept sort of this new pathway that we may be on.

So, again, families have to come to terms with what deafness means. What's really interesting about that also is that, in contrast, we never really have to define what it means to be hearing. If you're a person who's typically hearing, you really think about that as a thing. You're not like, oh, well, this is my typical hearing identity. Right?

The closest comp I've heard for some typically hearing folks is, yeah, you know, during the. During the pandemic with masking, sometimes it was hard to understand what people were saying. I had to lean in. But you never really think about what it means to be young. The caregivers are really trying to learn and figure out what it means to be deaf and to have a deaf child.

Another super interesting study, if you want to go back and look at it, is a pretty recent literature review article that covered 47 different studies assessing deaf identity in adolescence. A lot of really interesting thoughts that came out of that. Some of my most fascinating points, I thought was deaf identity is pretty inextricably tied to technology that is and isn't available at different times. For example, what it means to be severely profoundly deaf in, say, the sixties, seventies, and eighties, when you did not have access to something like cochlear implants, that identity has totally changed now that the implants available. My deaf identity as an individual would be totally different if I didn't have access to implant or hearing aids.

Right. And so as technology continues to evolve, what it means to hold that identity is going to evolve. We are sort of on the precipice of what feels like potentially a huge shift in audiology and speech and language therapy around gene therapies and gene treatments. Right. So, again, that might shift what it means to be done.

Excuse me, all identities, deafness included, they're complex, they're fluid, they're subject to change. And so I really like this term that talked about capital d, a, capital f, the capital f standing for fluid, because your deaf identity shifts and evolves. And so identifying with deaf culture is not in opposition to being someone who identifies with hearing culture. It has its own strengths.

We will hit our last section, which is psychosocial screening. So the reason I did want to touch on this. Oops. Is because in lieu of having all these questions and thinking

about having all this specific training and counseling, obviously using questionnaires and measures can be really helpful to kind of figure out where families are and to give you a good jumping off point for counseling. So let's talk about it.

Why use standardized screening in the first place? Certainly we know from questionnaires or measures it can uncover information that might not be shared verbally. Patients are more willing or more likely to tell you how they're feeling if you give them a questionnaire on pencil and paper on an iPad. And certainly if you push it out to them before they come in for a visit than if you ask them in the moment in the room. Using standardized screening can help to eliminate bias, reducing to whom we spend more time asking questions and when.

What's super nice now if you are tied to a hospital system or you're tied to electronic medical record, is you can push a lot of these measures and questionnaires out beforehand. They can get automatically scored. You can flag them and tell you who you might want to follow up on. So there's a lot of really good resources out there, and it can help you figure out if I use questionnaires and measures, who are the patients I want to spend more time with and who are the patients I can move through faster. So it allows you to kind of guide the use of your resources in a more efficient way.

But there are a lot of logistics that should be considered when we're thinking about something like standardized screening. So, for instance, you may want to ask a question. What exactly do you want to screen for? To whom are we screening? Who is doing the screening?

Am I in charge of doing the screening? Are we going to push it out through a questionnaire, through the electronic medical record? Am I going to have, say, like a nurse or an MA do it? How is that going to work? How is it administered?

How is it scored? I certainly think any opportunity to leverage digital options is important.

And then certainly for screening, what the heck do we do with that data when it comes out? Right? What's our game plan after we screen somebody?

So some considerations would be thinking about the age range of people that you want to screen of individuals. Are you targeting parents of little ones? Are you targeting teenagers? Teenagers and tweens? Who is doing our reporting?

Is that going to be, again, the caregivers and the child? Do I sometimes want teacher input? That would be a more intensive level of screening. Is there someone else who I think would be really valuable, maybe a tod or service care coordinator? Generally speaking, it's more burdensome, it's more intensive, but multiple readers is important.

There's some really fascinating research that looks like rates of psychopathology and the severity of psychopathology in teenagers. And the more discordant, the more parents in their teams disagree, the more predictive, that is of behavior problems. In other words, it doesn't matter if the parent thinks you're doing great and the kid thinks they're doing horrible or vice versa. If there's a big discrepancy there, that's an issue. And so in that way, getting multiple reporters can be helpful.

Also consider developmental and medical differences, right. In the measures that we're using and who we're screening, we got to be mindful of neurodiversity. Deaf kids in particular. We know that they can have some differences in language, linguistic skills, and reading abilities. And so can we be mindful about questionnaires that we're using that are language friendly?

Another question would be like, who do we want to screen for and what exactly are we screening for? So do I want general psychopathology like anxiety, depression, and ADHD? Do I want academic performance? Do I want more condition specific challenges like trouble accepting a hearing loss diagnosis, parenting stress, feeling different from other kids? Do I want a broader quality of life measure?

Do I want a parenting stress measure? There are a lot of different things you can screen for. So now that I've thrown out a whole bunch of different questions at you that hopefully have not scared you away from the possibility of screening, here's a super brief, but not exhaustive review of potential screening tools. Stop. Number one, the personal health questionnaire depression Scale, also known as the PHQ.

This is free. It's available through the NIH. You get eight or nine questions. There's also a shorter version that asks about symptoms of depression in the last two weeks. Add them up, score them up.

Pretty straightforward. We sum up the items. If it's greater than ten major depression, greater than 20 would be severe to major, major depression. So you're thinking, which of my kids who are deaf, who are most concerned about for depressive symptoms like these questions here, the PHQ is one way to do that. A quick aside, there's.

I mentioned there's an eight and a nine item version. The 9th item on the PHQ. Ask about suicidality. It is super important. I am not neglecting suicidality in any way, but if you are screening for that, I really want you to also think about, hey, how am I going to handle kids who tell me that they're actively suicidal?

What happens if someone's reporting that on their questionnaire? Do I have some sort of protocol or some sort of process to triage them? There also can be questions about legal liability if you're screening for suicidality. So it's a great thing. I don't think we

should turn our back on it, but just be mindful of how you're going to handle that if it comes up.

The sort of sister questionnaire to the PHQ is called the GAD seven or the generalized anxiety disorder seven item scale. This gets at symptoms of anxiety. Again, they fill out the seven questions for the last two weeks, and then you sum the scores you get these categories of a five is mild anxiety, a ten is moderate anxiety, a 15 or greater is severe. Generally speaking, a ten or greater would be some sort of referral for anxiety treatment. The GAD seven has a pretty high sensitivity rating, 89%, and a specificity of 82%.

So it's good and it correlates with things like panic disorder, social anxiety disorder, post traumatic stress. A lot of other pediatric illness groups are recommending annual screening of anxiety and depression. Endocrinology, hematology. So this is one option, screening for anxiety and depression. Option number two would be health related quality of life measures.

If you're not familiar with a health related quality of life measure, it's really designed to capture what the daily experience of someone with a chronic illness is four core domains, disease severity and symptoms, functional status, emotional and cognitive functioning, and social functioning. There are both condition specific, meaning death, specifically quality of life measures, and some that are generic. PQL has both generic and condition specific options. The promise is another free one that's available through the NIH. The here QL is deaf specific, and then the parenting stress index is another measure that gets it.

Obviously parenting stress. I'm not highlighting all of these here. There are links if you want to go look at their websites. Some of these are free, some of them cost money.

But just an idea of some different measures you can look further into if you're interested.

References thank you guys so much for your time. We have five minutes exactly for questions. If anyone has them, feel free to throw them in the chat. For the Q and A, I should say I can also keep blathering away if no one has any questions.

I appreciate. Lauren says, very interesting. Go birds. Thank you. I agree.

Lisa asks a question. Are the questionnaires free? So the PHQ, which is a depression screening, the GAd, which is the anxiety screening, and the promise are all free through the NIH. I believe the. And I also believe the p two L, which is a hearing, the quality advice measure.

All three, the parenting stress index costs money and some of the other ones are out there do. But if you want to do something like an anxiety screen or quality of life measure screening, there are definitely some free options out there.

That was a great question. I will also say, I certainly have the privilege of being in a hospital system and being able to be integrated into a medical system, right? So they have the opportunity to leverage me. For those of you who are in private practice, who are in smaller groups in the community, you can think about, hey, I want to ask about anxiety or depression or psychosocial functioning. Well, then what do I do with these kids if I have them, right?

Reach out in the community. Find psychologists or social workers, licensed clinical providers, email them and say, hey, I work with deaf kids. A lot of them sometimes need extra support. Would you be open to actually taking referrals from me? So network and figure out ways to send patients out.

You have another question. When a child needs a hearing assessment as part of their psychosocial assessment, and you're trying to build rapport for the child to do the assessment that the child is reserved and not wanting to do it, what are some tips you can give to these cases? So my number one move there is to be a little bit more preventative. When I have a kid and I can just feel them when they first walk in the room, they're like a little, just shy and reserved. I try and get them talking about themselves and talking about something fun.

I generally have like more time than most others, right? I have like an hour or longer for a visit. So I always start off that first five minutes of getting kids to talk about something about themselves and something they enjoy to draw them out a little bit more. Or maybe I poke fun at their parents. I can be very sarcastic and you can just pause.

That would also be a good opportunity sometimes to just pause and say like hey, I can feel that you're a little bit resistant or unsure. Tell me what's going through your mind. Or hey, we've got the psychosocial questionnaire in there. I can see maybe you're hesitating on filling out what are you thinking? So you can either kind of draw them out a little bit, give them a break, ask them what's going through their mind.

I think those are all things that can be helpful. Tina said, do you feel these tools can be applied to the high functioning ASD or autism spectrum disorder clients or do you have other screenings to help families help identify for further assessment? That's a great question. So I would have to go back and do some research to see if those specific measures have been validated in an autism population. But generally speaking I can't think of any reason why that would preclude someone from doing it.

Certainly if there are significant language differences then yeah, then they may not be capable of filling out the measure. But so long as that individual has language abilities,

whatever language they may use, ASL spoken English, there's no reason that a person with autism wouldn't be able to fill them out. That's a great question. That does also make me think about the McHat which is an autism screen, which you can also check out if you're interested in that too. That one is free.

Thank you for your nice comment Tina.

Thank you so much Doctor Hoffman, we really appreciate your time and your expertise. Thank you. Everyone sent in their questions and their comments for Doctor Hoffman. We'll go ahead and close the classroom at this time. We hope you enjoyed this presentation.

Thank you so much everyone.