REALTIME FILE

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HEATHROW AB – SESSION 5

HOW WE TALK WITH FAMILIES OF CHILDREN WHO ARE DEAF/HARD OF HEARING: REFRAMING THE DISCUSSION

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>> DR. RACHEL ST. JOHN: It's just now 11:00. I'll scream if we're not ok. I don't think that will matter.

Thank you for coming. I know you have a choice of workshops that you can attend. I always appreciate seeing an audience full of people, especially at this conference. I'm Rachel St. John. I've met a bunch of you, which is lovely, but I really appreciate seeing new folks in the audience. So for those of you that I have not met, I am the Physician Director of the Family‑Focused Center for Deaf and Hard of Hearing Children at Dallas Children's Medical Center. And I am one of your two American Academy of Pediatrics delegates to the Joint Committee on Infant Hearing. I'm not taking JCIH questions at the end of this, just saying. But it's coming. It's in process. It's with a journal. Hopefully it's going to happen.

So this is a talk I've given a couple of times. I'm always excited to give it to the audience at EHDI because this is a diverse and meaningful audience. So the title of my talk is "How We Talk as Professionals."

So I think we have to acknowledge the reality is there is a small but growing group of Deaf professionals who are working with families with deaf and hard of hearing children. But that is still a small number. And the real world fact that we're dealing with is that most of us in the field who are working with children who are deaf and hard of hearing, whether it's medicine, audiology, speech, early intervention, language support, whatever it is, most of us are hearing. So we have a huge responsibility to kind of be aware of how we talk with families because we do not occupy that space unless you're the parent of a child who is deaf or hard of hearing, you don't know what it's like. I've been doing this job for 17 years. I have worked with thousands of families. I am not the mom. So that is a very special role. And I don't pretend to inhabit it. So I think we have a huge obligation.

This clock on this computer is way off.

So I think it's really helpful to talk about what this talk isn't. Because I think it kind of sets the tone. And I have no financial disclosures. I was probably supposed to put a slide in but I did not.

Are you ok if we shut the door? Ok. Because I can't ‑‑ my microphone awareness is terrible. My hearing aids are on stun right now. But they cone in front of me so they're coning the lobby. Thank you, whoever just shut the door. Thank you. Lovely. Thanks. Oh, so much better.

So what this talk is not. This is not an expert discussion on Deaf culture because I am not the person to give that talk because I am not a Deaf person. I will talk about a few aspects that I think are helpful for framing the discussion but I am not giving seminar on Deaf culture. I'm not the person to do that. There are others who can do that more effectively. This is not the PC police. This is not a scare tactic. We're not here to talk about what words are dirty, naughty and offensive, though we will talk about terminology because it is very real.

This is not an indictment of the medical approach. I am a physician. I function in the medical model. I function very non‑traditionally in the medical model. But this is not about me saying my colleagues are a bunch of bo-bos, because several of them are sitting here and I know them so I can pick on them. This is not about saying, oh, these pediatricians don't know anything, or these surgeons. I'm not here to do any of that. And we actually need to get away from that because it's very counterproductive. I'm not here to tell you how to do your job. This is not a lecture about shame. I did not bring the bell.

Do you know who this is? Yes, my "Game of Thrones" people. There's not that many of you! Oh, just a few hands.

Ok. So I have no shame bell to ring at you and make you feel a certain way. This is really just meant to be a productive conversation or at least hopefully start some productive conversations.

I'm going to get my water because it's over there. You can tell I'm a really formal presenter. Normally I wear a ball gown but I just decided not today.

>> [Laughter]

>> DR. RACHEL ST. JOHN: It's cold. It's Chicago.

Ok. So this is a frank discussion about the way that we, who are primarily hearing professionals, approach and talk about and with individuals who are deaf and hard of hearing and their families. Because we are a bunch of hearing people doing these jobs. We don't apologize for that but we also can't forget about what space we occupy and that we don't occupy.

So, of course, learning objectives -- hopefully I will meet them. Again, while I'm not giving talks on Deaf culture, not giving a talk on Disability culture, I'm not the person to do those things, I am going to identify some core concepts and some differences between communities that can affect the way we talk with each other. So not a cultural expertise discussion by any means, but we are going to touch on a few characteristics that I think are important.

We're going to look at a concept of being deaf or hard of hearing that goes beyond what we call the ‑‑ what I call the medical pathology model. So when we are trained as physicians, and often as medical providers in general, the way we're trained, which is legitimate and works, is we identify a problem and we fix a problem. And that is a singular way that we tend to approach what we're doing. That model works a lot of the time. There are some times where it betrays us. And I personally think that there's one of them -- I think there's people in the room that have experienced that as well.

So we're going to try to get a broader concept of how we look at things. And then we're going to look at the critical importance of the ‑‑ when I say medical professional, I mean kind of anybody who is working with a family in some kind of provider capacity, so therapists, specialists, but how does the provider ‑‑ what is your role in valuing the family perspective in cultural context? And support family‑centered informed decision making, you know, what can we do to do this effectively?

So, again, not to get into culture because I don't represent anybody here other than whatever this is, but just to identify a few characteristics of communities that I think are helpful to look at.

If you look at the medical community, we have experience and a fund of knowledge that we go to a lot of school and pay a lot of money to get. We learn how to identify the problem. And we fix the problem. That's what we do. It's a valuable job.

If you look at some characteristics that we tend to see with the Deaf community, being deaf is an important part of the whole person. And a lot of goals as a person are very similar to others. They're attained through a visual pathway. But there's nothing in need of fixing.

So we already have a problem. Before a word is said, we already have a problem, which is, you have a provider saying I'm going to fix the problem and you have the deaf person saying I don't have a problem. This is not ‑‑ this does not set you up for success in a plan.

Then you have to consider the parent community, so a parent particularly of a child who has been recently identified as deaf or hard of hearing. Because I think most of the people in this room, if not all, understand what a critical time that is. No matter how old or young that child is, that is a moment, and it can be a short moment or a really long moment, that is really important for families to have what they need and the support that they need.

So if you look at parents who have learned that their young child is deaf or hard of hearing, it's highly variable. They may experience shock or grief or denial or fill in the blank. They may have all of these things going on at the same time. They may shift between these dynamics. They may find themselves in a position of advocacy. Sometimes that can be all I do is fight for my kid's rights and sometimes that's, hey, I'm starting something so I can support other people. Advocacy can look like a whole bunch of different things.

You may see families move into an independence and empowerment model where they're all about, ok, my kid's going to do what a kid's going to do at this age. And I'm going to let them fall down and let them skin a knee, let them get their feelings hurt and we're going to figure out how to get through this.

There are also families who view their child as vulnerable and may treat them radically differently than they would have if they were not deaf or hard of hearing. So sometimes that's a family model that's creating some other unique situations.

Some families are very open about what's going on. You see Facebook pages and blogs and vlogs. And some families are incredibly private.

In some family dynamics, one parent is incredibly public and the other is incredibly private. That's particularly tricky because there's a lot of feelings around that within that singular family context.

So where do all of these communities and all of these perspectives intersect? I think that's what we are working with when we're sitting with a family and negotiating some of this.

So when I broke this down in looking back over the last decade and a half of working with families with children who are deaf and hard of hearing, I looked at some of the things that not only I think are important but families have expressed to me are important. This is feedback that I've gotten from working with families.

Terminology I think is super important. Again, this is not about PC. This is not about, oh, there's words we use that we like and other words that are offensive. This is about how families view their child and the role and the impact that we have on that just by what comes out of the mouth part of our face when we talk.

I love Donna.

>> [Laughter]

>> DR. RACHEL ST. JOHN: You also love it when you know your interpreter. It doesn't always happen at a conference this big. I'm also a firm believer in the interpreter practice model. She is here and she is real and I can touch her. I know it's a little a‑typical but she's not over in the corner. I mean, you kind of are.

So terms. Use of words like loss and impaired ‑‑ oh, sorry -- paired with the term hearing. So hearing loss and hearing impaired. Even if you take hearing out, I don't love these terms anyway because they convey a lack of function that may actually not be there.

So I'm sitting with a family with a baby who is a month old, 2 weeks old or however many days in the world, and this baby is gorgeous, feeding, smile, pooping, doing all the cute things that babies do. And the family learns that this child is deaf. And if as a provider I look at this family and this 1‑month‑old baby who has done nothing but be a spectacular human for a month and make everybody around them smile and I say your baby is impaired, I have put the ceiling on the capacity.

We had a Texas EHDI pilot program where we worked with communities of families for years and got a lot of feedback from them, feedback from families I work with, things from conferences, we know that those first conversations, it does not matter how old you are, if your kid's in college, you always remember that day. I see a lot of nodding heads. No one forgets that day. And no one forgets ‑‑ they may forget the actual words but it's the Maya Angelou thing, they will never forget how they felt sitting in that room. And when I say your child is hearing impaired, I said there's a limitation. This kid has done nothing but been a gorgeous newborn, meeting all of their 1‑month milestones -- because there's not a lot to do to be a 1‑month‑old. Right? So this limitation discussion, if I'm setting it up right off the bat that we're not going to achieve, then those parents are going to be led to believe that their kid is not going to achieve. I set the pick. And this kid's done nothing but be a beautiful human.

I also think there's a practice and a discipline to this. Because I know lots of very well‑meaning professionals who say, you know what, when I'm with parents, I use certain words and then I'm with my colleagues I use other words. No, you don't. You don't. I don't. I certainly know when I screw up.

There's a reason I have a picture of a pumpkin patch up there. Because I may or may not have been part of a pumpkin patch charity project with a local church and I may or may not in moving all of the 1,500 pumpkins out of a truck on to the grass dropped something that may or may not have started with F and there may or may not have been one or two children around.

>> [Laughter]

>> DR. RACHEL ST. JOHN: Because ‑‑ be honest, the F‑bomb is alive and well in my home. It just is. I like to think that I am always just full decorum when I am at work, in a different environment. This stuff bleeds through.

Now, the good thing is I was not banned from the pumpkin patch. I was able to go back next year and help out again. So that was good.

But, if we don't practice it as day‑to‑day terminology, if we think, oh, yeah, when I'm with my colleagues and use the term auditory impairment or hearing impairment we all know what that means but when I'm with family ‑‑ it doesn't work. We're humans. That's not how we're built. We are good compartmentalizers -- we're not that good. At least I'm not that good. I don't know about you guys.

So I think terminology is really important because we're being perceived as an expert and we're giving information and when we saying things like lost, impaired, limitation, that's the tone that we're starting with, with families.

I think it's also really important to look at specific individuals and how ‑‑ the precedent they've set in this capacity.

I have to find out if my people are here. Are there any CrossFitters in the audience? Oh ‑‑ one in the back. Thank you. Thank you. I'm used to no hands. Because it's a cult that I'm very happy to be a part of.

This is Zach Rule. He is in my home State of Texas, in Houston. He is an owner and coach for a CrossFit Box in Houston. He was born with congenital absence of the femur. So he didn't have any long bones of the leg when he was born. And as a toddler, he had so much infection and damage that they had to amputate both of his legs. His mom ‑‑ I don't know him, just know from reading stuff in the public forum. His mom, her approach was ‑‑ I don't know if somebody said her son was impaired or limited in any way. If they told her that, she clearly didn't buy it. Because her response to this was to say, well, Zach, the world is not going to make excuses for you and I'm not going to either. I'm just not going to do it. So this kid, when he was young enough ‑‑ old enough to start helping out with things like setting the table, chores, his mom would just say, ok, get the plates down for dinner. And they were on the highest shelf. And she didn't move them down for him. He at one point said, How am I supposed to do this? She was like, figure it out. And he did. He got stools. He crawled up. He scaled things. I'm sure there were some broken dishes that were cleaned up. But the expectation was find a way. If you need help I'll help you but you have to navigate a way. So this was the mindset from the beginning. Do for yourself.

So I have, and I hope it works, hope, hope, hope it works. Oh, he didn't upload the new presentation. Oh, he did. There was a question of whether my YouTube video made it. I don't know if this is going to work. I have a four‑minute video that I hope you will indulge me in watching. I have gotten very good feedback about this video but, again, it's kind of personal to you.

This is four minutes of Zach Ruhl doing a very specific workout at his box called Tabata workout. So it is eight moves, 20 seconds of maximum work and 10 seconds of rest which is basically just getting to your next activity before you fall apart as a human being. And I want you to just watch how he approaches this and just take it in for four minutes. So let's hope this works.

Video unavailable because you did not upload my link, sir. Wow. Well, the good news is I was kind of prepared for this. So I don't think I'm getting ‑‑ yeah. You get no video. I'll have to have a talk with my friend. He put it in there but he did not upload it to this room. So I apologize. It's an awesome video.

Basically, he goes through ‑‑ I gave this talk in Austria when I had 20 minutes. So I had the video. So I have a backup. These are three pictures of Zach doing some of the aspects of the workout. He does everything from his performance to max chair which weighs about 21 pounds. And it's a performance chair. It's light. So this first one he's actually doing freestand hand stand pushups in the middle of the room with no support with his wheelchair strapped to him. This is a bar muscle up where you hang from the bar and pull your entire body on top of the bar. I've been cross fitting for 5 1/2 years, that doesn't happen without something strapped to me. And this is a little hard to see but this is a 15‑foot rope. And he is doing max rope climbs in 20 seconds with the chair.

So he's a beast. I mean, he's just not an average athlete. I would really struggle to call this guy mobility impaired. I can't ‑‑ this business of ‑‑ I need a wall. I can't do this in the middle of the room. I can’t do this with legs that I rest on. So he does legless rope climbs, all arms. I need everything to get up the rope.

So if somebody sat with his mom all of those years ago and said your son's going to be mobility impaired, I don't know if that happened but if it did, they're all laughing now. It just doesn't make any sense. Because we never knew what he was going to be capable of. So to make that proclamation at any time but certainly in that very, very newborn period when you have no idea what's coming, not only does it not make sense, I think it's inaccurate. I think it sets us up for some bad data.

I'm sorry the video didn't work out because it's fun.

So I'm going to use an example of an individual who knows he's in this talk. But this is somebody who is much more specific to our field. Yes. A few of you are clutching hearts because you know who this is.

Does anybody know who this is? You shush. Anyone? This is Christopher Moreland. He is an internist who works at UT San Antonio. He is the Residency Associate Program Director. He is completely deaf. I don't know if he was born deaf. He was identified in his toddler years. He is a very eclectic individual in terms of access. He uses everything. So when he's one‑on‑one with students, with colleagues, he uses lip reading and spoken language. When he's in a larger group, on rounds, in a conference, he uses American Sign Language. And he has a designated interpreter, Todd, who is an absolute rock star and I think has been with him for about 14 years now. He started with him as a student and they've just ‑‑ it's his work husband. But he has a designated interpreting team.

So these folks ‑‑ first of all, you have to think about the fact that somebody hired him very outside a traditional model. And then they had to hire an interpreting team that came with that and kind of create that from scratch. And you think, wow, this is kind of a lot to take on.

What I love ‑‑ and this is kind of the thing that starts getting me. This becomes a because of not an in spite of. I think we tend traditionally to have looked at folks who have some kind of difference whether it's mobility, hearing, vision, whatever it is, and talk about all the amazing things that they do in spite of their condition, they've overcome. And those things are true. But I think if you only focus on the overcoming and the catching up and the surpassing, you miss the what do I bring to the table that other people don't. And Chris is definitely one of these people. If you talk to Dr. Luci Leykum, his boss, she has this fabulous quote. And there's a great article on the internet about him. If you Google him, you'll find it. But this is her quote. It says, "Dr. Moreland has brought a lot of positive energy to the group and in ways I would not have expected. On a subtle level, having Chris in the group has made us more aware of how we interact with each other."

So he's better for their term because he's deaf not in spite of the fact that he's deaf. And that's the thing that if we are only functioning in the medical model and we're only functioning in a pathology mode of problem solving, we will never see this. We will never see the fact that you actually bring some diversity to the table that other people who are hearing can't do by nature of who they are. And that gets completely lost in the process. And I think it's a shame to miss stuff like this.

So I've talked a little about terminology. We talked a little about specific people as examples. I do have to focus a little bit on language. Again, I am not a linguistics expert. I'm not here to break all of this down. But I think there are some things we need to think about when we are perceived experts.

So when families are sitting across from us and we're giving them information, we are being seen as the expert. They are trusting us to give them good data. In our field, it happens fairly frequently that language choice is presented as single mode. You're sitting across the table from somebody and they say this is what you should do. And that's it, one path, one road. You do that. And families often don't know enough to say, Can we do more? Are there other things we should be thinking about? That doesn't necessarily occur to a family grappling with drinking from the fire hose and absorbing this information.

So this tends to happen ‑‑ do you think that's a fair statement? Ok, yeah. Lots of heads nod. Ok.

I think the reason that people tend to focus on this single mode, it may be impacted by a couple of things. One is just lack of knowledge about what else is out there and the legitimacy of what's out there and also comfort with what's familiar. It's the whole I'm a hammer and everything's a nail. It's such an easy place to slip into. You're just like, I'm in my lane, feeling comfortable with the information. I know you're here to see me for that. But it is quite one thing to say here's what I'm an expert in, here are some other things I really can't counsel you on. Let me at least steer you in the direction of finding somebody who can versus it's my way or the highway. Those are really different messages for family.

This is something I struggle with a lot in the south. I did not see this nearly as much when I lived on the East Coast. I see this a lot where I live. There's often a perceived lack of equivalence between spoken spoken bilingualism, and spoken visual bilingualism. So it's a rare person where I live in Texas who says: Well, now that you've been living here a long time and your kids are totally fluent, and they're going to school as English speakers, you should really stop speaking Spanish at home. Because, you know, what's the point? Your kids are surrounded by English all day long.

Actually, there are a couple of people who have said that to families that I see. It's disgusting. One of them was the principal of the school. That was a bad day. But the good news is they were in my office so I told them what I thought about that.

We don't usually tell people to give up your native language. I've never in 17 years counseled a family to take language away. I've never told hearing parents to stop talking with their deaf children. It's what you do. When you interact with your baby, if you're a hearing speaking person, you're going to speak, sing, play with the baby. I've never told somebody to stop. I've never told somebody don't do this.

Everyone's really comfortable with all the advantages of spoken spoken bilingualism. It's so great to know more than one language. That doesn't translate somehow into the spoken visual world. I think part of that may be back when we didn't have aggressive ways of identifying kids early and providing language support early. And kids were so derivationally delayed. It was like this last ditch damage control kind of model we were in and people were like, we've got to focus on something.

We don't need to be functioning that way anymore. We're all trying to get kids 1‑3‑6 at this point in terms of screening, identification, and intervention. We need to be talking about early language access. Because that's what human beings are designed to do, learn language early.

So there's a lot of disconnect here. I am not here to throw anybody under the bus. I may accidentally do it but I'm really not here to do that. I really appreciate when people put questionable data out because it gives me teaching points. I use it and I take it as the gift that it is.

So this was a workshop that I attended several years ago. Some of you may recognize the slide. I don't know. I don't know who might have been there. But there was a workshop that was given by a professional who was talking about measuring richness of language. And this person was very grounded in listening in spoken language. That was their expertise. They knew an awful lot. And it became very clear to me that they actually didn't know a whole lot about American Sign Language as a language. They only knew what they saw.

So this person was talking about ‑‑ can you see that? Oh, gosh. If I close this, are we going to lose CART? It went away.

So, this person basically said when you look in the Oxford English Dictionary and count how many words are there, it's over 170,000. Very rich. When you look at Random House Webster's Unabridged Sign Language Dictionary, there are about 5,600 signs identified. And I believe the quote from the CART transcript was, "So that's a lot of finger spelling that has to happen." And I lessened to this and I went, well, what you're doing is measuring a high contact language, which is American Sign Language, using a low context tool, which is word count. So, you can't do that. That's not how you can judge complexity, grammar, syntax, any of that stuff. You can't do it with number of. It's not a volume issue.

So the best sort of demonstration in real life that I have of this ‑‑ and I know maybe some of you have seen this before. So if you have, bear with me. Again, a speech therapist that I have known in the past who is incredibly bright and very caring and very well‑meaning once listened to a talk that I gave and she said, "You know, I've heard everything you said but, you know, we have all of these amazing descriptors in English like, you know, uh, schooner, catamaran, raft, and at the end of the day there's only one sign for boat."

So I have a slide called "There's Only One Sign For Boat." It's my favorite slide ever. I thank her every day for this gift. So, again, this is evaluating a high context language using a low context tool. So I'm going to do a little exercise with you guys. And for those of you who know sign, this will not be strange. For those of you who are unfamiliar with it, this will sort of be if I've done my job today.

I'm going to try to make the mic come with me a little bit for CART. CART is going to struggle here because I'm going to a whole lot of visual stuff. Now I'm in front of the slide.

CART -- I'm letting the CART people know that there's going to be no sound. So this is an eyes thing in the moment.

Ok. Ready?

Boat.

What is it? What is it? Kayak. Got it. ok.

Ready?

>> Sail boat!

>> DR. RACHEL ST. JOHN: Right. Ok.

>> Row boat. Or canoe.

>> DR. RACHEL ST. JOHN: I didn't do a good job.

Big, rich people, party, party, party.

>> Yacht!

>> DR. RACHEL ST. JOHN: It's a yacht.

So, yes, there is only one sign for boat because the way that American Sign Language works is we have this thing called topic comment where you have to -- because it's a visual language you have to put the thing in space first and then you talk about it. Most of the romance languages work this way, too. When you think about somebody using French or Spanish or Italian, they don't say a blue dress. They say a dress blue, not a dress that is blue. That's English speakers.

We -- in English particularly but in spoken language we do all of this lead‑up. And this is going to be super English: So yesterday you would not believe, Oh, my God, so much time, I just can't even believe how long, and I just stood in line forever at the grocery store. Like, we take all day to get there.

These languages just work differently. But if you measure one with the yardstick of the other, it doesn't look good. So I love my friend who told me there was only one sign for boat because I was like, you are correct, and? We add in all the descriptors. And at the end of the day if we want to be super specific, then we spell. If I really want you to know it's a row boat, I will ‑‑ you will get it. But you'll get it last. Because that's ‑‑ it's not English.

So when you are across from a family and you say things like: Well, you can learn both but, Uh, learning sign language as an adult is so hard. Ultimately a family will do what's comfortable for them. And I will support them 100% if they're informed. But if that's the setup and the family goes, well, the expert has told me it's too hard to learn, not only may that not be accurate, you've decided for them. But, again, we go to what we're comfortable with. We go to what we know.

When I function with families, I like my number one through 1,000 goal is early language access because brains, as we know from a lot of data, that are deprived of language early do not do well. And at some point you hit a point where it's almost impossible to catch up. So my feeling is as much language as possible.

And your child will show us what works for them. I have kids who remain bilingual. I have kids who shift from one to the other. I'm not telling them what to do. They've got access to both. They're organically using in the moment what works for them. That's how I know it's successful because the child is demonstrating to me that they not only have language but they have a language preference. And my crystal ball for who is going to do well with what is lousy.

So this I think, we collectively as providers, if we don't know what we're talking about, we need to defer to somebody who does. I do a lot of counseling with families as part of our Cochlear Implants team. When they start asking me specific questions about the surgery, I say: I am not the girl. You're going to talk to your surgeon about it and they're going to give you really good information.

I'm not going to pretend. I'm not going to make stuff up. They're perceiving me as an expert and trust me enough to ask me. I'm not going to make something up so I look smarter than I am.

I think there's also a tremendous need for parent organizations because, again, unless you have the parent experience and you've sat in the chair and you've received the information, you don't know what it's like. I have watched that unfold in front of me for almost two decades. I have not ‑‑ I've experienced it with families. I've been very emotionally affected. It's not me. So for me to think that witnessing it for 15, 16, 17 years makes me an expert, it's not how it works.

So I rely ‑‑ in Texas we have two very robust chapters. One is the Texas Hands & Voices, incredibly active. They worked with me several years ago so that I could directly refer under HIPAA to them. So we set up an online thing where I could go ‑‑ and Mikhail gets a referral.

The other one, Texas Parent‑to‑Parent, spectacular. They are a parent organization of parents ever children with multiple medical needs. And so these are the families who have six, seven, eight, 12 physicians they see. They live at the hospital. They should have their own parking spot.

This is really important in empowering families and popping that bubble of isolation. Because they're not alone but the next person who has a similar experience probably doesn't live next door to them unless they're real lucky. So I think these have been very helpful. And I rely very, very heavily on them.

I think this is where we have a lot of work to do. And it's hard. It's hard finding people. This is not easy. It's not like, oh, I have, like, 17,000 people lined up at the door. This is tough.

Bobbie Beth Scoggins. Do you know her? She's Former Executive Director of the NAD. She used to work in Kentucky and did a lot of outreach there. She tells this ‑‑ I don't tell the story nearly as well as she does. But she tells this story about how she was visiting ‑‑ she had done some very, more rural outreach in a small town. She was visiting a town. And she met a young woman who was a teenager who had never met a deaf person before. So she was thrilled to meet Bobbie. She was asking her all of these questions. She kept asking this weird question like, How are you here? Not why are you here. She's like, How are you here? How are you visiting? And Bobbie was like, What do you mean? And finally she pulled out of her, this girl thought if you were deaf, when you hit adulthood you died because she had never met a deaf adult. So she just assumed she was going to die. She had this death wish hanging over her head. Like, can you imagine? I can't imagine the anxiety that would go along with that and nobody there to say, no, no, that's not how it is.

So this is where Deaf role models become very critical. It's hard. You have to really work at establishing those relationships. I think Texas Hands & Voices forces us to work on beefing that up. I defer to colleagues of mine and lean on them all the time for making sure that families connect as best they can and take advantage of whatever kind of access. Some families are very proactive about seeking out deaf adults to meet and some don't know that would be helpful. So even just letting them know that that might be a really helpful thing for you to see somebody who is grown up and what your baby might look like in the future.

I think this is a really big one, the need for identity development support. We mentioned that parents may view their child as vulnerable. And that definitely frames the conversation and how those interactions happen in a very different light.

The anxiety of missed information. You know, I used to ‑‑ I think I used to. When I was really young in my practice, I used to really miss how important this was. And in working with families longitudinally and seeing children grow into young adults and have to learn to advocate for themselves and make their needs known and interface with hearing people all the time because, you know, as we all say, you're living in a predominantly hearing society, I've really become very appreciative as to how anxiety‑provoking it can be. And the weird thing about this -- the way I view this, this is like winning a pie eating contest and the prize is more pie. Because the more ‑‑ and I use this term very loosely ‑‑ successful you are, right, the best ‑‑ have the best [Indiscernible] to with my Cochlear Implants, I can talk on the phone. The better you look, the less likely people are to acknowledge that you're actually still a deaf person regardless of what is on or in or around your head. It is still who you are.

So there's a huge amount of anxiety that goes along with this. It doesn't affect everybody the same. Some kids and young adults power through this with minimal impact. Some are leveled.

Has anybody seen this on social media? This was written by a young woman, Tory McPherson, a young deaf woman ‑‑ I don't know her. I only know of her what I read on her blog. But this was making the rounds. If you're interested, you can easily search for her and you'll find this. I think it's on Facebook or ‑‑ it's not on Instagram or Snapchat because I don't have any of those.

So she's a young deaf woman who has Cochlear Implants or two. I don't know actually if she's bilaterally implanted ‑‑ who went to medical school. This was a very driven, bright, motivated young woman going to medical school as a deaf person. Hard to do. Medical school is hard anyway and then you've got all of these paralinguistic factors on top of it.

So she shared her experiences about deaf anxiety. She found there were all of these people out there going, yeah, me too, me too, me too -- and I just put up some quotes for her. I don't want you to misconstrue these. This is not about how Cochlear Implants don't work or how being a listening spoken language user doesn't work. That is not what this is about. This is when it does work, all of the stuff that you still have to manage as a deaf person, even when your technology is working great and you're getting great results. We haven't replaced hearing yet. We haven't done it. We might at some point. I don't know. There's research going on all over the place. This is not native hearing. This is different. This is supported.

So I just put up a couple of quotes just to kind of illustrate what people might negotiate. Because I don't live this. My auditory processing stuff is what it is but I pretty much essentially function as a hearing person.

“I learned to compensate for my deafness in a hearing world to make hearing people around me more comfortable with my deafness. I always said sorry I'm deaf knowing I shouldn't have to apologize for my deafness.”

So coping mechanism. Right? I'm the minority and I'm figuring out how to make it work.

“I learned how to mirror hearing people's facial expressions so well that it appears I actually understand what they're saying. With groups of hearing people I laugh when they laugh, nod when they nod, and hope to God they don't ask me a question. Because even if I did ask them to repeat something, my voice was ignored and two minutes later when everybody started talking on top of each other again.”

This is not about having crappy friends or crappy technology. This is about being in a group of people and the way that people who use auditory language function. We interrupt each other all the time. It is normal discourse for us. And if you are compensating for that in any way, shape or form, there's an added layer that people don't usually see.

This one kind of got me a lot. "When I'm alone, I'm always looking over my shoulder thinking someone might be calling my name or trying to get my attention. I never want to appear rude or like I'm ignoring anyone."

This actually happens to me at work all the time. So on the occasion where I don't have any hearing aids in -- because I benefit tremendously from the coning in the background damp and the filtering, and if I'm not wearing them, I think I'm awesome. And everyone knows I left them at home because I walk away from people. People are talking to me and I walk away. And thank goodness my nurses and APP are like, Ggirl, did you not wear your aids today? Like, they know what's going on.

Being aware that you are missing stuff, little kids manifest that in a very funky way. Older people can write blogs and share and talk about it. 5‑year‑olds, they don't know how to say it but you will see it. You will see them getting anxious in very specific situations when they become aware.

“A lot of people assume I'm not that deaf or I'm hard of hearing because I can speak well. I'm profoundly deaf.”

So, again, it's the like if I'm looking more hearing, then people, of course they think you're hearing. That's how this works. This is not because anyone screwed up. This is just how things happen.

This was interesting. "When I was in medical school, I would try so hard to make it look like I was on the same playing field as everyone else. In reality it would take me five hours to get through a one‑hour lecture, having to listen to some parts several times to understand what the professor said, give up, try to find last year's notes because this year's wasn't uploaded yet. God forbid the professor had an accent. So I was stressed, exhausted, miserable by the end of the day but I didn't tell anyone. I didn't want it to look like I was making excuses. “I'm fine. I'm great,” I always said to everyone except a few as I kept on drowning."

This is not because the stuff wasn't working for her. It's because she was a human being and she had to navigate some additional layers that the people around her who were hearing didn't have to. And if we don't see this, and we don't help parents predict that some of this is going to happen and be prepared, seen when it starts coming up ‑‑ it's not like, oh, my gosh, my amazing, wonderful honor student is falling apart. Are they doing drugs? No. Well, maybe they are. I don't know. But they may just be hitting that point where the amount of cognitive overload is so massive that they're having trouble negotiating it.

So that's a really important part of the identity piece. And this goes along with the child made hearing. You know, we don't change kids by giving them access to sound through technology. We don't change who they are. We change how they access their environment and how they access language and how they access people but we don't change who they are.

So when all of this stuff kicks in, when you have a really successful kid who wants to go to medical school or law school or get a Ph.D. or whatever it is and they start bumping up against that wall, wherever it starts affecting them in school, whether early or later, where the overload and the anxiety of what I'm missing and the need to do extra work to try to stay with what's going on becomes so overwhelming, when people don't acknowledge that you're actually a deaf person and they really say, hey, you know, you've got all the goodies and we've got all the right FM and all of that stuff, you're good, there's things that have to be managed.

So when I start talking about this with families really early because I don't want them to get to that moment where their child is 16, 17, 18, and gets really mad and says, why didn't you give me, fill in the blank, whatever it is, why didn't you give me sign, why didn't you give me a Cochlear Implants, why didn't you give me a hearing aid on the other side, you pick, there has to be an acknowledgment that these kids are who they are. If we don't, they're going to find out on their own and then that looks really different than if their family has been with them during that process. Those are two really different situations.

So I'm going to wrap up. I might have a little time for questions. So this is really like a miraculous day for all of us. I just want to share a couple of things that I have found very helpful for me. You can pick one or 10 or none of them if none of them appeal to you. I just like sharing what I found to be really effective in working with families.

I aggressively refer to Early Childhood Intervention. And I empower my colleagues in other fields to do the same. So I work in the Department of Otolaryngology. I'm a bit of a mut. I'm pediatrics but an associate professor but I'm not a surgeon. You can ask my boss. I don't know.

In an ENT office, which is classically surgical, when I arrived and said how do you refer to ECI, they say, oh, we give the parents a brochure. I said, awesome; that stops today. Because what happens? You give them one more piece of paper and it gets lost with all the others. Families are busy. I empower my colleagues to take away those barriers so that they can make those ECI referrals, too. So they go to Alicia and say I need an ECI referral. And then the magic happens and it's made.

I just have to acknowledge that parents are swallowing massive amounts of information. It is overwhelming. The number of appointments sometimes is overwhelming when you're talking about kids who have multiple medical needs. I might be one piece of their day. It's really important for us to sometimes understand when a family no‑shows or has to reschedule, I haven't seen them in a while, often I find there's been some intercurrent real life stuff going on.

I have found -- and this is me and my strategy. You, I'm sure, have your own strategies. When I am first working with a family who has never encountered any of this, terms that they ultimately come to embrace like deaf initially can be very scary and don't carry the same meaning that they will until families have kind of been in it for a little bit. So I tend to start with descriptive language that's person first. So it's fairly emotionally neutral. So I talk about, you know, your child has changes in their hearing. That's how I start. Then I walk them through what it means. Then we have lots of time together. Over time they're getting comfortable. And then at some point they come to me and tell me the word they're comfortable using and that's the word I use with them. And it can look like anything. I have found that this gets me more traction in helping families find their own identity. Because it's getting redefined every day.

Focusing on strengths and maximizing opportunities for learning. If we talk from a pathology paradigm, if we talk from a needs to be fixed paradigm, that is what parents will cognitively assume, period. We are the perceived experts. And we are experts. We don't have to apologize for our knowledge. We just have to be smart about the way we talk about it.

Connecting families with outside organizations is my everything. And just acknowledging that even though I work with families like yours, I don't sit in that chair that the mom and dad sit in. And I think that's really ‑‑ sometimes it's one of the most powerful things I do.

The visual audiogram. I know not everybody's comfortable using this information and that's fine but one of the things I do when I sit with a family for the first time, I take their results and I put it on this graph that's on the right which shows you this lovely speech banana and where all of these things happen. I can draw the two ears in two different colors. We can talk about access under the line, no access over, what does that mean specifically for you.

And I've had families sometimes who have 10 years of audiograms in a binder and I just ask them have you ever seen one of these say, oh, I've never seen it. Then they go, that's why when I call their name they turn around. I thought people have been pulling my leg. It's very powerful. So for me that's been incredibly helpful, to show families where that's happening. And it's not that our audiologists don't do an awesome job that first time, but you know the goal studies; up to 80% of information at time of diagnosis can be lost because it's a massive amount of information families are trying to retain.

So my parting thought and then we'll have a couple minutes if anybody has any questions. I have a parent in my parent panel and her son has been wildly successful as a bilingual, bi-oral Cochlear Implant user. So he signed, got implants at 6 months old, and now at age 3 is using both sign and spoken language and just tested out at a 5 1/2 year level for listening and spoken language at age 3. And this is a kid who had language from the get‑go. So this is your poster child. This is his mom's quote. She said "Poor communication can discourage and alienate families so quickly but great communication can be such a stabilizing force in a very uncertain time." And I revisit this all the time.

So I hope this has been helpful and that you've been able to pull a couple of nuggets that might work for you. And I would be -- in the last four minutes that we have, I'm happy to entertain any questions that you have.

Hang on for a mic so CART can capture you.

>> As a diagnosing pediatric audiologist, I heard you use terms such as changes in hearing and I typically talk about the audiogram and access. I would love to not use loss but I guess ‑‑ what other terminology, I guess, would you say? Or if I say change, they're saying, were they born like this? Is that indicating a change? I could see that being potentially confusing. So having that conversation on an initial diagnosis.

>> DR. RACHEL ST. JOHN: Such a good question. I love it when your colleagues and friends are in the audience and then they whack you with a good question.

I'm actually going to punt a little bit to the new impending ‑‑ the terminology section. And the way that we have approached this -- because we know it's complicated, we know that people use these terms differently. We actually talk about the term hearing loss very specifically as late onset and that at birth we talk about deaf and hard of hearing. So when I'm talking about where you are in a moment, we talk about a hearing level or a hearing threshold. And that can change, change for anybody.

It's weird because in visual language we can illustrate it no problem. In English some stuff sounds weird. Like you write it and you say it and you're like ‑‑ like grammatically it sounds weird. So I think we struggle with that.

The way that we've tried to make it a little more consistent ‑‑ I don't know if it's super clear, but, loss truly is ‑‑ I started here and I went to here. If I was born without, I was born without. So we say deaf and hard of hearing and here's where the level is. There is no level. Your child didn't respond to anything. Or the level is down here at 90 decibels and here's all the things that you don't hear above that level. So that's what has worked for me.

I think as a provider, you have to figure out what feels good for you. There's some stuff where you're like I've tried saying it 50 times and it's not working. Then, yeah, find something else.

It's an awesome question. Thank you.

Anything else? We've got ‑‑ we have two golden minutes.

Hi, friend.

>> I just want to address Zach, the CrossFit guy.

>> DR. RACHEL ST. JOHN: Feel free. I'm so sorry. I would have gone over if we had watched the video so there you go.

>> So, I'm in a wheelchair obviously. I think it's great that Zach does CrossFit and can do anything that a person who is not in a wheelchair does but ‑‑ I'm in a wheelchair but I walk. So at work I walk to the bathroom. And Special-Educators will say, “It is so great to see you walking. You must feel really good today.” And it would just irritate the hell out of me. So you know, I asked another friend who has been in a wheelchair since childhood why does that make me mad and she said it's because what they're really saying is don't you wish you were like me, don't you wish you could walk. So I have a little concern about holding Zach up as the role model for all of us because -- I guess that's what I want to say.

>> DR. RACHEL ST. JOHN: First of all, you are the best. Thank you. And, again, when your friends are in the audience and they hit you with the hard questions, it's my favorite moment.

What I take away from this is, number one, absolutely. Number two, I think the way I need to talk about him in the future is that he does it in the way that is functional for him. And this is not the standard for anyone.

See, every time I give this talk ‑‑ the last time I gave this talk I had a mom say, you know what, when you talk about the visual audiogram, could you please go up there and point out what's typical hearing? Where's the cutoff? It never occurred to me to point out 25 decibels because that's where speech starts and she goes if you just made a dotted line there; that would be so helpful.

So thank you. Because, again, my intention was not to hold him up as this is the pinnacle. I mean, nobody's going to do what that guy does. I don't care, wheelchair, not wheelchair. He's just an athletic dude. But your point is so good, which is he does the way that works for him. But if we tell somebody you're not going to do any of that, then they're not going to do any of that.

And I think you illustrate the other piece of that so beautifully, which is the assumption is you must feel great because you look more like everybody else. You are not an in spite of, you are a because of. You are who you are because of who you are and not in spite of necessarily. And I think it's just like that. It's just that easy to miss with me standing up here preaching to the choir. So thank you for that. That was awesome.

I think that's it. Thank you so much for your attention.

[Applause]