1:45 pm‑2:45 pm MT Capitol 3 Block 6

Self‑Care 101: Creating Sustainable Support for Parents and Providers

>> Good afternoon. I hope you all had a good lunch. This session right now will be Hands and Voices conversations engaging families and leaders in the diverse world.

There's drink in the back, restrooms are out here to the right. I will pass out your evaluation if you can just leave it or fill it outset it down or hand it to me on your way out, I'd appreciate it. If you have a problem hearing or it's too cold or warm in the room, let me know and we'll get somebody on that right away and these ladies will introduce themselves. Have a great afternoon.

>> Aid like to welcome everyone. And this is going to be a conversation and I want to give a little history of how this came about. We're all part of Hands and Voices some way or another. We sent time last September in our leadership conversation talking about why the discussion of culture, ethnicity, background, how does that affect us as parents of children who are deaf and hard of hearing? And how does it affect the work that we do as professionals who are deaf ‑‑ who serve children who are deaf and hard of hearing? And so we had a pattern that talked about our own personal stories.

That also talked about stories of the families that we serve.

And so that's what we would like to duplicate for you today.

We will be sharing our own stories. We will be sharing the stories of the families that we serve.

And I want you to know that these are our stories. These are our perspectives.

And then we invite you, the audience, because we are going to have audience participation today, to ask us those questions that you ‑‑ that you may be thinking in your mind. I have a family that I want to serve but I don't know if I'm serving them in the best way. I'm pleased if you have a pen or paper, just write down some questions. So we're going to introduce ourselves in our fashion and then we will have some information and then spend the rest of the time fielding questions from the audience. So we really want this to be a conversation. We don't want to give you information and send you on your way. We want to hear from you and hear how we can possibly end with strategies and tips as we're going to serve the families from diverse backgrounds

I'm going to ask my friend Rana to talk about the purpose of our workshop today.

>> RANA OTTALLAN: Good evening everybody. We're here to address three points of diversity. As service providers, how do we reach families from a different background when we go to offer services? The second one is how important is it for families to receive services from people who they can identify with? That they're similar to. And the third one is when you as providers go into the homes of families who are from different backgrounds and different diverse backgrounds, what tips would you like to have? So that you make that experience more enjoyable and more beneficial for everybody? So we'll talk about it this further. But these are the three points we'd like to touch on. Thank you.

>> Good afternoon, my name is Rosabel Agbayani, and I'm honored to be part of this panel. We're a diverse group and we come from different areas of the country. I'm from San Diego, California, Apryl is from Los Angeles I'm a board member and area representative for San Diego and imperial county. Apryl Chauhan is a parent and president of Hands and Voices. Jennae is president of hands and voiced apparent education coordinator. Rana Ottallan is Louisiana Hands and Voices board member and also a parent guide and lead Astra advocate. She's the director of Latina support, Hands an Voices healthcare and board member of California Hands and Voices and also represents the Los Angeles area. And we have Alendra and she's an audiologist and board member and chair of the Spanish committee of Illinois Hands and Voices.

>> Good afternoon, everybody. Last time we had this panel it was so interesting and for people in the audience. I'm an audiologist. I don't have children, so I cannot relate to the parents.

However, I serve many Spanish speaking families in Chicago.

I'm bilingual if you didn't notice that.

So I work with many children in the Spanish community in Chicago.

I just wanted to touch on ‑‑ to touch on some key terminology because it's very important that we get this right when we are, I guess, addressing diversity.

So first of all, we need to know what's cultural? What's ethnicity? And what's cultural competence? So culture is an integrated pattern of behaviors and beliefs. It's pretty much how we view the world and how we value the world around us. And it's influenced by socioeconomic status, religion sexual orientation, occupation, et cetera. So pretty much not everybody born in one country might belong to the same culture.

Ethnicity is actually belonging to a social group. Ethnicity describes how we belong to a group that shared the same nationality of core traditions so I can speak for my country. Ecuador we have many different ethnical groups that even though we share the same nationality, we have different traditions and therefore, different ethnicity. And cultural competence is understanding the importance of social and cultural influences in someone's behaviors and beliefs. It's the ability for us as providers to interact with patients or clients that are different to us.

With that I'm going to pass this on to ‑‑

>> Are there any questions?

>> Sorry, this is what happens when you have people from all different parts of the country and all of us are were very busy to trying to coordinate this was a little bit of a challenge but we make it work. So you know, just to give you kind of an idea of how diverse the children are that we serve, and each of our regions are very different, 20% of children in the United States have one parent who is an immigrant. I'm a child of an immigrant family. My parents immigrated from the Philippines in the early 70s, and so I have a ‑‑ it's really influenced how the decisions that I made in my child's care and treatment.

Children of immigrants just a little bit of statistics, 51% are Hispanic, 25% live in homes where no adults speak English very well. 27% live in homes where neither parent completed high school education and immigrants are more likely to live in poverty or low income households. So you know, these are some of the different things that we have to keep in mind when we're talking about providing services to families. And just really, really being mindful of being culturally sensitive.

>> At this Ontario I'd like to ask the panel to introduce ourselves and tell about our families but answer this question. How has your culture where you come from affected the choices you've made in having a child who is deaf or hard of hearing?

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>> APRYL CHAUHAN: My name is Apryl. I was born and raised in Los Angeles and I was born into a multicultural family but within the African‑American culture, you will find a lot of diversity. So I grew up in the valley in Los Angeles. So I like to say honestly that my culture was a valley girl even though I'm black as my ethnicity, I definitely ‑‑ that was the culture that I knew. That's how I grew up. So being a minority in a predominantly white neighborhood, predominantly white school, I really stood out and I really experienced a lot of isolation and bullying and I kind of have to develop my own code of arms and arm myself with my own personality and I got involved in the entertainment industry and as you can see, I have no problem standing out.

I really feel very strongly that that experience growing up in as I child is what gave me the strength to raise any daughter Zara who is profoundly deaf. It is such a foreign world for me and for my husband but I was able to embrace it because I was comfortable being in an uncomfortable place. So it really definitely affected and I now look back on my childhood and I'm thankful for it. I almost feel like it was all meant to be.

>> My name is Rosabel.

>> ROSABEL AGBAYAN: I'm from San Diego California and my culture I'm Filipino and I'm also Chinese.

And in my culture we value education, family and community and when I found out that my son was hard of hearing, I kind of went overboard on the education. One, I became the best researcher, so I was out there looking for information. And I went so far to actually go back to school and get my second degree in communicative disorders and deaf education.

As if that wasn't enough, I decided to go back and get my degree in public health and so I focused now I work for Children's Hospital as a clinical researcher and I've done research in the field of deaf and hard of hearing and specifically in studying outcomes for cochlear implants.

So that's really it, that influenced a lot of things. So I kind of know a lot of different things a little bit of audiology, a little bit of speech and it's kind of helped me really fine tune what I feel was the best decision for my son.

In addition, like I said, that's family. And family is very important for me. And so my family comes with me everywhere. And they're not here with me today. Only because I'm going to be here in a couple weeks for another conference. So they're going to come with me next time. But we travel as a pod. And it was really important that anybody who was going to give us information was really going to take into context how our family was going to interact because when you become ‑‑ when you find out that your child is deaf, the whole family becomes a deaf family. And it really impacts the dynamics within family. And communication is really important. And how are you getting families to communicate not only in the schools with the community but with each other. And that was always really important to me. So ‑‑

>> Good afternoon, my name is Genae Morris and I was raised in Bronx New York. I had an interesting upbringing. I was raised by a very strong single mom who thought that she would solve the world's problems and her and my father protested everything. But I was also raised household of southern grandparents who thought just pray everything away. I had a radical single mom and Christian chin grandparents and a father who was Muslim. (Christian grandparents) I became like the butterfly. I just adapted to each area. I was at the mosque with my father and at children with parents and learning to protest with my mom. In my family education, culture and family connection was very, very important. We when I was a kid I liked to call it the underground railroad or South African refugees during apartheid. My mother married a South African refuge I and when someone came to America, we would how's them and feed them and I was taught don't say anything about any visitors when you answer the phone. Which as a kid made me think the FBI and CIA is following me. But I had to learn early on that there are people that are oppressed. Not only here in America but people are oppressed abroad and we as a family and community have to help them.

I did have family men's who were deaf and I learned sign language from them. We're a close family. I got married and my husband and I worked ‑‑ I was a psychology major and my dream was to kind of help solve the problems of the world through the family. He and I both. We decided to go into the ministry. I ended up working with families of children who were deaf and hard of hearing. And as I like to say, 10 years later God had a sense of humor and Malik came along.

And at that point, the tables were turned for us.

Because my helping the families and by helping families and being in their lifers I became one of the families. I started to see hmm, this is interesting. The things that I wanted to say or was saying to the families I started to hear being said to me.

A lot of them were good. But a lot of them weren't. Because when the tables are turned, and you're in that situation, often times you have an aha moment. You go that wasn't very sensitive. Being in the ministry as you can imagine, going back to my roots. You pray it away or you just be faithful enough and everything will turn out. And I ended up having a son who we didn't know if he would survive his first month, his first day, his first several years. He's now 22. We started this year with him being in the hospital for several weeks. It's been a chronic situation with him. But going back to how I was raised and how that affected me making the choices I did for Malik, we were raised to love everyone and also to educate ourselves. That's what I does. I was a stay‑at‑home mom I had two other children within five years and I just educated myself. I became part of whatever community thought Malik was part of. And he is ‑‑ he has Charge syndrome so he's deaf‑blind multi handicapped. And we were living in Boston at that time and we had a wonderful early intervention teacher who came. I call her Mary Poppins and she came in and had lights and bells and whistles and got Malik to do things I couldn't. He literally was like this on the floor.

And then I started to realize what was going to be his future.? What was going ‑‑ what was this little kid that was on the floor going to be able to do? And it was an early intervention teacher as well as a woman who was deaf but taught us sign language that kind of rebuked the fear out of me into action and they told me will do what he will do in his time and that was the best lesson for him. To me. So we tried laids and we didn't like hearing aids. Okay. We'll put that aside. He had vision issues. We tried tactile. He was very tactilely defensive. So we tried a total communication. We enrolled him in the Boston ‑‑ in the Perkins school for the blind after he graduated from ‑‑ or after he left early intervention and ended up going to court against the Boston school system because we felt that Perkins school was the bet for him. So the radical in me I was raised with, I said well I'll just take it to the newspaper. You don't want boss done public school doesn't want to pay for his education, I'll take it to the newspaper because this is a specialized situation for him. So the decisions that we have made for Malik have been to really fight ‑‑ it's been a constant battle. Malik is 22. He's doing well. We are looking for a group home for him that he's being accepted to for deaf adults but all of that came through what I was taught growing up. You fight, you don't give up, you always consider the next person and it's not only about you and your child. It's about the next person, the next child, the next family that comes along.

>> I'm from California. I was born and raised in Southern California with two parents of Mexican descent. My dad was born and raised in Mexico. And my mom was born in Mexico but raced in L.A. county. However, being raised here in California I was ‑‑ they always instilled our culture within our family. Both my parents were bilingual. However, in the household we only spoke Spanish and it was a matter of making sure that I spoke English during school hours. But at home we spoke English or I'm sorry, Spanish so I was raised bilingual. So that was actually something I've always appreciated for my parents. Each though they were bilingual and my household it's very difficult to do that because my husband doesn't speak Spanish.

So I have difficulty raising my children bilingual with Spanish and establish, that is. But the question is how did my culture impact the choices that I made with my son? And if you know me, I'm very ‑‑ I'm like the he rebel in the family. I don't like to pretty much just hear out people and kind of just go with whatever is said. I like to do the different options and what I can do as my own choice. Had I listened to my culture and family, I would still be praying for my son's hearing loss to go away. Be waiting because it was going to improve and I'd not be using sign language with my son because he needs to learn how to use broken establish one way or another. So because of the person that I am, the way I was raised, I remember my grandfather telling me (speaking language other than English) meaning don't let anything else win. So there's nothing in this world that you would want to do that you cannot do. So my thing is I wanted to raise my son to be successful. Different choices, different routes to take. What was the route? The route I was going to take with my son. I think part of my culture and being raced as a strong women kind of made me realize that I ‑‑ as a mother of a DHH son I was his advocate. I was his voice, he couldn't make decisions for himself. So I needed to make decisions for him. Whether it was something that was going to satisfy my family or not. At the point when my son was first identified and even to this day, I have family gatherings, we have an Okra who listens, no hearing loss, okay?

Listens to the TV completely glossy and we can't even talk to each other. Westbound my family it's like hey you're not deaf. He doesn't even care about the TV. So that's parts of my culture. We joke around thing. Even ‑‑ just priority. But at the same time it's also very tab ooh. I have a cousin that was just born my cousin's baby, hearing family Down's Syndrome and hearing loss. Outside the family we just don't talk about it. Thankfully my little cousin who is the father of this baby has kind of seen the steps that I've taken and becoming an advocate for my own son. And I get very emotional to say this. But it's sad that he has to hide from the rest of my familiar family to ask what steps he should be taking or how can I correct him to other organizations because he's afraid that somebody else with our own family is going to judge him biased on the decisions that he's making. Sign language is something we are interested in learning but he's afraid. Photograph and so I've told him you know what? We have to put our traditions aside and worry about our other children because we're honestly the I'm ones that are going to carry enough phone it changes later on it's okay to decide you want to go to a different path and in our culture and I don't like to say Mexican culture because as I believe Jeg said earlier even with our own race we have different cultures within every family. So my household culture is I have different from my sister's culture. She talks about making sure ‑‑ her son has G6PD. I don't know if you know what that is. But it's a condition and I couldn't even know how to complain it but it's condition where there's a lot of allergy reactions, can't take Tylenol or any painkillers and if he gets a cough. He has to have a blood transfusion is it's a very critical situation, she always told me how can you leave your husband and children behind? I'm like what's wrong with you? That's not mart of our culture. I explain to her it's more to educate our self more than to be there for my son.

Well, this my son has this and I don't do that. Okay. That's the culture you're raising your chirp. To me it's more have those connections for my child leather than sit back and pray for my child as disability. I like to use the quote. Our culture is very strong and I think as well it with that said, women are raised to be very strong as well as far as adults. I said in my earlier presentation, yes, the men tend to be the decision maker but behind the screens, the women really make it in the decisions and I believe that goes for a lot of culture.

>> RANA OTTALLAN: I'm Rana Ottallan. I identify with multiple things. I'm Muslim. Arab. Palestinian, American. And every one of these things carry a big wait for how I raise my kids. How I interact with municipal kids and how I make my decisions, the biggest decision in my rife was about Dahlia I was a stay‑at‑home mom not doing anything in my life and then she was born and I had to beer voice. While I was doing that I need to look ahead and make sure I'm making the right decisions for Dahlia. I'm looking back at my family. I grew up with a friend of mine. She was deaf in her mid 40s and still not married. I grew up with two maternal aunts who were deaf and never got married. I wanted to make a choice that will impact Dahlia in a different way. I wanted to make sure that the same way that I look forward for her wedding, I look forward for her to have kids, I'm not going to change that because she's deaf. I'm just going to give her a tool that will make her more accepted within my culture as a deaf adult. My culture, not my religion is very, very harsh on disability. It's male dominant so find a deaf mail, getting married, having kids?

But you will not see a deaf woman getting married and having kids because in the view of the culture, there's something missing. That applies to all disabilities. So as a parent, first I was trying to figure out this is the best way for her to not be isolated. I cannot expect every person in my family to learn sign language to be communicated with her. I wanted to go with a choice that will make sure they all can communicate with her and that she can enjoy the experiences that my culture brings. I speak Arabic, that's my native language. My mom speaks language. My ‑‑ in Arabic, music and everything is in Arabic so I needed to give her access to sound so she could have the same experiences within my culture as her siblings have access to. Talk about the next child.

s night before I came here, I thought that I needed to go to this conference and she said I will miss you. I said I'm doing this for you. She said no. You're done with me, I got it. Go be there for the other kids.

And I think that's the message we all start with our kids. But once we move a little further, and our kids are doing okay, our mission becomes the other kid. What can I do to make experiences for my Muslim community, Palestinian community. Hidden loss. I'm serving a mom who has three deaf kids under 6. She lives at an apartment and every time her kid went out side, she would take his processors off. She could go home three months in a time and takes the processor off before she leaves for the plane and put it back on when she comes back because of reviews of people overseas about why is it this child cannot hear? A close friend of mine the same. She'd go back home and she'd say wait your daughter cannot hear, I know that. Why isn't her processor often. I don't want to get feedback from others that ‑‑ culture matters, I'm so proud of my religion because my religion is all about acceptance. I sit on a board. Where our founder was always saying that having a child with disability is your pathway to paradise. Whether it's sensory or orthopedic is a way for you to get into heaven because we believe that everything is for a reason.

We have a audiology program and schools for the deaf. My friend I talked about growing up, now she's a deaf teacher of the deaf of about how successful very can be. So culture matters, background matters. Once we finish the introduction we're going to talk about that. How do we take it into different cultures or backgrounds as and how can we be a resource for each other to make sure we have more effective providers.

>> I would look you to answer as a professional and some of us are going to answer this question, what motivates you in working with the families that you serve.

The biggest ‑‑ is this on? Can you hear? Can I hear me now? What motivates me to work with this family is that they really need to learn about hearing loss in order to make the best decisions for their children.

So I know that hospitals and organizations in Chicago go many ‑‑ not only in Chicago but all over the country go out of their way to accommodate and to create materials from communities that speak other language than English. Hour I encounter materials that translating things is not enough. Culture is not within the translation.

So then I read things and I'm thinking oh, that is that's a straight translation from establish and how are families going to take that information? I've been working with Hands and Voices community to create resources that parents can use and that are ‑‑ that you don't need reading proficiency.

We're creating webinars and videos because is that is very is he easy to share. We can ‑‑ as somebody said, in the panel that having a child with a hearing loss affects the dynamics of the whole family and in certain cultures the whole family is not only parents and siblings, it's parent, siblings, grandparents, uncles. Cousins and so on. So I'm educating the whole family that ‑‑ right? And doesn't require high reading proficiency.

So I guess to answer the question, I'm motivated to educate families that might not be able to learn from English materials.

So they can make the best decisions for their children in an informed way.

>> I wanted to add I consider myself not just a parent. I think that's the most morn role but I'm also professional. Like I said I have a degree in public health and moat motivated me to go in that direction is the importance of community and creating those relationships that are really important to ‑‑ for my child and for other children and so are kind of involved as well as professional I work with audiologists and speech pathologists. I work with teachers of the deaf. I was a special ed teacher. I worked with ‑‑ in a classroom with kids with autism and in every role that I was in, I was looking for ways to connect. With the family. It really is important. The amount of time that someone spends with a child is so minimal to the time the family spends with the child and for me it's really looking at the whole family and really building is that community that supports the family. So that's kind of motivated me to, one, do research because I think that data is really important to understanding what his ‑‑ has worked. I align myself with Hands and Voices because in doing my masters, I do a lot of research in how important organizations like Hands and Voices and parent to parent support is for improving outcomes for kids who are deaf and hard of hearing.

It's also motivated me the relationships I created with the individual providers that I have kind of evolved into a professional relationship where I was collaborating with the ENT finance physicians and speech pathologists on studying outcomes. So that's kind of shaped my direction of my career and it's good for me because I follow my passion.

And it's kind of taken a life of its own.

>> For me, I want to kind of get you guys to think about when it comes to professionals and doing the work that you do and serving parents, is to really think about the culture and that it does matter and I think honestly we're seeing that happen. We're seeing that play out in the real world with the Black Panther movie. I am going to bring that movie up. Because it's all about representation. This is just a very simple superhero movie that has broken records left and right. Why? Because we finally see a black super hero and they have this new character to look at and to look up to and to pretend to be and yes, that matters. That also plays out to how we interact with families. It was in the forefront of my mind and heart that she was a black woman as well as audiologist because I wanted to make sure our board represented everyone, represented our state. This really hit home for me when my daughter was presenting about a film that she made. It was a diverse class of elementary students and after the film was finished this girl walked up to her and this little girl followed her around for the rest of the day. And I told my daughter see? This is why you're going to become a leader. This is why ‑‑ this is your purpose here because this little girl made a connection with you and she was only 15 at the time. It does matter. So food for thought for you that you might be just as educated and as well trained and as competent and you can possibly be in your role working with parities but, if you have an opportunity to introduce them or to bring someone along with you, that can reflect family's culture, grab that opportunity. Try to make that happen.

Norm side of the story is when I as a professional go into this pace of people who dot no look like me. I will get a call for advocacy and talk about the phone and when it's time to look for the family, where's the hejab.

>> I wonder if she knows what I'm talking about. That first impression expecting those who don't look like you to be less informed. Sob let competent, to not be able to do the things that you do.

So it's challenging because the first thing they see is that my hejab, they see ‑‑ they hear my accent. So before I even open my mouth, they already perceive me in a certain way and that's an extra challenge for me to make sure that they get that I'm their advocate.

The minute the meeting starts and I start asking the questions, that will come down. They barometric pressure this is a professional person regardless of what she looks like or her religion represents. The more we go back and forth, that is done. Per exemptions in life, might not know what she's talking about. Second thing is one time early intervention provider called me and said we have a family who has a child with multiple disabilities. Hearing, cognitive, swallowing and mom is refusing service and I need you to come talk to the family and I said I'm not an early intervention provider. Go sign up as interpreter. And I did. So I set up as an interpreter and I called the mom and said I'm an interpreter with this early intervention, I would like to come visit you and if it's okay I come with this provider and I took my daughter with me and she was about six months older than the daughter. Armed worked in and hi, ho you are, speaking air big and then my daughter is talking to the girls and ‑‑ I think your daughter is deaf. Yes, she's deaf of. She can talk, yes? So immediately that mom wept along with early intervention. It does not start with hearing intervention. Child needed speech for feeding, speech for talking. Child got a cochlear implant at 8. Walking, talking. They did not expect him to make the progress but eight years later that child got the early intervention he needed. So me being similar to what she looked like another child from the same Arab child going through this did not have the outcome. Laying back. Doing nothing.

And just that visit changed his life.

So relating to somebody breaks the barriers. We can do more. And again, can being a resource for everybody. Last time I got a call from Chicago about an Arab family that needed somebody to talk about. So having a diverse service provider within your agency is important.

So that you can reach fore families.

One more thing.

>> Hold on.

What I would like to do is open it up for questions. We have about 10 more minutes. And I wanted to give folks a chance. One of the things that we want to look at is how do we? You know, what are the questions we need to ask perhaps or how do we meet the needs of families when we may not be from the same culture because we can't know everything. We can be as educated as we want but we can't know everything. I'm going to open it up but, if each of you could share a tip or professionalism parents helping to educate themselves for meeting the needs of families. I know there have to be questions out here.

>> AUDIENCE MEMBER: I think something to be said for your experience when you went into the hall and you made ‑‑ because you shared ‑‑ you know, you share your cultural background and I totally agree that culture is ‑‑ plays a huge part in a lot of decisions we all make. So I guess what I'm wondering is do we as a national organization, I say ‑‑ do we as an national organization, have any kind of running list or way in which we connect each other or say if I'm me being in Arizona if I run across a family or run across a family who is from a cultural background of say, we have an idea, but you do or you know, or Apryl does. We'd love to be able to connect with that individual and link across ‑‑ and maybe across states. But nevertheless, at least they'll have a phone conversation. And maybe are not have a phone conversation but I'd love to know more about this culture. Give me tips about that. Have conversations about that sort of thing. Do we have resources in place or say where somebody's raised their hands and say yes, I've come from this culture and I'm willing to talk to anybody.

>> That's actually a great question. And I know it's something that has been brought up in the past. But Janet is here in the room so I'm going to see if she has any input on that.

>> Janet: Two chapters report back to headquarters and we collect the data on what kind of ‑‑ the data in front of me. I know I think there are over 17 cultures represented in ‑‑ and so ‑‑ it's a really good idea to I think expand it and make sure that everybody within our organization if you're a part of Hands and Voices I can tell you that that's one thing we did talk about at our leadership conference last year is having a clearinghouse list. There is one but having ‑‑

>> Hi, my name is Ann I'm from Connecticut and just basically a Part B to what you talked about in our state meeting. That question came up specifically from one of the audiologists who came. Can we have a Hands and Voices person who is Spanish speaking and we do have one but being able to have that connection what we ends up using a lot the providers use a lot as a language line. So it doesn't always bring across communication and they know that that's why they're saying it doesn't bring across ‑‑ it doesn't translate the words correctly.

Sometimes. Or the meaning 689 and it's not a person in the same way of somebody being in front of them. So I do think having access to somebody even in that person is in Another state, it at least it's a person who can have a back and forth communication would be better than working with a language line if you don't have someone available in your state.

>> My question actually is kind of off yours as well. But as you're saying, your culture is different for your family.

And so I'm wondering how do we connect with those parents who have a culture with a child when he is deaf and autistic because their family culture is much different.

A special need's family culture is very, very different. So how do we ‑‑ my son is deaf and autistic and adopted so there's a lot of pieces to my puzzle. And so there are ways I can connect with the adoptive mom and there's ways I can connect to the mom has a child who is deaf and was I can connect to a mom who as an autistic child. But very rarely someone who has the whole fibbing pure but how do I connect when I don't necessarily know what it would be like to have a kid with cerebral palsy who's deaf. I can connect kind of but that's a very specific culture.

>> Ands you know, when I said that, I meant ‑‑ because you know, I did have a presentation earlier about a Latino families and it's very important that we don't stereotype a specific race or religion because like I said, my family thinks very differently from me. So it's a culture within a culture.

And so I think the best way to do something like that is just ask questions. Don't be afraid to ask questions, you know? And take it mon pop whatever their answer is to respect their culture, respect their decisions but have no problem with asking questions. We prefer for you to ask rather than just assume.

>> While you're passing the mic, we ‑‑ from our leadership conference last year, I don't know if you're part of it, we started a Facebook group. And you can see me afterwards because it's a closed group for parents of children who are deaf and hard of hearing with additional disabilities. IT's been a wonderful group where it's one thing to have a child month is who is deaf but when you have additional, that's a whole other culture, we ran out of space we can ‑‑ wanted a space we where of where we could celebrate the experiences we had. See me later and I'll connect you with that.

>> I also want to encourage you to encourage your families to embrace the culture and to incorporate that into our family culture because we talk so much about a culture of being deafer hard of hearing and we're just focused on that and we forget about religion and race, ethnicity. That's such a huge part of a family and I cannot tell you from my conversations with parents, they're lost. They just don't even know how to talk about their family traditions, about the holidays, so, if you can help them with that, that's a start. Because you might not be able to ‑‑ find ‑‑ that perfectly matches up with family culture but you can empower them to share their culture with their child and in Los Angeles, when I was living there, we did something I thought was phenomenal and we did it with food because food is something everyone can share and enjoy. What's interesting about that is I'll have a good friend who as a many child charge and a lot of food allergies and is Hispanic so she's autistic the recipes that are gluten free and she's still able to share traditional family recipes that she tweaked that would work for her child and she was able to plug in that to our events. So food a really easy way to start. But yes, today if you can't find that match, just start with empowering your parents. Let them know it okay to share their culture with their child.

>> In you go to an Arab household and they offer you food, please do not refuse it. This is a we to break bread and gain trust. This is really good. But do not reject it whether it's a drink or food because that's the way to make you get familiar in their space.

>> Any questions? I grew up with my father who was Muslim. And where I live in North Carolina, there are is a huge Muslim community. So what Rana is saying, I understood. I was asked to see a family and I did an A and B home visit because I wasn't sure what I was walking into. I went and knocked on the door because we couldn't get this family on the phone. So I let them know who I was. That I wanted to provide them with some information and support. I was able to look to the house and see what was going on. It was a wonderful dad and he had a wife that was there in full hejab, I said I will come back next week. When I came back, you made sure I have a long skirt and long sleeves and I had a scarf. And I wrapped ‑‑ and I walked in, took my shoes off and I said would you mind if I covered myself? Because I understood that as a woman, even a nonmuslim woman, that I would be able to connect to a father who was not letting anyone in the house more so, if I were to adapt to his culture.

And that ended up being about a 3‑hour home visit. Just ‑‑ and he opened up and talked about you know his son but he also talked about the professionals. How when he took his wife how there were prejudices there or assumptions. They went through this whole list. We were able ‑‑ so this boy was about eight years old and had not received services. By just having this little bit of knowledge and asking permission, we were able to bridge the gaps with the professionals. This is his culture, no judgment, whatever. As a father making a decision on his first son who is profoundly deaf, and he is new to America and I was able to help them to understand a lot of cultural nuances that he may be going through because professionals they knew well but there was a block. You know what happened. We started using some terms and so when they started to understand, the wall started to come down. We went into the IEP meeting and I got there early and I told them, I walked into the IEP meeting like this.

And so you can imagine I'm a in North Carolina and you know, all white folks in the room.

And they looked at me. And one of my friends said I didn't realize you converted but today I am. And I explained it would help the father to be more comfortable. And we got through that IEP at exactly what the professionals ‑‑ is ‑‑ and it was a great ‑‑ fantastic IEP. But because culture barrier is broken, the father was able to sign the IEP and able to get his needs met and he's doing fantastic now and we're still very good friends with family. But I had wonderful food and ‑‑ so sometimes it's great just stepping into someone's culture.

And taking a risk

>> I wanted to add something the question of this entire EHDI conference to me has been we don't have a representative that speaks Spanish in our state. Or within our culture or agency. How is it that we can serve the Spanish speaking community that we have? And you know what? The honest answer to that is make one of those Spanish speaking parents an ambassador. Get them involved.

Just because they don't speak English doesn't mean they don't want to get involved. They're going to afraid to ask how can I get involved but as professionals, I really suggest that you encourage them, offer them, give them duties to do and get them involved because they want to get involved. And if you don't have that Spanish speaking representative, get what, you have one now.

>> I just wanted to add to what you guys said. It's really important for parents to collaborate, professionals to really collaborate with parents.s special I when it comes to understanding cultural norms. Accepting medical knowledge as gold and taking care this is going to cure my child and it creates an unrealsistic expectation for them. So really finding ways to make sure that they understand information is very key. The last thing you want is an upset parent and understanding ditch norms and how different cultures view disabilities. It's really important for us to connect with our families. Both in rituals and culture and just understanding and then you make that connection. And then they feel like you know what? This person cares about me. And you develop a sense of trust and that trust is so important and it will take you and that child further in meeting their goals. And that's ultimately the most important thing.

>> One last question. For the panelists. What would you offer as tips or advice when you have a family that you know is from a different culture in order to meet their needs best. Just tips on what we can do as professionals? Alejandro, I'm going to start with you and we'll go down.

>> I think it was mentioned before. Stay away from stereotyping. I think a few years back there was some publishing of lists of how to deal with the Hispanic population. How to deal with the Hispanic population there is so many different cultures.

My advice would be stay away from that. Try to be as open and as questions, what can you do to make a family feel more comfortable. And as I ‑‑ as people have mentioned here, having somebody within your environment like I don't know. If ‑‑ in different places where there is a bigger population than others, like if you have somebody at the reception, that maybe can greet the family, just trying to get diversity within your organization.

>> I would say educate yourself and ask questions. I moat a lady at an early intervention meeting and she said every time I went to the family's household they made my take off my hues shoes and this that made me uncomfortable stopped serving family. The reason is they pray on the rugs. Whole house has nice rugs and they can pray anywhere but, if you walk with your shoes you don't know where the shies stepped into. She felt horrible that she didn't ask and stopped serving the child. So please ask.

>> Talking about taking off your shoes at somebody else's house, I live in an Asian community and so our early intervention teacher was used to goings to Asian households taking off her shoes.

When she first came to our home my husband was there. I know the Asian community very well. But my husband had never been in an Asian household and here comes the early intervention teacher, takes off her shoes and gets on the floor and my husband is like that's so disrespectful. She didn't even ask. We were fine with it. But maybe as a teacher, she should have asked is it okay to take off my not just assumed that I because I lived in the city of Roland Heights at the time we expected that. We respect the culture. Ask questions. Ask questions. Ask questions. And respect it. Plaintiff

>> I would say we started out yesterday have those critical conversations be willing to lean in and have the hard conversations. Microsoft people we're not experts at all. We're just experts on what we do. But for me, what has helped me is I'll go and ask. What is the best way I can serve you? I know ‑‑ and I'll ask those hard questions that people ‑‑ I don't believe you asked that. If I do if with respect and love, I want to come into your world, and the whole purpose is to serve your family, what can I do best to serve them.?

>> I think mine goes in line with yours, you meet them where they're at. Understand them, understand are they ready for information? Maybe they ‑‑ maybe because of their culture they're not ready for it. So you have to understand that.

Or maybe they want a lot of information so give them what they need. But really trying to understand who they are and you know what their expectations are. And have those difficult discussions, if you don't, we're always going to be thinking in our head this is a ‑‑ this is frustrating. So really take to heart the ‑‑

>> Before we wrap this up, I want to say too, let's not forget about the dads. Because the dad culture is a culture in and of itself and there's so much power in connecting fathers to other fathers and I've seen miracles happen in a soccer field in a park. You're going to make the effort now guys really start thinking about these conversations and that put yourself in that uncomfortable place.

Start caning yourselves questions that don't know about another culture and you know, talk to a good friend and say hey, you know, what do you think about if I ask this family if they want to speak to a black mom. Do you think ‑‑ you know, start having those conversations. Because I can tell you right now and I think we've all have expressed this, that yes, it does matter and that you will gain a great deal of respect from these families if you show you care about their family, the culture and the background.

Thank you.

(Applause).

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