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EHDI Annual Conference 2024 - A Diversity Toolkit..... 3/20/24 8:00 AM - 12:30 PM (MT)

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START TIME: 8:00 AM

(Captioner Standing By).

A Diversity Toolkit: The Power of Multicultural Programming and the Power of a Connected Community.

(Captioner Standing By)

>> Good morning, everybody. If you are here for Diversity, Equity, Inclusion and Accessibility toolkit you're in the right space. If not, we'll make space for you. Everyone here belongs. My name is Rosabel, and I've been doing this work with Hands & Voices since 2020, so in the middle of the pandemic. I was tasked as the Diversity, Equity, Inclusion and Accessibility consultant to develop a plan for diversity, equity, and inclusion, and truthfully, I didn't know where to start. I know I was a diverse person but everybody has different experiences, right?

During the pandemic each of us experienced so much fear, discomfort, unknowing what

the future held. Some had to live through sickness or see our family members suffer. And so it really put things into perspective to me as far as what this needed to look like. So I came up with a concept of the circle on change. It's changing the way we interact with each other, right? It's looking within ourselves, tapping into our inner child and remembering what brought us joy at one point and putting that into the heart of the work we do, which is to serve families.

So these values include being caring, having integrity, having respect, having conviction, leadership, and excellence. And I hope in this presentation, you find the power to unleash the power of multicultural programming and a power of a very connected community. Again, I said my name is Rosabel, and I have a masters in public health and doing this work is ingrained in my academics and I will go ahead and have everybody kind of wave your hand and acknowledge yourself. We have Michelle Hu, audiologist, we have Dr. Rashaun Davis, we have Rana, Djenne Morris and Anna brooks and we have snacks over there.

Feel free to help yourself. We want you to be sustained through this journey was. This is a welcoming environment, so no formalities, we want you to feel free to share your experiences. If you have a question, this is a safe space, no judgment. And I think that this hopefully will allow you the ability to feel connected to this community and therefore connected to the community out there. I'm going to go ahead and introduce ourselves. We'll start with Ana Brooks.

>>ANA BROOKS: Good morning, everyone. My name is Ana Brooks. I'm a mom of two. My family and I reside in Oregon. I was born in Mexico to El Salvadoran parents.

I pretty much lived up a down the Pacific north coast, following the whale migration because I lived in parts of Washington as well. My oldest is what brings me to this work. So she was diagnosed early on with hearing loss from birth pretty much and then my youngest one is what keeps me going in supporting other kids with different disabilities.

My passion, really, is to help community thrive. Especially those that don't have access to information, don't have proper support systems put this place for them. Rana, do you want to go?

>>RANA OTTALLAH: Good morning. I'm Rana. I'm a single mom of four children. Any youngest brought me to the deaf and hard-of-hearing world. I'm an advocate in Louisiana and been involved with Hands & Voices for about 15 years, but last year felt that we need to do something different, so my partner and I established AMANA. We felt we need to be there for our community because we need to be heard and we need to be part of the process because throughout my journey from sitting at state level, especially education advisory panel to being a commissioner for the deaf, we still were not heard enough as Middle Eastern Muslim community is we need to establish our own organization to collaborate with others. My daughter Dahlia is 19 years old. She was born three months after hurricane ca Trina. We had to figure out how to do things. She failed her hearing screening but passed follow up.

Then she's not responding. All the noise of other three kids happening and not responding. My mom said don't worry about it, she's fine and I talked to the nurse practitioner when connected after evacuation and she said let's refer to EMT. Fluids, antibiotic, all the above until at nine months old diagnosed with severe to profound hearing loss and our journey with figuring out what to do started. Right now she had bilateral cochlear implants. She's graduating this year. I'm going to share more later. Thank you.

>> I love my sisters here. Good morning. Good morning. Come on. Help me be dramatic. Good morning. We should have had hot coffee here. Thank you, thank you, thank you for being here. This is really, really exciting. My name is Djenne Morris and I have many hats. For the last 40 years I've been involved in deaf and hard-of-hearing disability community. I know I only look 25, but it's been a journey. My family is in their pa jams a. I started my

journey on a bus. I was bussed to school, two city buses going to school out of my own community with, in the back of my head, my mother and family telling me that you have to volunteer. You have to see those that are less fortune.

I'm dating myself. But they paved the way in family, community, religion, and education. And they pushed us and they said wherever in those circumstances you see someone that needs support, support them and through that support, you also get support. So it's reciprocal. I'll share more about that later. Fast forward, I always say that God has a sense of humor. In college I needed a job and I had a crush on a deaf boy and he made me sign. He's very cute. I wonder what happened to him and I need to tell this story because it's important. Taking two buses as a high schooler in the Bronx, snow, sleet, all that. We see a bunch of deaf kids on the bus signing my senior year.

Now, I had just signed up for an ASL class, because the teacher was cute. You see where I'm going with this. I was a New Yorker in the '80s but I thought this is going to be a gut class. Easy class. I know a little. I have deaf family members blah, blah, blah. That experience changed my life. Why are the deaf kids taking the bus with us going in the basement to the back and we're taking our classes upstairs. My family are revolutionaries. You think you're a fighter. I said this is wrong. They deserve the same.

That started for our class, we went to the principal and said if we're learning someone's language why are we separate? That's the first time that class came together and we learned from people that speak that language but not only that the culture. I'll share more, there's a beautiful end to it. I needed a job in college, worked with deaf adults and learned the bad words and craziness. I worked this group homes. I worked with them in Massachusetts in group homes and learned a lot. Fast-forward 10 days later, the king who we are grateful fors that destined to do great things. Malik turned 18 last week and I can't tell you how amazing.

When you're preparing to come to something and you get a hug and kiss and you see your kid that you fought so hard for and he's not a huge signer. Not a huge communicator.

But to me that said, mom, you've done an amazing job. My other two children, because this is a family affair, not just about the child, Zakiya is sitting with the dog Boston. The dog is a therapy dog, of course. Zakiya just got accepted to three audiology schools for doctor of audiology to work with young people with multiple comorbidities. Imani next to her, in school for masters in deaf education. She's got engaged. And then my husband Michael says all three of my girls are going to be in grads school. He's going to be the dumbest one in the house and he's been an amazing support and we work with families to support them and you'll see the pictures on the take there to support families in learning how to -- whether it's your partner, grandparents, this is a great road, but a difficult road so we support families.

So I want to welcome you. That's my story. I just wanted to say, I'm so proud of each one of my sisters and my brother Rashaun. I've been the president of the Hands & Voices headquarters, been involved about 20 years, just retired from my two and a half year term but once you get caught you never leave, so this is how I met these amazing human beings.

I have worked at two schools for the deaf, one this North Carolina, Texas, supported families and it didn't -- during the pandemic, you just said I've got to do something different, so I came out of working world to provide 24-hour, 7-day a week support and consultation for families of children with all disabilities, but primarily hearing loss. Part of that is working at UNC-Chapel Hill supporting them. I'm proud of each one of these women and man, because I'm their elder. I met them in different circumstance through Hands & Voices and through the work we're doing and each one means something is to special. What you're seeing today is a culmination of many years of tears and laughter. We were on Zoom last night laughing and preparing. So I want to give that to y'all. It's not about titles of any of that. We're here as

people that love our children. I wanted to give that to you. My best friends are not in my state.

They're in different zip codes. My sisters and my brother. That's why we're teaching this. So many different cultures but nothing that -- for example Anna is hanging out with my daughter when he goes to Pacific to look at graduate schools. Michelle has talked to my daughter. This one has practically helped my daughter to get engaged and she brought a dress for her. Rashaun and my husband are friends. Rosabel, I won't talk about I'll cry. She hugged me at a conference. I'm taking a little bit of time but I want to set the tone in here. If you hear anything or understand if we can communicate anything before you leave, it's that community that we are all different. We have different roles, but we are a community for our children.

We may have a lot of degrees, all of that, doesn't matter. Our children need us. So I do want to ask if each person, if you don't mind, if you can take a piece of paper and write your name, individually, and e-mail and hand it to me before you leave. We want to keep in touch. This one is amazing. She's our tech support. We want to keep in touch and we'll tell you about this later. We're starting a movement, no a program and we'll tell you about that later. Forgive me for taking so much time.

>> Good morning, everybody. I'm glad to be here. I'm excited about the work we collaborate to do. I'm Rashaun Davis. Can you hear me? I am from New Jersey living in Delaware currently.

>>RASHAUN DAVIS: Some of you, I tell my story every time. Without my story, I wouldn't be here. So I'm from a hearing family, so about probably 12 years ago to the day, my wife and I found out that we're pregnant, I found out she was pregnant, and we were preparing and we get excited and we purchase everything, the crib, the stroller, had the baby shower and find out December 142012 that she does not pass her ABR. She fails in her right ear.

So they say that's okay. It might be fluid. Only one ear. They tested the next day and fails in her left ear. So now my wife and I were uninformed, ignorant at the time and we have questions. Now, the test is inconclusive. The third test the following day, she fails in third ear, or the third test she fails in right ear again, so now we leave and we become intentional left to follow up or loss to follow up.

We don't return calls, because now we have to balance whether we accept their results or accept our feeling and what we believe. So, at the year appointment, we take her back and we find out she has conductive hearing loss minimal to mild. So, at that point, we had seen over that first year her responding to sound, not realizing how much sound that she had lost, but when the door chime would sound, she would go to the door. As she began walking and crawling she'd move to the door knowing mom or dad was coming home. Now at three, we get a second opinion from Yale and move forward with behind the ear hearing aids. We see her responding to sound. Wasn't until she began speaking she was unintelligible. When people couldn't understand what she was saying we realized she needed more testing.

Fast forward now 11 in 5th grade, number one soccer goalie in the state and speaks

English in Chinese immersion class and stated highest on cheese immersion test. That was a
journey, when she was in third grade coming out of pandemic her teacher told us we should
think about taking other out. She was so far behind after having been on Zoom or a year and
having to try to read lips from the screen and missing language and just already hard Chinese
immersion is. Now being at 4s and gets ready for middle school, it's a great accomplishment
for her.

Over the years, she has written three books and published three books about her lived experience A has taken us all over the world and people purchase the books, she talks about inclusion and talks about trying other kids the way they need to be treated. We're proud of

her. My wife and I are her strongest advocates. She's where she is, we wouldn't let them take her out. She's 100% in mainstream and we do participate and allow her to participate with other children who are hard-of-hearing but she does acknowledge she's part of this community.

But Madison isn't my why. 2020, I attended my first EHDI conference in Kansas City. Was anybody there. Two days later the world shut down. I'm sitting in EHDI 101 conference. I had never heard of EHDI. I was spelling it EDHI forever. Didn't realize it was EHDI. I had no idea. I was selected by her nurse who was a part of Delaware Hands & Voices and they were looking for a parent to attend. I'm an extravert, if we talk in the halls I can talk all day.

I went to this conference and my eyes were open to a world that I had no idea existed. I was familiar with sign language, cued speech, ASL. We had no contact what the deaf and hard-of-hearing community. I sat in EHDI 101 and I heard the statistics, I heard the data as it was important for early detection, early intervention and realized how much we lost and realized how much we had gain and the blessing that she is where she is now. I sat in that room and I looked around and what you see now is 3 to 4 times more black and brown faces that what it was in that room just four years ago.

So I stood up, it's a testament to effort to hard work, I stood up in that conference first time in the room and took a chance and I asked Carl white and those on stage, where are the black people? I hear your stats, data, how important accessibility is. If accessibility isn't accessible to all, it doesn't matter. From there a little lady by the name of Candace lin Dow Davis. She came up to me after that and said I need you on my team. I need you at the table, so from there I've been invited. I say it in every session, if it wasn't for Candace, I wouldn't be here. I posted her on social media, I'm here because of you.

So from there, now I am a board member of the state of Delaware EHDI and because of

my big sis jay nay, I am a board member of the national headquarters of Hands & Voices. I am because she was and I thank her all the time. My why is because I need to see a concerted effort to make sure that everyone is included. Muslisms are included, Hispanics are included, black and brown of all are included and have a seat at the table to make sure that no child is left behind in the words of a politician from years ago. That's my story. I'm excited to be here and salute every one of you for being here as well.

>> How do I follow all those amazing introductions. I'm Michelle Hu, I'm American born Chinese, grew up when Ohio and living in San Diego now. I'm profoundly deaf with cochlear implants. I'm comfortable saying I'm hard-of-hearing and happy to say I'm a mom of three and experienced as a military spouse and I am always transforming, always learning, change and progress is when you're uncomfortable. I'm getting so much more comfortable being uncomfortable to the point I used to have sweats and get really nervous and shake and now it's the same physical feeling but it's excitement now.

This is one of my favorite presentations, because of the ladies and Rashaun and Karen in the back of room. All of these workshops and relationships and moments that we get to be together in rooms like this have these kind of conversations. That's what fills my tank and my soul and I think I just came up with this one when Rashaun was talking, because it gives us a chance to see and hear that inner child within us that maybe was scared when we were young and 4 or 5 years old and now in adult form we still carry it and choose if we let them stay small or grow and flower and grow as big as a tree and reach up to the sky.

I am going to share more in-depth about my story, but in a quick nutshell. I'm a pediatric audiologist now. I've been part of deaf and hard-of-hearing community or 41 years but because I group that way, but it wasn't until maybe four years ago that I started the transformation to feel strong and proud and comfortable in this deaf and hard-of-hearing

community.

I was identified with mild hearing levels when I was 3 to 4. My preschoolteacher told me mom Michelle sneaks off at story time. I wonder this you might want to get her hearing levels checked. My mom was floored, don't you mean my son. This little chatterbox is running a mile a minute understanding in broken English and Chinese. Are you sure you mean her? She's asking why, why, why. Can I be your friend? She was just floored and she was -- so my mom and dad grew up 10 minutes away in Hong Kong but met many Minnesota. My mom was like there's a tall Asian that I'm related to. I want to talk to him.

But growing up in the United States around people, different foods and different cultures that you're not used to and people don't act the way you did was hard for her and then she's finding out that I'm identified as being deaf and hard-of-hearing put her many another isolated state. Who am I going to talk to? Western medicine is so different. How do I bond with other parents that don't look like me. I don't know what it's like to be in this world. My hearing loss is large vestibular aqueduct. That's tied to progressive hearing loss, so every time I hit my head my hearing would go down and hearing aids need to be reprogrammed or I'd have to get bigger and stronger ones.

I have bilateral cochlear implants today. I got my first one when about to become an audiologist. I was a Children's Hospital in San Diego and I now mentor audiology students at San Diego State University. I started mamma hue hears. I missed my everyone on my maternity and during COVID. I missed connecting with them and being able to provide, not necessarily the services to them, but I missed being able to exist and give them hope.

I missed being able to allow them a safe space to ask me silly questions, can you hear in the shower? How do you wake up at night when your babies are crying? I needed to create my social media, where they can ask me anything. The sky is the limit. I realized in that moment, I don't live my life exactly the way my hearing peers do. I was just doing what I needed to do. I'm going to have babies. I need to tend to them. I didn't realize those were special skills and now being able to share every aspect of my life is influenced and inspired or affected by my being deaf and hard-of-hearing of it's grown into a successful community online where I can connect with people worldwide. I thought I'm going to do this for a year, if I still have fun I'll figure out a way to better bring me or my skills and expertise, my personal and professional experiences into the hands. I created a program, I created pajamas and when I look at that pattern on the pajamas, I feel seen, heard and connected to those 5, 6, 7 years old middle schoolers who are struggling in that identity.

But the biggest gift that starting this business gave me was my own transformation and journey. I grew up with a mindset where hearing was better than not hearing. I grew up, I need to know how to thrive and succeed and reach out to the sky and blast off and when a successful human being in spite of the fact I feel broken and I feel like I'm not good enough and the fact I know nobody is really saying it in my family, but I know that I'm different.

I know there's something a little bit different about me the way that I see, receive and approach the world. So really starting a business gave me such a gift, because I got to connect with myself and I never would have been so strong in my deaf identity or hard-of-hearing identity as I am today, so....

I'll get more into my personal story as we go on. Thank you.

>> I'm tasked to follow up after these talented individuals. I want to say the power of connection, right? Djenne was talking about how she met me and I remember that day, I saw her as a leader and I said I don't know what I need, but I need you, and from then started this just this connection, a life connection that we have. My connection is due to my son who's deaf and hard-of-hearing. He's not 16 years old. He was diagnosed in 2010 with bilateral

conductive hearing loss. I'll share more about my journey with that later, but just moving forward, again, this connection, Rashaun, Djenne, Rayna, Michelle, I've known them as a colleague, as my son's audiologist, as a copresenter and someone I can learn from, because I don't have all the answers.

I am a senior clinical research coordinator. I've been this healthcare for almost 30 years and I work at the center for cancer and blood research. I'm involved in the deaf and hard-of-hearing community. I was a regional representative and I work with families connecting them to resources in San Diego, California. I served as the board president or California Hands & Voices and I explained that I became the consultant for diversity, equity, and inclusion for headquarters and I also serve in a community as a volunteer secretary for the Asian American Native Hawaiian Pacific Islander group in San Diego and I'm the chair of special education advisory community at the school district.

Those opportunities, I think, came because of seeing myself as a leader because I surrounded myself with people that were leaders that I wanted to aspire to be. That's why I'm here. I say my son, he was identified as deaf and hard-of-hearing and he gave me this connection, but this connection grew into something more beautiful than I could ever imagine. Okay. Moving forward. Anna.

>>ANA BROOKS: So we wanted to give you guys an opportunity to introduce yourself and share your journey. So if you can we're going to pass around the microphone, please say your name, where you're from, your role and what does Diversity, Equity, Inclusion and Accessibility mean to you in your community and what has been your experience implementing Diversity, Equity, Inclusion and Accessibility?

>> As you're doing that, I'm going to ask to just focus on Diversity, Equity, Inclusion and Accessibility, how we can do our part to transform our community for all families with children

who are deaf and hard-of-hearing. Keep that in mind.

So I'm going to come around quickly, so you can introduce yourselves like we did. Not as long. We're long-winded. At your tables we're going to have you discuss this and then -- does that make sense?

[Off Mic]

>> Yes. Let's start here. Why don't you go first?

>> That's true. Hi, good morning. I am marvel la. I'm deaf, hi. I am one of the very few really blessed, honored people because I have deaf parents. They have deaf parents, so I was born and raised in a signing, visual, accessible environment and that's not common. That's not the way of the world. For me I had instant access, so I have this passion to grow other parents. Celebrate your child, your child is perfect. Does God make mistakes? Absolutely not. So I've been a teacher of the deaf for many, many years. I work with deaf plus meaning multidisabled children, autistic deaf, DeafBlind, you name it. That's me. That's what I got.

[Off Mic]

>> Indiana.

>> You're next. It's you.

>> Okay, then. She's my sister from another mother. Love that girl. Also we're college classmates. I was born and raised in Texas. My name is la Trina and my parents are hearing. My parents although they were hearing they knew they had to provide access for me, so they gave me speech, sign language, my hearing aids came later. When my brother was born he was hearing, he learned sign language. His sister was deaf and we didn't have anybody else in the family who was deaf. That didn't matter. Sister is deaf, everyone learns to sign. Then we had a blessing baby and then a second 'cause who was deaf but raised oral. In short, I'm an elementary schoolteacher for 23rd grade. I'm an advisor. I do a lot of other stuff too. I live

now in Arizona, a cool place to live. I work at the school for the deaf. I used to be in a mainstream public school or 12 years. I worked with deaf and hard-of-hearing and CODA children. Then I moved to the Arizona school for deaf and blind. Worked at Gallaudet University with my sister. That's me in a nutshell. My host important role, I'm a mamma. He's learning to drive. I'm not ready or you to drive. She's ready to drive. She's a CODA. Her first language was sign language and she learned her speech as she grew.

>> Good morning everyone. I'm Michael low. I'm from Atlanta, Georgia. I'm Michael, I'm the epidemiologist with Georgia department of public health. In the past year I have a second hat as part C data manager. One thing from the data epiworld is looking at DEI. That's a major area we're looking at in public health and in fact part C, daisy, one of the partners of the state Part C programs is hosting, we count data equity workshop I'm attending in April. So how do our data reflect DEIA initiatives. Glad to be here this morning.

>> Thank you.

[Off Mic]

>> To EHDI?

[Off Mic]

>> Oh, so, well of course as alternative to what I was studying in college. I'm glad I did find alternative in epi and public health. That was behind-the-scenes and then looking at population data and then informing what actionable aspects from that, so that's kind of how I ended up in -- I initially did injury epidemiology and worked for three and a half and a half years in Alabama and looking at blast injuries and mild to moderate brain injury and those resulting in human loss. So that was my entry into the hearing area and then when my family moved to Atlanta, I couldn't commute from there to Atlanta every weekend so I did find a position at the Georgia department of public health. I had a connection with hearing and

hearing loss. That's my story of how I ended up in EHDI going on nine years now. My 7th EHDI conference. My best one so far.

>> Good morning. I'm Donna, I live in North Carolina. I grew up in Alabama, so in the south, very much the Bible belt of the south. My sister and I called it the buckle of the Bible belt. I went to graduate school at Gallaudet and got my masters in parent infant education and lived north on Seattle, Washington for a long time and I joined the Peace Corps and lived in Kenya for two and a half years and moved back to Portland, Oregon and moved to Montana and in a brilliant God has a sense of humor moved to Mississippi and realized no, no, I did leave the south for good reasons and now I'm in North Carolina. What else am I supposed to say? That's it?

>> Hi, I'm Alise Presma. I met Michael before and I'm here from the government accountability office. I'll explain a little bit, we are the congressional watchdogs, so we look at all the federal dollars and where they go to different executive branch programs and we assess if they're being spent with effectiveness --

(No sound)

>> I'm from Missouri, I've had the pleasure of getting a job with bureau of special healthcare needs in Missouri and we actually have a family partnership program, so I don't like to say that I supervise, I like to say I mentor. I think I learn more from my families than I've ever learned from myself. I've always been a strong self-advocate. My background a developmental disabilities intellectual, so when I was looking for a position, I was like what is that. That has to be a way to give back and advocate.

What the bureau we believe in that family, that lived experience, all six family partners are lived experience. Four complex medical needs, two specialized and deaf and hard-of-hearing. So I'm the lucky one to be here. Thank you for letting me come in. I was so excited to come

to this training.

>> Hey there. I'm the nurse educator for the state of Tennessee newborn training program, so I kind of do things across the spectrum with dried blood spots and EHDI program. I do a lot of outreach to our hospitals and midwives, health departments, pediatricians, so just looking at our follow up with our diagnosis and our early intervention, so just kind of getting things that I can take back to the pediatricians to let them know how important the medical home is in their role of following up with they had kiddos and making sure they don't get lost and they have other resources that they need patient navigation and services in Tennessee that help navigate those families. Thank you.

>> Hi, good morning, everyone. I'm Rachel and I come from Washington, D.C.. I work at Kindle school. I serve in DMV area. I'm in a toddler room now and I do home visits and a lot of baby visits, but our numbers in that area are growing. We're trying to see how we're doing with our programs so families will reach out and receive our services and I'm a mother of two and have one on the way, yay!

>> Well, I was nervous about going first and now I'm intimated to go last. So nice to be here with awesome people today. I'm a person with low vision and the proud parent of a child with intellectual developmental disabilities. But I'm here today as the director of family voices of Tennessee. We work this close partnership with EHDI program and provide family to family support to all the newborn hearing programs that they offer including the dried blood spot and newborn screening. I'm here as the supervisor of five incredible women of color who are parents of children who have kids who are deaf and hard-of-hearing or deaf plus and this is fitting for me to come and listen and to learn and to go back and better support them. Thank you.

>> Last but not least, we have a visitor. I want her to not introduce herself.

>> Hi, everyone. I'm Karen Cuts. I was born hard-of-hearing and became deaf at 19 while skiing and fell and got up and was deaf. Later on found out it's a rare gene I have in my finally. Few families that have that. One of the only ones. A mutation gene. I work with moms. I have three deaf kids, born hearing, became deaf at different ages, different times, 2, 4 and 2, all deaf now.

I'm a counselor, have a BA and BS in counseling and I like to help people. I've been part of Hands & Voices since the beginning. I've been here many, many years with role of involvement and I've retired from Hands & Voices, I realized my missed my family so much and I looked around and in my free time, few of us with free time.

>> And so we came up with the parent circle concept. Parent circle program, it's online and the reason we felt it was necessary is it's such a wonderful resource for all of the -- look at the table? What? Oh, you have information on your table, yes. Look on your tables. To fill a gap missing related to emotion, mental health. They have all these options, language options, school options. We don't talk about mental health. This came out of conversation I had with

(Laughter)

another parent in the hot tub.

(Laughter)

>> We were talking about getting to a healthy place on your journey and how parents can get to that place and look to the place of looking at your child as a blessing and the journey as a blessing. It's a beautiful journey. I had so much shame in my background because I didn't sign. I tried to be hearing my whole life. Talk about a God moment.

God's funny like that. You had a problem and that's why God made you deaf. That kind of concept and guilt. But again it's a blessing. My world before I became deaf that was my before deaf world and now my world after deafness is enormous and welcoming. Welcome to

the parent circle we give support and resources. Thank you. Thanks.

>> Okay. We are going to take a short break. Five-minute break. Get some snacks and come back to the tables.

(Break)

>> I'm going to give it about two more minutes, and if you're having a conversation, don't worry, you'll have an opportunity to have a conversation with each other soon.

I know we all love each other now, but if we can just have a seat. We're going to get started, restarted.

>> So we're going to have our first group discussion. I want you to take some time, you've been chatting a little bit, we got to know each other. I made a couple besties over at this table and that table, so I just want to chat and get a good gauge as to what might be some of those barriers that hinder like engagement or participation. Feel free to start talking amongst yourselves.

[Off Mic]

>> This one? So the questions are on the screen, in case you guys are needing to reflect on them. We're going to ask one person from each table to do a summary from your discussion. (Group discussion)

>> I'm going to let you finish that last thought and then I need you to pick a person from your table to summarize some of your discussion. So, sounds like you guys were having a good time talking to each other about this topic, so please pick one person from your table. If they can present a summary of some of the topics that were discussed as far as barriers that they've experienced. Share some of those expectations on problem-solving or collaborative problem-solving and we'll start over at this table.

>> I'll summarize. I've been hearing everybody's responses here, so I've been absorbing what

everybody is taking about here. So I'll be the spokesperson to summarize everything and I think I can't add anything more, but I think at this table, the main idea is inclusion and equity to the population we're serving. One of the issues is visibility to have a service provider who's not aware of other person's culture, lived experiences and historical traumas to be aware of that, so to have providers who are reflective of the community we serve, so how do we increase access to black providers or interpreters or someone that understands the community and be able to service in a cultural sensitive way, so, I think that's, at least for me, one of biggest take home messages, how do we increase access to people to provide services snivel and appropriately to these populations, in this case hearing populations that we need to serve.

So there have been efforts like Virginia shared and I saw buries last year that have representation of all the diverse communities they serve. It makes a difference. At last year's EHDI conference, having a seat at the table, representation does matter, visibility does matter and it goes a long way to be able to effectively service the populations that we're all trying to serve here. I think that's pretty much it. Just to increase access and inclusion of everybody at the table in terms of the serve providers, the portion of the population that we serve.

>> Thank you. That makes a pretty good point about representation and having diversity, so last year when I came to the EHDI conference and there was a lot of stats being shown on-screen, I always question them, because the buy chart is always wider and numbers are higher when it comes to white families. You can't tell me there's 20 families in Indiana all white and five that are Hispanic/Latino and only three African-American families being served. Doesn't add up.

And this was not even considered a rural area in Indiana. So then I always question what accommodations were made to sample that data? What are we doing to accommodate the needs of those families to get that information. Do we know that families have dual income?

They work full-time jobs throughout the day. Do we know they need child care for them to participate. Do we know whether or not the one parent stays home is overwhelmed and might not be able to take this on right now. Maybe they don't hoe how to read at that well. A phone call would be better. Or don't have access to answer online survey monkey, right? We might have to print that out. All those things are what I think about when I see sample data. I work for a family to family program for the state of Oregon. Those are the things that I always, always keep my team in line when we're doing this. So, great point.

I'm going to move on to the next table.

- >> All right. Should I stand. Do you want me to stand? Or am I good? [Off Mic]
- >> Okay. What if I were over here? Over here? Yeah? Cool. Yeah. All right so we discussed many barriers. Actually, we didn't have time for the solutions. But here are things we mentioned. Agency buy-in. There's not enough BIPOC representative particularly at the leadership level. Immigration status, access to information, people who have immigration status and afraid of the government so they don't receive services or get supports because of that, or, perhaps, providers who don't provide that information. Doctors who don't know anything about hearing loss. They don't know who to send a person to. They can't refer because they don't have a referral list and then, you know, that's lost to follow up for sure. Families not receiving information, programs not knowing about one another, so even the program's representatives don't know about other programs. Did I miss anything at our table? Okay.
- >> Thank you. So programs not knowing about each other. I can tell you from the parent perspective as a family representative, even myself have gone through this. This is what what happens when those organizations don't work would each other. We have a newly diagnosed

kid, and parents are not given next steps. If they are, here's a phone number and you need to call this, blah, blah, blah. They call, hey, you were not referred, we don't have the proper support. I don't know what to do with you. You need to go back to the person that gave you the number. What happens to this kid? The kid not being supported. Oftentimes this is the work I have to do with attempt families is trying to get them to find resources and connect to the right person to help them.

Everything is such like a rush, like time matters. It's not equitable, for English speaking family to be able to find a resource within a month or 2 months for a newly diagnosed kid. But because not English families, the delay is sometimes 6 months until he find the correct person. Not equitable at all. So great point. Important for the whole community that supports this one child to work together.

>> In Latino, what the doctor says is the law. If the doctor says you have to drink 8 milliliters of water a day or drink a gallon or a tank, that's what you need to do because the doctor said so. So, if the doctors know that we have all this to service or at least one, just one, that would be more than enough. Just one. And that's it. And I chose to speak by myself. Just one. That's it. Just one flyer, I would say. That's more than enough because that person, that flyer would connect with the other ones and then you would jump and jump for the next one and you will receive and then go back to the doctor and say, hey, do you know we have this, this and this? And the doctor says oh, that's good.

Maybe I will ask my assistant for more information. So in our programs on the SSTV we're trying to send some boxes to the audiologists with all this information, especially to the south. >> I like that. So those are vetted resources. That's what we call vetted resources and that's the other important key to this, right? So not only the community collaborators working with each other and communicating to support the community overall but the resources being

vetted so cultural responsive. Great.

>> I'm a clinical research coordinator and I know about protocols and I'm trying to follow our agenda, but I'm also a clinical research coordinator, so I also know sometimes things don't go as planned. If you look at the slides and it seems off, we're going off your vibe. If we need to move along because we do have stories and things to share to make sure your toolkit is full, excuse us.

So we'll focus on the objective number 2 to discuss the value of multicultural family engagement in supporting all families of children who are deaf and hard-of-hearing.

Dr. Michelle Hu start us off.

>> Okay. Cultural chameleon, I want to touch on ableism and audism. Is anyone not familiar with them? Ableism, the pretense that being fully able-bodied is so much better than not being fully able-bodied and that term vetches to audism the pretense that being able to hear is so much better than not being able to hear or being deaf and hard-of-hearing or whatever term you want to use. Having hearing loss, hearing-impaired or hearing deafened. You're here in this country to happiness.

If we grow up-do you want to see me better?

Okay, fine. Being able to agree up feeling like, hey, I am comfortable in my own body. I am accepted and I have access in whatever environment I have or I'm in and want to go to, that sends a feeling of freedom and feeling free to choose and find my own happiness.

Growing up I heard Michelle you speak so well. I never knew you were deaf. Many, many people have said this to me and for the longest time when I was young I took it as a compliment. I wanted to blend in. What kid when growing up doesn't want to be like everybody else?

I knew these feelings of wanting to be special and wanting to be like everyone else. That is

developmentally appropriate for young kids, but the difference was I viewed my hearing disability as something that was a burden, something not to be proud of and I was saying to myself, internally, silently, that hearing was better than not hearing.

I can blend in the hearing world instantly. I can wear my hair down, no devices on. I can read lips from across the room. Sporting events, I can see from far away. I was putting myself down as less than and ultimately holding myself back to who I could be because I couldn't hear. I thought that hearing people were more successful than people that were deaf and hard-of-hearing and when I had this epiphany I was so disgusted and ashamed, but I realized that the faster I could get that in my past the faster I got move on powerfully and live a happier and healthier life for my family and my children. I started recognizing myself as a cultural chameleon. Deaf and hard-of-hearing are much more like chameleons like you think. I do wear a lot of bright colors.

But chameleons can hear a few sounds in low-frequencies, between 20600 hertz. They can here the presence of sound but no details. That's a cool similarity. They don't have middle ears, because of lack of sensitivity their bodies have evolved to have an amazing set of 360-degree rotating Omni observant eyes. They can check out what's going on over here and focus on what's going on in front on them. So while my eyes can't rotate 360 degrees my observation skills are impeccable.

Talk about lip reading across the room or watching my kids or my husband, you have to go to the bathroom or you are going to get hangry here's a snack. I can read lips in the windows and mirror reflections and that's how I know my restaurant order is ready. Try telling me a lie and I will see it on your face in an instant. When watching TV, they stick out like a sore thumb to me. The chameleon skin is pretty thick. As a deaf and hard-of-hearing I say I've grown-up with a thick skin. I've been called dumb, a troublemaker, I've been left behind and stood up

and told I wasn't a good enough friend because of my hearing disability. Once I was reprimanded on a date for not putting hearing disability on my profile.

What is deaf supposed to look like? Is it supposed to look like someone with huge hearing aids on ears or someone with whose primary communication is ASL? Am I supposed to have a deaf accent so heavy that you could understand me. Deafness is in invisible disability. I'm speaking from my own experience, so everything is how I grew up. Agreeing up I attended speech therapy for decades to learn how to express students that I couldn't even hear.

I had to rid myself of my list so that patients would be able to understand me. I underwent two, \$90,000 cochlear implant surgeries after wearing top of the line hearing aids, so I could access the sounds and I still couldn't hear what I was supposed to say. Now I'm able to correct my deaf speech and sound like a normal hearing person, but I could fill drawers full of hearing aids, alarm clocks, remote microphones and batteries. I went through years of therapy, mental health counseling and audiology appointments. I'm constantly eavesdropping to figure out what's going on around me, especially in the classroom. I would plan ahead so I could be ready for school and be prepared for the birthday parties. Well this is a swimming party, I'm not going to go because I can't wear my devices. I'm afraid to go in the water with my devices. I'm afraid to go in water without devices.

So much anxiety around a simple, happy and easy swimming pool party. One analogy that I use when I'm counseling patients and families in the clinic. As a kid every fall school would begin and I would come home exhausted. You can imagine I was like a duck on the pond, just appearing calm, cool and collected, but I was paddling furiously and working hard underneath the water and went unnoticed. My parents had the same expectations from me as my brothers, get good grades and do good in school. I had to work harder to keep up. Children who are deaf and hard-of-hearing have a ton more on their plate than average student with

normal hearing. I was always paying attention to my surroundings and if I had time to I had try to prestudy, what are they going to say? Am I getting enough rest? If the topic or less is difficult, and I had a bad night's sleep the night before, forget trying to hold on to one sentence during a lecture.

I'd end up asking friends what was said and I was worried because I wanted to fit in. Those are the jeans that people are wearing and those are the things that typical children should or get to worry about at that time. So duck or the chameleon is invisible disability. It's easy to fool hearing people into thinking we heard them. Laugh, smile in the conversation. I got good at reading people's body language. I knew if a smile started to break out on people's faces, I would do that too.

Nobody would notice if I didn't hear it. Sometimes I had no idea what was said or how quickly the conversation moved from topic to topic. Inside jokes forget it, they were softer mumbled to the person next to them. Never mind .

No wonder that so many people are surprised and frustrated when we do misunderstand things. I don't want to draw attention to myself or ask for repetition. What if my confused face a misinterpreted. I would crash, burn, get sick easily. Why I'm so cognizant today being prepared, I want to leave this conference feeling energized not drained. I learned the hard way how to deal with listening fatigue. That is one of my biggest challenges and still is one of my biggest challenges today, I feel empowered to take that on.

I often say they're having so much fun. Now, I love staying home and filling my tank. Maybe because I have three kids under five. I love to have silence and take my ears off and relax and be with my thoughts. They've been running all day. Oh, can I have 15 minutes to myself to process my thoughts. For 15 years I didn't go to movie theaters until closed captioning became available. One matinee. For 20 years I didn't talk on the phone with

anyone other than my mom and it was just what time can you pick me up?

Being deaf and hard-of-hearing, especially hard-of-hearing in my experience is an in between or limbo space to feel trapped in. I can hear quite a bit with my devices but I can't always understand what's going on. A huge misconception that hearing amplification levels the playing field for children in the world. Just because you have an electronic device, you'll be able to hear the intonation, inflections and speech, inside jokes. Being deaf and hard-of-hearing is not straightforward. Everybody is different, even between your two ears. I might hear you when we're talking in a restaurant but maybe not in the car. I hear five, but not six. I cannot pick up on sarcasm. And my husband is the most sarcastic person in the world. But I can hear your car's turn signal. I can't hear the GPS voice but I can hear when my kid opens a bag of chips in the pantry. Every single situation has infinite variables and differences.

My hearing abilities may not make sense to hearing people or deaf people but it affects every aspect of my entire life, so subconsciously when I was little I was creating stories that I'm not good enough, because society told me time and time again the ableist thoughts or audism thoughts happening. My daughter would tell me teacher, my daughter is hearing impaired, she needs this and this from you.

My friends would answer questions for me without letting me use my own voice. I know their intentions were good but that's not the message I took to my heart. That's like the filter that I group with. So I thought I'm broken. People not good enough and not like everyone else. Chameleons adapt to surroundings. Just receiving good intentions from people.

It just was on their body, on their face and I could see it and these are the survival skills that I grew up honing in on so I wouldn't ruffle the feathers or be a teacher's pet but really to not draw attention to myself. Today I've twisted it. I like to use my skills of empathy,

relatability, and observation so I can take care of my family, I can cultivate and nurture friendships. So it's really good I'm now much better with my boundaries, I know how to say no and how to take a break and what fills my tank.

That evolves over time, especially as a mom. So the chameleon effect is code switching and we shift the way we carry ourselves, change our mannerisms, what kind of language we use based on who we're with and what environment we're in and I bet you've done this yourself. When you're having a conversation with your manager or somebody in your office or a professor, it's so different when having a conversation with parents or best friend. Code switching happens when two worlds meet or collide and whether the two worlds are different languages, cultures or different settings. Doesn't matter if between different cultures, countries. The chameleon effect happens when internal need to quell or stop this. I need to find some neutral ground, where can the two worlds meet.

So to you kneel down when you talk to kids? Do you dress more professionally when you go to work. With COVID do you dress nice on the top, but not on the bottom. When you travel to another country to you speak their language or pick up accent when they're talking. That's the chameleon effect. When I was growing up any feel right until a few years ago.

I never explored this aspect of me because it made my feel so adequate. I don't have my regrets, but I look back at younger Michelle, open your eyes. I wish you would have opened your heart. I wish the world would have been more accessible.

I wish that we had had more conversations and used in type of vocabulary so I could have been like, oh, I don't have to think this way, I can think whatever way I want to, but so affected by my environment and receiving and taking that in that it really built a cage around me.

As an audiologist, I had a mom burst into tears when she saw I was engaged several years ago. Did I say something wrong and she said to me, Michelle, I'm crying because you being

engaged means that my son will be loved and possible for him to get married and have children. My heart just sank. The intentions are good, but that's the shadow that deaf and hard-of-hearing children grow up in. Do you think that child disabilities -- how you think as a parent, talking to you as parents, how you think of your child's disability significantly affects how they think of their disability. Why wouldn't her son grow up and find someone of love. It's his choice, right?

She thought that someone might not love him. You know the quote only a face a mother would love. As a parent now, I used to want to shelter my children from every little thing but what I want for them now is to go through and embrace those challenges with me behind them, so I can catch them and teach them and talk about the situation that made you feel that way. If you're ever in that situation again, what would you do? What do you want to say? Maybe you'll be in that situation again. Don't discount your children's lives before they've had a chance to live them.

If you know Emily Burke she is the chair of -- what's your position? Deaf and hard-of-hearing inclusion council. She's amazing. But she told me this quote, hearing people have as much to learn about deaf people as deaf people have to learn about hearing people. The only thing is deaf people have been doing it for the entire time that we've been deaf and hard-of-hearing because we're living in your world. Kind of like outsiders. So let's change that with education, awareness and holding to the highest standard of accessibility and inclusivity. With access to team building, maybe you, referencing you as hearing community could learn to be a little bit of a cultural chameleon as well. You think sign language having inclusive environments when each individual feels welcome and supported and have their voice as big and as loud as they want it to be.

So building connections between families, meeting them in middle ground, this table was

talking about the barrier that different culturals get and I was getting so excited listening to -what's your name? We're getting so fired up, we have all these resources here. Come, come,
come. It's hard too. We have everything but how do we get that out to people. Groups that
may not necessarily talking what we're aiming for but situations where we can be together find
similarities between one another. Oh, cool I love Indian food, I'm learning to cook Indian food.
Chinese. That's how you celebrate Chinese new year. You happen to be deaf and
hard-of-hearing or related to that community. That's when those bonds get so strong they
become your family and they become a resource and maybe for information but a safe space
where we can say you know what? I'm having a hard day, this sucks and you feel seen and
heard. One of my biggest misses, children, including the young children still within your hearts
are seen and heard and empowered.

My mom, when I had a develop of hearing in my senior year of college, we're sitting in the waiting room, I'm crying because I declared my major and applying for this school and that school. At that time I wanted to go prelaw, I thought lawyers are only in the courtroom yelling and fighting for their case. How am I going to be in the courtroom if I can't hear anything? How am I going to get those details? What if they mumble something that I can't get. My mother said you know what you might make a good audiologist, you can relate to them. You know what it's like to have anxiety in the booth or a sore ear mold but you still want to wear it. Wearing it half out, feedback everywhere. I was floored. Yeah I knew I wanted to go in some field where I got help people.

Nothing was really pulling me to that. Just meet your patients where they're at. I can meet them this middle ground an find something in common and usually it's a feeling of sadness, loneliness, anxiety, or celebrating. I heard my dad fart for the first time and that opens a safe space to be and you can be a resource.

Without community support -- wait, go ahead.

Without community support parents of newly identified deaf and hard-of-hearing can feel lost. Do you have any questions so far?

(Laughter)

>> I'm back in 1980s when I was born, no newborn hearing screenings in the hospital, so I don't know if I was born with a mild hearing loss or maybe I was and later identified but maybe I was later deafened. My preschoolteacher told my mom she's sneaking off on her own. She's reading a book. My mom didn't have Google, she had encyclopedia, microfiche with microfilms. She took me to the office and I'm identified with mild hearing loss in both ears. Children with mild hearing loss are in a gray limbo area because we can slide under the radar and fake our way through social situations very easily and we can say I don't need hearing aids. I heard you. People believe us. Back in the day doctors are like can you hear that. That's a great hearing test.

But we can hear enough to get by, yet we don't have access to the details. We might hear the difference-we might not be able to hear the difference between first or thirst or if someone asks you to get bread or thread. Children with mild hearing loss are at the greatest risk for falling through the cracks.

What about their parents? My mom experienced pain, devastation. She took on blaming herself for what was happening. Where did she go wrong? Did she eat something she wasn't supposed to when he was pregnant. She thought she was punished for going back to work because she liked her job. But what happened to me had nothing to do with the story my mom was creating. Every children's journey is different and every family member's journey is different as well. My parents felt lost, I thought my life is pretty good. My parents on the other side were wondering will hearing aids hurt my daughter.

Will she ever get married and have a family. So she need that community support. So my parents are struggling as new immigrants raising children. They're Chinese speaking, what St. Patrick's day and why do my babies have to get dressed up on Halloween.

I have a slide that says when you have one person in your family who is deaf and hard-of-hearing, you become a deaf and hard-of-hearing family. My children, they've learned how to talk to me and they've learned how to be with me. I finally figured out what do I need? I need quiet time. Mom's ears are off, if you need me, which you will not for the next 30 minutes. You will flicker the lights and they know I'll get down on their level, not to mess up the project they're doing but because I need to see their face. My 5-year-old daughter knows how to change my cochlear implant batteries and how to put on, but she respects and says herself, I need quiet time I'm going to take my ears off.

It makes sense to her, because that's what I've said. I feel like I empowered them, at birthday parties when it's too overwhelming. Mommy can I sit with you for a moment? Absolutely. Good job knowing what you need and let's go do it. Do you want my company or not want my company? My middle daughter is so used to saying I need to see you face, I need is to see your face and she'll smile at me and turns away. Can you describe it without looking at it. It's hard for a 4-year-old. But without community support parents who really feel lost and disempowered, when you change that mindset to shift to we're a deaf and hard-of-hearing family. We don't play loud music during important conversation.

Let me finish the dishes before I address what you need. Let's not yell from downstairs to upstairs even though some of us can hear that. Or tell me what was said. Don't let anybody feel left out. Give him access. Include them because they are your safe space and they are the team, it's you against the world that if you're having challenges they're the ones you can get back to. So you're a core family and this is really a village.

>> Just a public service announcement. I see people taking notes. It's wonderful. The way we teach, we're not going to give you a strategy sheet to go home and do. So as everyone is sharing their stories, they're also sharing a lot of nuggets and strategies, so I wanted to point at that out.

>> Thank you for reminding that. I don't normally share my story. I'm a researcher so I like being behind-the-scenes, taking data, learning about people and connecting people and making sure the right people are in the right spaces to elevate voices but I feel that my story has value to share, so hopefully you will come away with nuggets like Djenne said.

Family culture, when you have a deaf and hard-of-hearing child you become a deaf and hard-of-hearing family. I wrote this quote a while back when I wrote an article about my experience, my son was 8-year-old at the time. He's now 16. Sometimes we think in order to make a change we have a make a lot of noise. But what I learned from raising my children and especially my deaf child, you have to be able to drown out the noise and just listen to your heart. My son, Michael, was identified with bilateral moderate to severe conductive hearing loss on September 30, 2010. Up until that point, he was two and a half by that time, he was a happy and healthy child who was social and silly and full of personality.

He had a language that I kindly referred to as Mike's language and because I was a stay-at-home mom I had the privilege of spending every hour of day and night, I knew exactly what he was saying and I was the only one who understood. I casually translated to my family, he's calling you. Or dad, dad, come, come. Daddy he's calling you. Or his baby sister, hungry, hungry. We were a family heavily enjoyed in the joy of play. Michael would play and make friends with kids easily and connected to people and knew how to comfort you if you were sad or cold or tired or hungry. He may not have had the perfect language or the words just right, but he definitely knew how to communicate.

Michael's love language with you joy. After he was identified September 30, 2010, we were overwhelmed with a flurry of information. I remember being in the audiology office and hearing the words your son has a hearing loss. My heart sank. This overwhelming feeling of shock took over. The audiologist had a lot of great things to say to me but everything just went blurry and sounded like jibberish. What is my son's life going to be like? Is he going to say he loves me. What is our family's life going to be like. Pretty soon our schedule was filled with appointments and one day blurred into another.

To calm my nerves, a cousin said we're going to see uncle Romeo and he'll help us.

Although he didn't treat children, Dr. Romeo knew how much it meant to us and he did a full intervention and he reassured us you're not alone. You got this.

But did I? I cried myself to sleep. I cried not knowing if I had done something wrong. Like Michelle said, her parents questioned and I questioned as well. Why didn't I insist on another screening. What if I ate something when I was pregnant that caused this to happen. Was this karma for something I did in the past. Did I go to sleep with my hair wet, or wearing nail polish or color my hair. The noise became so loud that all I could do is yell and I don't yell often, but I was angry, confused and I was lonely.

Meanwhile, it was hard to see family members and friends who I thought were biggest supporters become estranged. My parents kept saying well if I tap on the door he can hear me and they told me take off his hearing aids because people might talk about our family. We stopped going to birthday parties and social gathering where people play. Can you hear me now? Can you hear me now? My son was too young to know what's going on. In Filipino culture, it's not easy to minimize because having a disability is not something you should be proud of. But my biggest teacher, I tell him, one day in between 2 to 3 points for the day. I was nursing the youngest baby and we were out all day. In the parking lot they took off his

seat belt and was walking around watching his movie and I put my head down and I started to cry.

Michael looked at me and he grabbed my face and said ma, why cry? It's okay. It's that moment that I realized that my son was not broken. I was the one who was broken. I was the one who needed to be fixed and he was just Michael. You know, joyful, caring, toddler with his own unique language. His hearing loss didn't change who he was. We needed to come to terms with the choices we had to make. Like Karen mentioned, it was important for me to fix my mental health and my purpose. Most importantly I had to unleash the power and connections I needed to make in my family's community.

I had already had my degree in human development but raising a deaf and hard-of-hearing child was a new world for me so I went back to school and got second bachelor's degree this 2013 and got involved in child's school and we took ASL as a family and we make connections within and outside our DHH community. I soul searched to find a way to be productive and I found my passion in public health and health education. I credit the cultural values as the underlying power of being resilient. As a Filipino it's ingrained in our blueprint, the values of respect, to be respectful or give respect to a person.

Debt of gratitude, helping others. Prioritizing family. But also as a Filipino American I understand the values of independence and self-determination and the importance of shaping our own identity and destiny through choices, ability and efforts. It is because of my bicultural values to instill in my own children. Regardless of what they're able or not able to do. Respect others but also learn to advocate for your needs. Something that us as Filipinos don't like to do. We want to assimilate, we try to stay low but as American I knew if my child was going to get anywhere we needed to be advocate and I needed to teach him to be advocate for himself.

Be grateful for opportunities but also know that hard work and determination are the key to

success. Helping others. It is important to help others in community but also to leave space or other personal growth. Prioritizing family. For us we were not just raising a deaf and hard-of-hearing child. We needed to become a deaf and hard-of-hearing family. My 15-year-old then and my 6-month-old hearing daughters, they learned how to be empathic. I love to see each of my children stand up for their convictions and love each other unconditionally, no room for pity or resentment in my home.

According to the international journal of social science, Filipino spirit is indomitable spirit.

It's a basic unit of society, full attention and love is focused on it to the point of sacrificing own lives for their needs and wants.

I was not -- I'm trying to show you a photo of my grandmother and myself. I had a photo of my first trip to the Philippines. I was six months old. My grandmother was holding me and my brother he was likely the same age as my son when he was diagnosed. On the far right of that picture is uncle Caramello and he was identified as deaf at a young age. In Philippines no education for the deaf. But she learned how to adapt her skills to teach other own child. He never learned sign language but communicated with gestures. I wish I could ask her how she did it but somehow my uncle learned how to read and write and graduated from high school. He immigrated to Canada when he was young and worked at grounds crew or American Airlines and lived a peaceful life. As a child of immigrants I have a deep respect for the sacrifices my parents and grandparents made to afford me the life I live today. It made me resilient in hi journey and find a way that worked for my family.

We may not fit the mold of a typical American family but we're the family that made the challenge of raising a deaf and hard-of-hearing child to something that we are and as parents we're changing our blueprint to who our children are meant to be. These roots run deep. I truly believe we need to recognize the wealth and not the deficit of a culture and value the

lived experience of families from all backgrounds. I'm grateful for the joy on raising Michael and proud of our family and how far we have come and how it influenced me to be a strong advocate in this community. Any questions? Thank you for letting me share.

>> I'm here to share a similar but different story. This is Dahlia. Today she's a senior graduating this year but that journey was long. Like I said at the beginning, we had evacuated post-Katrina and Dahlia was three months old and nine months old we got the diagnosis and that's what our journey started. Host ABR and profound hidden loss, the doctor said only choice is cochlear implant. I came home to an apartment half furnished trying to figure out how to put our lives together, massive Katrina, hurricane. I said a prayer a thousand times and cried my heart out and started researching what to do with a deaf child.

I researched cochlear implant, cued speech, and I started looking up how many signs I need no learn and it's endless so I froze. But I did go back and took a class and I was connected with an amazing lady, Jeannette Webb. She told me what I need to do. Me came to my house sat on the floor and did the signs with my daughter. At the time post-Katrina a lot of hospitals were close and we didn't have the interventionist. Before I had Dahlia, I had three kids before I learned how to drive.

I was born in Jerusalem. My dad immigrated and lived in Wisconsin area and came back home but we were citizens by birth. So at 20 left college and I was still not driving. I was getting around any way I could. Just before my third baby was driving, just around the areas. Not the highway. Then Katrina hit and we had to leave. I said I can't drive that far. So my sister-in-law was driving. We tried to figure out where we were going to end up. We ended up in Louisiana. Three and a half hours from New Orleans. That's where we got the diagnosis that Dahlia was born with severe hearing loss.

So I had to drive to New Orleans to see the ENT that's going to look into her implant and I

needed to do it before one, I didn't want her to have any delays. So the choice to go with a cochlear implant, as I looked around there was no way that I could get my mom to learn sign language, my ex-husband to learn sign language or any extended family to learn sign language. So I didn't want her to be isolated. I wanted her to have access to music, culture, so she could bond with everybody. So I'm not driving on the highway. The highway takes hours and I'm looking for nonhighway roads. Five and a half hours just not to take the highway and I would have to stop, take a nap, until she got her first implant. Somebody told me ENT had a God ego. I asked all the right question.

So at the time we were under Medicaid insurance, they figured one ear is enough in Louisiana, so we got one implant. We got the first implant and mapping and she's starting to say words and stuff and we ended up going back for a second implant. This time we had to apply for a grant, we switched hospitals and this amazing Dr. M was seven years old and instead of making a nice incision behind her ear he made a big scar. When I saw the scar I cried for three days.

I called the audiologist and said look what he did to her. He said focus on what she's gaining with that implant. He's not going to notice it. Then she had eye surgery that came with complications.

I was so depressed. That was the straw that broke the camel's back in my marriage. I set her up for early child oral school and I fell into deep deep depression, divorce, surgery, single, I hit rock bottom. One day I was passing by her oral school and I passed by a community college that was offering a degree. Stopped by signed myself up to major in criminal justice. That took me out of that depression. I finished an associate degree in nine months, 4.0 GPA and I had to say a speech and that took me out of that and that brought me closer to being the person I am.

So when she was at the oral school we were told stick with one language, if you want good outcome stick with one language. Every therapist that speaks English, speak with one language. Mom try to speak English with her. Okay when she was about four, at the time I was part of the PTO for kid's school and I was excited going to the meeting. Dahlia is coming to the school next year. The principle said I don't have a place in school or deaf child, and I said not. Not your school. You don't own the building or the education system. She's going to be registered and obligated to take her. She started by that principle whatever stopped her from getting access to teacher of the deaf because that teacher of the deaf did not have early childhood certification. So they appeared her with a teacher with zero background.

So we finished pre-K, moved to kindergarten, and still that same teacher is with her and not doing the best she could be doing and struggling and somebody tried to say she might have cognitive client. Give her what she needs first and say if she has cognitive disabilities or not. That teacher did not believe that Dahlia was deaf. She said she can hear, respond and speaks. She's not deaf. I had to fight back in IEP, I said you not knowing about that different type of people with hearing loss doesn't mean that you should not give my child an accommodation. We repeated kindergarten because she was not yes she needed to be. An amazing teacher of deaf came long and she started working with her and she started doing great. She was on top of things. Then there were opportunity to apply for charter school.

I wanted to apply for my son, so I figured the charter would take her for IEP funds and her brother would come along with her. Not a good plan. They did not understand her needs. Went from fully included to resourced to struggling not keeping up. Refused to use assistive technology that was included in IEP from the district. Years later I discovered they had equipment. They worried about the device captioning private conversation of the teachers and there was option for this to be printed out and coming home. I said just use in the classroom,

they refused.

We ended up going back to public school in 8th grade with a lot of support but COVID hit. They finished the school year and 9th grade came and a lot of virtual. Only one of the deaf students that benefited from virtual. It was one-on-one. She did not sign but the captioning was on. She got three services and then 10th grade I signed her up for charter school that has a deaf program and teacher of the deaf, and she started at that school and she started thriving.

Throughout in journey, I start growing in my leadership and advocacy. I joined a special education advisory pan at the state-level and I served there for many years and testified at the board of education for changes. I took policy-making leadership class. I looked at the Bill of Rights that was not meeting the needs of kids so I worked with a lot of groups, but I led the effort to amend it. We have one of the best bills out there, it put a lot of demand if implemented on the school district. I followed with another bill that took the word impairment out of language in Louisiana, more funding for deaf services. I was on a roll.

Also our previous governor pointed me as commissioner to the deaf, so I served there for a couple of years. I was everywhere and I was working with Hands & Voices. I took the guide by your side training and I took the Astra training and I go to the point that I can humbly say I am the best advocate in Louisiana. Then we get to a point that I start noticing that Muslim families are not getting the services they need. They don't have interpreters or information in Arabic. Top language is Arabic in Louisiana. We had pockets of middle easterners so we have to do training. Now Dahlia is a senior. She's an honor roll student about to graduate May 18th and she got accepted in RAT and I did everything that I could possibly do to make sure that her outcome is the best outcome possible.

I know she's capable and wants to get into cybersecurity and I want her to meet other deaf

students to get into the culture. She's been oral all her life and she took two ISL classes, but she needs to be around others who look like her. We did a small camp last summer and she's going to start what a camp in July and we're on a roll.

So two weeks ago I was planning her graduation party and I was looking for -- I was trying to put together a slide show to show she was a baby born to where she is. Looking for a song to express how much I love her. I found that song. But she did not understand Arabic. That broke my heart. I am the worst failure mom ever. My own child cannot understand Arabic.

This is me entrusting this lady who said stick with one language. I wanted her to access sound because I want her to hear this language and understand it and hear music and understand it. I found the most amazing song. I wanted to see how much she changed my life by being my daughter and she could not understand it. I had to translate the Arabic words into English, put it a subtitle on that slide and share it with her in front of 125 people, friends and family. At this point I failed to hold on to my language, to my culture, to my heritage because somebody told me stick with one language. As much I advocated for language access, I did not understand I needed to do it the reverse way that why do they have to learn English?

They need no deal with us with our Arabic or Vietnamese or Spanish. We should not lose who we are just to have access to sound. That access to sound can give us access to every language in the world and now research is coming back to say that deaf kids can learn more than one language.

At that time, 18 years ago, that advice broke my heart when I was ready to celebrate my daughter. I'll share the song and the words to see how much it meant for her to lose it. A lot gets lost in translation. Is to Rosabel, are we going to play it? Make it low, so I can use the English words. I'm going to read the words. Whatever you are my love to you is as big as the

world. As much as my soul adores you, I feel you are you. It's like the breath I take. How can I describe the air I breathe. I don't know my sweet heart, how to express how much I love you. I love you from the bottom of my heart all the way to the 7th Heaven. I can't imagine my world without you. Ever since you came to this world I see life through your eyes.

Whenever I hear your name you're my greatest accomplishment my heart jumps to provide all you need. You have grown up and became a beautiful young woman more than I ever dreamt for you. My I gave you happiness and brighten my days for you always. I ask the Lord to give you a long life. Amen and see you as the happiest woman ever.

It feels so much different than Arabic.

[Off Mic]

>> Yes. So as much as tried to get the best outcome for her, I missed that part. I'm hoping that as she's older right now she's going to seek knowledge in Arabic and seek to be able to learn the alphabets and recite it. When I was doing the research I found something that touched my heart. Someone talked about it. Koran has different recitations. I learned that one of them being used in South Africa, North Africa yours was required by a deaf gentleman. He used his lip reading and the power of God to put the whole Koran recitation -- the same car ran and this recitation for generations to come and this has been 12, 1300 years ago, based on his lip reading and focusing on meanings of the word.

That touched my heart to say the deaf person able to hold down the village this much. As you work with families it's important to acknowledge their culture, language issue beef system, because in order to us to do better for deaf kids not just erase who they are. A lot of times I told her that deafness is part of who you are. You are a Muslim, Palestinian, deaf woman. Each one of those words is part of your identity. Each one of those identities makes Dahlia who Dahlia is. I'm sorry to get emotional, but two weeks ago I talked to the ladies and I told

them about this and it really upset me while I'm celebrating so much accomplishment that she should not understand my words.

>> This is it y'all. This is the reality of what we as families and practitioners go through. We're going to take a break and we'll be back to wrap up. So maybe five or so minutes and we'll get the song on and you guys will break.

(Break)

>> So I mentioned to my group or this group, this table when we were having the discussions a little bit earlier, when we think about the toolkit, right, we are not just up here lecturing and not just one way, but I think one great thing about coming to these conferences and what I can't out of it most is the network that's been established. The conversations, not necessarily in the sections but those around in the lobby or those walking back and forth.

So this time is very instrumental for us, because we're not just giving you your toolkit, we're allowing you to establish it as a result of what you hear from us and what you hear from those sitting at your table, so what someone in Tennessee is doing and hearing what someone in Georgia is doing, saying you know what? That might work. Eating the fish and spitting out the bones. What's the meat and enrichment I can take from this or saying this won't work. Currently that's what we establish with our group discussion. So with moving into group discussion, let's think about who are you serving? I talked about it a little bit yesterday with our diversity in thinking about when we market, right?

What is your market really communicating? What type of biases is it communicating or not communicating. Thinking about the diversity, right? There's six of us up here and then the 10 to 15 of you guys when we shared our story how rich it was and how vast, even though there's similarity in it the variety and vastness of our different stories and those are the communities in which we serve. So thinking about as different positions we all serve, who is it that we serve.

One thing that was great after our session yesterday, we had different dialogues and there was one woman who missed a session but she saw us talking and she asked an important question that I'm taking away as I move into diversity discussions in the future, when you're thinking about diversity is it even diversity within the deaf and hard-of-hearing community? I took that away, because I'm sitting in that space, that was a bias that I had and I was going to talk about this. I didn't know. The different class systems in the deaf and hard-of-hearing community and are we diversifying the program at that level, so not just making sure diverse racially or culturally but in the deaf and hard-of-hearing community.

How many of us are break it down to that level. So a quote I use why power is greater than what power. Why strengthens the what. Right before our break it was an emotionally charged segment of our conversation. That have emotion that we all sat with, that's our why. That is why we come to sessions and why we're employed. I don't know about you, I don't know who's making 7, 8 figures working with this, right? So it's not to get rich. Our why is so that the emotions in which we share or felt we're able to combat so that nobody has to feel the way Rana felt 18 years ago or the emotions in which our different communities feel because of the disservice because of our providers and what we do with our programming.

So remember that as we leave and move forward and don't forget that's our why. So here is our small group discussion, describe an instance where you were unable to fully support a family we're what barriers do you think limits them from the access. What barriers in the system limits your ability to provide services. What other stressors and resilience and how do you support the team that provides the services?

So we're going to take 10 to 15 minutes. Will that work? 10 to 15 minutes and have great dialogue and discussion.

(Group discussion)

>> It's mamma. Wow. This has been incredible. What an incredible day. We could do this all day long. I think if we locked the doors, you guys would not fight us, right? Just want to share a couple of things and then I'm going to ask y'all to share. Thank you for all those discussions. It was amazing. We don't have time to report out. One of the things I wanted to share really as, I think, one of the key tools in your toolbox is this slide. I think that's what we've talked about all morning long, that's what we've discussed all morning long. Having setting for our families, but also for ourselves. We're professionals in the field and we're just as important. It's us, the family, and the child. The child is in the center.

We have to get around the adults. We're the issue, right? The kids are themselves. They're great, so having a place where you feel psychologically safe. We all have a history and families. As April was saying when we first started, we have roots. We all have culture and they run very, very deep. It determines how we walk in a room and how we show up, it determines how safe we feel, even being open and even in this rooms that's why we took so much time early in this session to just share and have y'all share, so we can have a sense on safety.

I can share something deep, I can cry and get angry, all the emotions that we often suppress it's so important we create that. We did the in less than 4 hours, so imagine in our offices, in our clinics, as I work with professionals, the one thing that we all say is what? What don't we have enough you have? Time. And I said, no, it's what you do with that time. In 30 seconds, '1 minute, you can determine that your place, will the phone, virtual, that that's a safe area for the families to feel that they can share what's really doing on. A sense of belonging. I mean look around the room. Look at how different we all are.

We came into this conference -- someone said it was their first time. Oh, my goodness, the whole table of first times. Did you feel nervous? Awkward? Intimidated?

[Off Mic]

>> So what she said she felt behind, I need to learn so much and now day four, do you feel like you belong?

[Off Mic]

>> So she said she feels like she belongs, but there's so much to do. We can bring our uniqueness. I have a kid with CHARGE syndrome, he's 28 and unique. He'll do funny things and flap and clap or goose a woman in the store. You never know what Malik is going to do. That's his uniqueness. Our kids are unique.

We shared all about our children. They have unique needs within that you are hearing and communication differences. Their authentic self, this one means more to me than anything. Can I come in or you come into my house, wherever it might be, and I be myself? Code switching, we all code switch, as woman of color we take about how we code switch, from Spanish to English, from Tagalog, Rayna and I have been this the whole time. Even how I address Rashaun, he's my brother and I'm his big sister, but he's a minister, so I'm going to give him respect. We all code switch but can we be ourself? We have just been ourselves. I'll tell you a short story, one of my families in North Carolina for 15 years I did home visits in North Carolina for families of children who are deaf and hard-of-hearing and I had to -- I'll change the name -- Muhammad, it's a Muslim family and no one had been able to reach them. It was put in the pile of try one more time and we'll close the case. I trapezoid and called and called. I said I'm not going to try again.

I showed up at the house. I did know the mother couldn't drive, she had just had a baby and she has an 8-year-old that couldn't go to school and she had a 2-year-old and from Somalia. I showed up at the house and door like this and he opened the door and the father opened the door, which I was surprised and his mouth and he was the only one that spoke

English in the family and he goes well who are you?

And I said I am a mom.

A mom?

Do you know that your name is Arabic? Do you know what your name means? Are you kidding me? And remember we were talking about where we come from. My father is Muslim. It's my heart. I was raised between a Christian and Muslim world, so I can live and exist in Beth very, very comfortably in both worlds. Do I know everything? No. I've learned so much in the last couple of days. What ended up happening to that kid he went from everyone thought he was a problem and everyone thought the family was a problem. They were black, they were African, they were refugees, and noncompliant because they weren't in school.

That's right, he probably has autism, 'cause he was all over the place. I just sat and this mother gave me the best tea and I had the luxury of time and week after week I went and sat and found out what the issue was. The father come ahead, and then the mom came with all these kids and pregnant. All the barriers we talked about and by doing -- by taking a part of who I am and letting that be and having the courage to let that be, it's not about me but about the courage to do that.

This kid went from no language to we were able to takeaway the diagnosis of autism and the kid just couldn't hear and he was immigrating from place to place to place to place. I would been of the floor if that happened.

It was is interesting when we went to his IEP. I showed up like this and I said where the father needs to sit and the school looked at me-this is this North Carolina -- so they had seen me as you saw me earlier. I hear the whispers. I sat and I didn't answer them because it's none of their business. We orchestrated a table to the dad could have the respect he needed as a Muslim man. I explained to mom didn't drive and she had other kids at home. We had to

set the table culturally, so this IEP team -- before we got to the IEP, can you imagine -- and then we got to say what is missing.

Did he need interpreter? No he was fine. What if I was having trouble getting through to his dad. This was his oldest son. There was a lot of hurt and pride. He deny want us to admit the son had something wrong and they were from Somalia but they came down through central Africa and then came here. So the cultural nuances, the thought that his son is acting up and here is where he was diagnosed, so who's missing? Did I need a cultural broker. No. I am one now. This was about 10 years ago. I didn't know if I knew that term then.

So these are the things. Who is missing. One of the thing I want you before we leave to see is all of us and look around all of you, we are each other's resources. I said earlier, all my best friends in different time zones. They don't live in Atlanta with me. So who's missing? And if you don't know who's missing, or if someone comes up to you and says, hey, why don't you call grandma and have them come sit in the IEP. Because there a Latina family she could be the one to make that decision. That's not what we do, but that's what we do.

Look at the family, who's missing from this family? Who do we need? What will help you make decisions and we sat at that table many a day, long IEPs and I remember I went to another IEP, and this boy came and hugged me and he called me DJ and he started signing. He was so happy.

He picked up that language. He's amazing. I'm standing there crying. It's happy. As a young kid you see a young deaf kid, another culture, so I had to kind of no, no I'm happy. We started this whole cultural thing, teaching thing, when you cry you're happy. But you're sad. Sometimes mom cries. Do you see where I'm going with this. In a second in terms of engaging environment.

>> I just wanted to add something, it doesn't have to mean only your family on this side and

the medical part is separate. You can ask for a second opinion and ask for another provider and ask or if you can't create that conversation with your medical provider or hearing healthcare provider or counselor, you can try to have that conversation with them and if you still don't break down that barrier where you feel like your authentic self. Ask for another audiologist. If you don't feel comfortable, I still don't like it, or I don't feel safe asking you dumb questions, I don't want you to see that person. I know you're here to help me.

>> And last, but not least, culture is resistance. Thanks Michelle. I took doctors or providers, you can be fired, you know, but culture is resistance. What did I say? You see I'm starting trouble.

(Laughter)

>> Right. Well, culture is resistance, yeah, and resilience. We're in a crazy time in our country where people of different cultures and different beliefs, we can be so separate, when we see our families, ask their story.

I don't care where they came from or what language they speak. We're resistant. See. I was raised by radicals. We are all resilient. Think about what it took to get us here what we're going home to. We are resilient. My friend here can't wait, Djenne stop talking, I have stuff to do.

What I want to share on the bottom picture is how we started, we started at a Hands & Voices conference and Janet said we need to do something cultural. I didn't know these women at that point. We ended up how many years later, here we are. Before we end, I want to invite anyone to ask questions and/or to share one thing really quick that you're going to do. Today is Wednesday. Everyone getting home tonight, tomorrow. Okay. Thursday.

Monday morning when you get out of bad and ready to tackle the day what's one thing you can do from today. I'm going to come around.

- >> Sure so I was able to connect with Dr. Rashaun Davis and he provided helpful feedback to what I'm facing in my agency. He gave book recommendations, I took those books and sent to Executive Director and said can I start a book club and she said yeah we'll put money behind it. Whenever having these conversations it takes someone that looks like me to have conversations with people at that look like me.
- >> Amen sister. You said you had four black women working for you. Please don't start a book club. We're tired of book clubs. Can I give you honest feedback? Read a book and do something about it, because in my mind that asked all four of those sisters, I'm starting a book club they're going to roll her eyes. These white women started book clubs. Being honest. Take that and I'm here to help. We all are.

But what is the action. The book clubs have been done. Can I read the book by Sarah.

You read one chapter, okay what are we going to do? So that's that kind of thing. I had to say that. Go ahead.

>> I'm inspired by this workshop meeting so many parents here. It's just so heart touching and it touches me on the emotional level, so I want to go to the national Hands & Voices conference and learn even more. And I believe the deadline on Monday is for presentations as well, so I'm going to look at that to submit presentations. April is one of those people. She's working on it.

(Laughter)

- >> Really, you know, looking at the families, deaf families in Riverside and really connecting with more families and seeing we could start some type of program.
- >> Anyone can share.
- >> So this reinforces one of the things working on in program is to do parent focus groups and I'm looking at one of our divisions. It's like the office of faith and community engagement and

they have a few Hispanic associations and American Muslim coalition in Tennessee to reach out to these different parent groups, so that we know what families that we are serving in Tennessee because we have such a broad range that we are as a program meeting the needs of everybody that we service 'cause everyone in newborn screening is getting dried blood spot and hearing and screen. So make sure what we think we're doing right is what we need to be doing.

>> I just wanted to say this is our 4th time presenting. Different people present in this space at different times and always a unique spirit to who is in that community, so I wanted to say thank you from the bottom of our hearts for being here and sharing your time and your spirit with us. I hope you have safe travels and I wanted to do a plug for the diversity, equity, and inclusion guidelines that's posted on Hands & Voices Web site. It's basically stories and there's no like blueprint for how this can be done, but it was created with the hopes of helping to bridge the understanding of what you know and what you don't know and what you need to know more and trying to find those resources.

My contact information is there, I'm the diversity, equity, and inclusion person and I'm happy to help in any way and really find ways to connect with families. So please use me as resource. Michelle is a resource, mamma HU, her Instagram is great. Anna leads the Latino council. Hosts parent leaders who are supporting other members who are Spanish-speaking. So tap into that resource, their information and journeys and their unique experiences are such a wealth of knowledge and then Djenne and Rayna are great leaders in the community and being out there, we are here for you to support the families you serve and I appreciate learn from all of you, so thank you.

- >> The family voices FAMU toolkit is another great resource.
- >> So I'm a parent in St. Louis, Missouri, and I know that Hands & Voices doesn't have a

chapter there currently. I don't know if anybody in this room might know what's something I

can take back to try and get it started?

>> You can reach out to, I think it's Lisa Kovacs, who is in charge or Terry Patterson who

handles chapter support moving forward, or if you have a family based organization tied to the

EHDI system tap into them as a resource.

>> White you're waiting for it to be established, a great resource to have for support is the F2

F program and P2 I. Sometimes they're combine. You can go to family voices Web site and

see who's running that program. It's a great resource for support.

>> Everyone take a bunch. Don't leave any on the table. Give to your families. We're doing

another one. Parents can join for \$1, and have access to parents that have different

experiences. If parents want to join, it's a membership and parents can join for a dollar. If you

go on our Web site, you'll see. This is a complement. So many needs and trying to fill them.

Parent coaching and access to seminars, et cetera. Take a bunch.

>> All of us give a one hour included or free with the membership ask us anything. We are

there and you can guide the session monthly and everybody is a different day and you know

what, the time you did the during the day on Thursday didn't work for me. It's fun and different

every single time because it's led by your questions.

>> Thank you.

>> Thank you, thank you, thank you so much for being in this room with us. You guys are

brought a cool energy. Travel safely.

END TIME: 12:30 PM

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