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EHDI - LONDON

CREATING COHESIVE DEAF AND HARD OF HEARING LEADERSHIP IN EHDI SYSTEMS AND BEYOND

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>> Hi, everyone! I am Michelle Mendiola.

I would like to introduce our topic, Creating Cohesive Deaf and Hard of Hearing Leadership in EHDI Systems and Beyond.

So the yellow paper on the middle of your tables is your evaluation, and you can do that by writing or through the app.

>> This is where we're starting today, and we decided for a change, instead of having, you know, those formal portrait photos and stuff that we would have fun photos here because, just what we'll be talking about today with deaf and hard of hearing leaders in the system and potential future leaders, that we are diverse in everything that we do. We crave and want that diversity for the systems and for the families. One size does not fit all. One personality does not fit all.

So today we have Candace, and she will introduce and talk a little more.

We have Karen Putz. And Candace is on a mission to take a photo with cows. Everywhere you go, animals... not just cows... animals.

And this is in the Highlands. Beautiful

And we have Karen Putz, who is doing a backwards water skiing.

And then Stephanie Olson, in Colorado. And we have Elle Mendiola hiking on top of something very high... we'll have to find out more about that.

We have Allison Cunningham. She'll be on the panel.

And I love this photo, because she's at the movies, and I also know

Where are you?

She was right there. You moved.

And I know Allison from work and she did a lot of concerts and theater performances and all kinds of fun stuff. So it was neat to see that.

And we have Anita Dowd right there, who loves her chickens and her goats and dogs and animals.

Very good.

And we have Nan Asher, doing a 3D puzzle of London.

Amazing!

And then we have Emily Wielding.

Oh, she's going to be late. She's flying in, right, Karen?

>> She'll be here at the last minute. She'll just make it.

>> Okay. So starting with Elle and then down at the bottom, these people will be on the panel when we get part ways through the afternoon. So we'll see more of them and hear more from them in a little bit.

Candace...

>> Good afternoon. Thank you again for all being here. I know the afternoon lull can sometimes take place as the sugar levels, I don't know, start to drop off. We'll try to keep this interactive and engaging. We'll work together on that. But I'm candies, and I am a mom, a ‑‑ I'm Candace. I'm a mom. My eldest is a 23‑year‑old young man, going to be 24 soon, who is deaf, and a lot of health conditions, some emerging as we speak. So that led me into looking for others to engage with, and so some 18 years ago, I started the Minnesota Hands & Voices program and really found my passion into connecting with other families and leading them to resources and providing support to them

But really along that journey of both working as a professional and a mother, I met so many amazing deaf and hard of hearing adults who had a crazy, incredible impact on my life and even today continue to shape my development in professional working in peer‑to‑peer support and my son's life, so we're gifted to have those many opportunities. It was with that exposure to deaf and hard of hearing adults I realized that parent‑to‑parent support is one silo. Without deaf and hard of hearing adults involved in everything that we do, how are we possibly going to get ahead?

There is so much wisdom and experience there. And so that is really why. Why is FL3 talking about this? Why is Hands & Voices, a parent organization awarded the FL3 program and why is there something about infusing deaf and hard of hearing adults under a parent organization efforts?

Well, it's because we feel that we have a unique opportunity and responsibility to raise the awareness and value within other parents of how deaf and hard of hearing adults can make an incredible impact on their lives as parents and on their child's life as well.

So that is why we're talking about this. That's why you see a hearing parent up here, because I have personally found that benefit.

Also, my son is 23. He's growing up. And we have many of us who have children who are now entering that world of employment and career. And what lies ahead for them. And all that early intervention. If we didn't do something during those years, that really led them to being in place where they can be out there, being that strong deaf or hard of hearing adult, then we've wasted those rich opportunities.

So, again, that's why you have a parent involved with this effort as well, because that's my son's future. That's the future of the parents' children that I work with as well. So, just wanted to enlighten you to that perspective too.

But, for systems change, we really need to have everyone on the same page, and I do believe that we can get there.

We can work collaboratively together to use the advantage of where parents are out there and they have grabbed a stakehold and they have a place in the system, then we need to look around and go, where are the deaf and hard of hearing adults?

I learned this from my work, actually. It's a little off the subject, but I did a lot of work with robotics. My deaf son let me to the world of robotics and this career exploration in the field of robot ticks. It was a gentleman who came in the room with the idea that he was going to talk about female involvement and female leadership in STEM activities. It was a guy upfront, right? And the women were outraged. Who is this man to show up and talk about female engagement and robotics. He is of the majority. He is of privilege. He can go wherever he wants. He is not being, perhaps, marginalized in a system that is geared towards men. And the women were ready to get him. Let me tell you... they were in the back of the room just eager. But what he said when he got to the microphone was... I know what you're thinking. I know what you think of me. I think there's assumptions going on here. But I'll share why I'm here.

Somewhere, someday, there will be a closed boardroom of men, and they will be deciding the future of who is going to be a leader, who is going to get in, who is going to lead a project, and there will be no women there.

Who is going to speak up for them?

I need as a man, it is my responsibility to make sure that I enlighten my male colleagues to the benefits and the beauty of having women as part of our team.

And so he saw himself as an ally. And the mood shifted and you could see the women just back on down, you know, because they were ready to get this guy.

And I use that story to draw an analogy, that we really have a place, all of us, in being allies in this work. So I hope you see it this way.

And I just want to preface, too, that today our objectives are, as you can see here, varied. But the whole point of this is that we walk away today with some collective discussion around this topic. If you came in here expecting a presentation by a bunch of people to tell you what they already know and what has been discovered and it's so easy, you go back and do it yourself, I'm going to be sadly disappointing you.

These pre‑sessions are really built on the premise that there is wisdom in a room. There is perhaps issues that have not been solved. And so this is a forum for those discussions. This is to draw the wisdom from you, guided by those that have come together and said this is important and the time is now to fix this issue, but it is not going to be to present to you, it's going to be to facilitate with you. I hope you see it as that if we get off topic, Karen and Stephanie will help me come back to topic and where we find the common ground, because I believe the time is now and we cannot wait to bring more and more deaf and hard of hearing leaders to our midst. Our objectives are here. We would like all of us to walk away with ideas around sharing what are the characteristics of an effective deaf/hard of hearing leader. We would like to collectively gather, you know, what are some examples of current practices and services that support integration of leaders who are deaf and hard of hearing in EHDI systems.

And we also would like to develop some strategies and changes that will increase family access to deaf and hard of hearing professionals and leaders.

And then through those discussions, we would also like to specifically dial in a bit to how do we create strategies to ensure opportunities for growth of deaf and hard of hearing leaders amongst low resource communities as well.

So that's our mission here.

So I hope you signed on to what you feel passionate about as well as us.

All right, so I'm going to pass the mic over again.

Oh, sorry, no, I'm not. I take that back. One more slide, I apologize.

Before we get started, we're going to just talk amongst ourselves at the table, if you will. So just wherever you are, or if you want to scooch in, you feel disconnected and want to bunch up, you're welcome to do that. But we want you to go around at the individual tables and talk about first, who are you? Describe "Who am I?"

I'm a parent, mentor, whatever you are.

And what led you here today? What were you hoping to take away?

Okay?

So we're going to do a little bit of that at the tables and then we'll come back together.

How much time do you want, ladies?

Ten minutes?

>> If there's too small of a group, you can join other tables.

>> Bunch up if you like. If you feel a little lonely, bunch up.

>> Everyone... if anyone needs an interpreter, we have a staff here.

You need an interpreter?

That table... we can get you covered.

Another one?

>> Okay, everybody! Hello! Come on back. I'm flashing the lights up here. Just like at deaf school. Here we go. Hello!

I could run back there, but I'm not going to.

Everybody!

Wonderful... bravo!

I hope you enjoy your little kibitzing with one another. We have not introduced ourselves, but we will, I promise. I do have questions about why you came here. Do you mind just sharing a little bit? I won't call on everybody. Just a few people. Just let's stand up and tell us why you came.

>> AUDIENCE MEMBER: Hi, my name is Laura Grammar. And I work with hearing professionals, and I really I want to move up the ladder, but I got to pull up other deaf people with me. I want to reach behind and pull them along. I want collaboration for the purpose of deaf and hard of hearing children. That's who we want to serve.

>> AUDIENCE MEMBER: I work in a Children's Hospital and I...

>> I'm having trouble seeing you.

>> AUDIENCE MEMBER: My name is Katie. And I work at Boston Children's Hospital. In Massachusetts, and we're part of the EHDI Committee at the local level.

And so I would like to be involved more in the system nationwide to gain experience that system. That's why I came today.

>> Don't be shy! I want to know. Come on!

Tell us why you came.

>> AUDIENCE MEMBER: Hello. I'm an administrator in North Carolina department of deaf and hard of hearing. I have focused on some mentoring in the mentoring aspect of deaf and hard of hearing individuals. And the reason why I came here is actually for me to learn, of course. I know that there is a lot of information, a lot of wisdom and knowledge here in room. So I'm excited to learn from all of you. And I basically want to gather all your business cards and take them back with me.

>> AUDIENCE MEMBER: I wanted to let you know that my name is Jan, and so really before I get started and dive right into the work, I want to come here to get more information, so I can apply what I've learned here to my work in North Carolina.

>> I need steps.

>> AUDIENCE MEMBER: Hello, my name is Jacob True. And I am with the Hands & Voices of Oregon. And we have a parent guide program and we're interested in branching out into deaf mentorship program and are just sort of looking into it. It's part of our plan. And just gathering information.

>> Anybody else?

Yes, ma'am?

You in the back?

>> We're getting our exercises. Hello, I'm Emma, and I am from... I see y'all are wearing a different ‑‑ you're wearing different hats. It's a wonderful experience. You have so much experience. I want to learn from you and I want to bring it back and my hope is to set up a program in Texas for mentorship for deaf and hard of hearing people. I hope to collaborate with Hands & Voices, Guide By Your Side.

And also I hope to really expand and our services from zero to five.

This is the place to start. So I'm here today.

And I hope to learn from all of you, thank you.

>> SPEAKER: Anybody else? Okay. Thank you so much for your feedback and your answers. It's really great to see you all here and you all involved. I've been involved with EHDI for many years, ten years now. And there are so few deaf people. As I sit and look for them and we talk with each other, every year it's growing, and that's wonderful, but in the beginning, there were very few of us. But we need to do more work. We have to roll up our sleeves and really put the work in to make sure we have the opportunities to really learn from deaf and hard of hearing adults, professionals. We've got a lot of work ahead of us, we know that, but this is where it starts. We've got to expand our pool. This is where the metamorphosis will start.

My name is Karen Putz and I'm here in Chicago. I love my hometown. So welcome here to Chicago!

We ordered no snow for you. So, so far, Mother Nature has listened to us.

So you can thank us.

I was born hearing. I grew up hard of hearing. And then I became deaf at 19. And I remember ‑‑ remember that picture I was skiing?

I had no skis.

That's called barefoot water skiing. I fell. So when I got back up in the boat, I was deaf. It was instantaneous.

At that time I didn't sign. My family spoke to me.

Mom was deaf. Brothers and sisters, nobody. They all spoke.

My mom is deaf. Father was hearing. But we used spoken language in my family. There was never any sign language. When I became deaf, I was lucky. Because I went to NIU, Northern Illinois University, and at that time, really, a few weeks later, I went to NIU, right after it happened. And I was in the dorm with deaf and hard of hearing students. And I learned to sign. But I came in shocked. It was culture shock for me, because I never really was exposed to sign language before. So it was a bit unsettling at first, and I was pretty upset. I said, please move me! I don't want to be on that floor.

Had quite an attitude back then I'll say. I'll look back and think, oh, my...

But I had no exposure. I did not grow up with deaf role models. Not a one.

So that's why I do this work. Because I look back and I think, "Wow, one morning I was thinking about my life and I made a decision to learn ASL, and I went ahead and I learned sign language.

And when I look back, I always say... before I became deaf, my world, after I became deaf, my world was huge. My world was little before, because I never really met or communicated deeply with anyone. Once I became deaf, my world ironically opened. My husband is deaf. We have three deaf children. They were all born with ‑‑ were born hearing, but we have a gene in our family that is very rare. There's only one family in the U.S. with that gene. Four in the world. It's truly rare.

You're born with regular hearing and then hearing loss hits you. And you become completely deaf.

So our three children were born hearing and then two, four, and two, they became deaf.

And we raised them with sign language. We raised them with spoken language. I don't use cued speech, but they have been exposed to every single communication mode on the planet.

So that large world is available to them.

My background is in counseling. Bachelor's, master's in counseling with deaf and hard of hearing people.

And then I was a stay‑at‑home mom. And I worked with EHDI. Well, I worked with early intervention, excuse me. Almost 14 years.

And I was one of the first deaf mentors in the system in Illinois here. One of 45 trainers. Few deaf people involved. There were a few of us. Why is that the case? Because they never called us. We worked with very few families. If a kid wasn't developing by the time they were two and a half, then we were called. We need to change that system. Now it's sad because it's worse. There's no mentors. No deaf mentors. Or one. I've stopped because I focus now on Hands & Voices and work for them. That's my long story short, but that's who I am. That's my story.

Stephanie, your turn. Take it away.

>> I'm Stephanie Olson and I work with Hands & Voices headquarters in the FL3 project for Deaf and Hard of Hearing Infusion. I also work with Children's Hospital Colorado as a family consultant. So after families and children have been identified with hearing loss, I reach out to them and connect with them and support them, as well as the professionals involved in that system.

I was born deaf/hard of hearing most likely, but not identified until the age of three. And there were absolutely no support services or anything for my parents, so it was a long, long time before my mom could get comfortable with having a deaf and hard of hearing child. And that's my motivation for being in this field. We don't want parents to have to process this when their child is rapidly growing 10, 11, 12, 16 years old and the mom or dad finally getting comfortable with who they are. That needs to stop. And part of that comes with early intervention. It comes with the newborn screening. It comes with services. It comes with parent‑to‑parent support. And it comes with deaf and hard of hearing involvement in those systems.

Last year I had a colleague of mine tell me something very, very wise. She called me up one night and said, hey, can I kind of give you some information or resources. Not resources... more like... not advice, but kind of some input, some thoughts I've been having? And I was like, sure, go ahead.

She said, I'm just thinking about where we're at in our system and our state and what can we do to bring forth the new leaders, the deaf and hard of hearing people to be involved in the system, the new leaders?

And honestly, the younger leaders, the younger people... where are they? How can we get them involved? Because we know that has such an impact on families and professionals and systems. And that's part of our motivation for being here today, is going out and not only enhancing our own leadership skills and talking more about that, but looking to the future, where can we pull in these deaf and hard of hearing people and have them involved in these systems?

I have three children. And they are not deaf or hard of hearing. They are young adults. And I've been married for 37 years and my husband and I live in Colorado, so we do a lot of running and biking and fun stuff like that.

So I'm very happy to be here. And, you know, just talking about this topic today. We're really eager to hear about you, your state, your systems, your hopes. And ideas and strategies to having more involvement in the EHDI system and our own state systems.

>> This is a question. I'm curious. What is your perspective about yourself? Are you a leader?

Who thinks of themselves as a leader?

A few of you?

I look back, and in my time, I never thought when I was young... I never thought I was a leader. Leader who is a person who is an expert. They have an educational background. I was just a mom. You know?

Many parents feel that way. "Just a mom"

"Just a dad."

The baby is born. I'm not there to lead anyone else. That should change.

At the same time deaf and hard of hearing leaders need to be increased in the system. Those numbers need to be increased. We see many deaf and hard of hearing people work so hard and we need to grow that group. We see the hearing people working hard, parents working hard. We need to increase that group, those numbers. That's why we're here. We want to grow those numbers in your state. So there's parity. And there's a platform for everyone to lead.

So here is a story. Everyday leader. His name is Drew. I never met him. But I was fascinated with the story. Here is his story.

Drew at that time was working at a college. First day. Student. He arrived. All the students were arriving. And Drew's job was to welcome everybody. One girl seemed to be quite shy. She felt... she seemed very uncomfortable. Drew happened to notice and came right up to her and said "Hi" very warmly. "How are you?"

The girl was shy. Drew said... you know what, there's a nice looking guy right next to you. Tapped that guy and gave him a lollipop.

You now give that lollipop to the girl.

So he said, "Sure." He gave the girl a lollipop and she gratefully took it and said "thank you."

That girl's parents were standing right there. And Drew said "Hi. Guess what. Your daughter has arrived the first day and she already took a candy from a stranger! "

ha‑ha‑ha.

That moment of laughter is called what?

The lollipop moment.

Because years later the two of those people with the lollipops got married. And that boy what gave that lollipop to that girl... they became newlyweds. And when they thought back on it, how many... when you analyze it, how many times have you had lollipop moments in your life where you have led, you can influence a parent? Maybe we didn't even know we influenced that parent. I happen to be deaf. I happen to be hard of hearing. I tell them just a bit of information. And that parent learned. And our influence changed their life. In that moment, we had an impact. We influenced that family. And the parents learned from us. I call that a lollipop moment.

We can have those lollipop moments every single day. Every time you lead every day, you have the opportunity to have a lollipop moment with a parent. Because you are deaf or hard of hearing. And you are rich in experience, because it's your life.

So think about that. When you leave, how many times can you give a lollipop to a parent?

So think about that. How you can help parents and their families on their journey. Not control their journey... no, no, no. Guide. Influence.

Help them make their decision themselves, but give them the information that will allow them to do it. That's being an everyday leader.

>> STEPHANIE OLSON: The time is now. Yes. To start building leaders in the systems.

And a lot of times when we look at, like, elementary or high school programs, we're very passionate or motivated about developing new leaders and maybe you could share if you have a program or you know of an organization that is working on developing youth leaders or young people.

I'm not talking about us. More like high school, middle school students, are you aware of camps or schools or programs? Anybody?

Yes?

A camp?

Can you share with us?

>> AUDIENCE MEMBER: Sorry about this.

The northern California services or to the deaf and hard of hearing, we have an annual camp for deaf and hard of hearing children. Ages 6 or 7 to 15.

And they have CIs or CIT, counselors in training, and then they become counselors if they want after they have the CIT training. But it's not only deaf or hard of hearing. It's also CODAs, children of deaf adults. Siblings of other ‑‑ of brothers and sisters. Quite the variety of folks involved. There's deaf‑blind, there's Deaf+. All kinds of kids are involved. About 100 kids come for a week every year for 21 years now straight.

>> STEPHANIE OLSON: That's great.

>> AUDIENCE MEMBER: It's leadership. We encourage them to be leaders. We give them different duties, different responsibilities for camp. They do competitions with each other. They have lots of fun games. And teach them things about being leaders.

>> STEPHANIE OLSON: There was a question where. Did you say Northern California? Is that where your program is?

>> AUDIENCE MEMBER: Yes, Northern California.

>> STEPHANIE OLSON: That's a great example of starting future leaders in a camp‑like setting.

Nan, did you have your hand up?

>> NAN: I'm the treasure for Michigan coalition for deaf and hard of hearing people we have Camp Chris Williams. It's ages 11‑17 every summer in Greenville, Michigan. It's very similar to that. And usually we have a STEM theme that week and we invite deaf and hard of hearing professionals. Like when you ‑‑ like you're medical. We have doctors and nurses and psychologists who come who had hearing loss to talk to the kids. And then we've had engineers and stuff like that. That continues on.

>> STEPHANIE OLSON: Very good.

One of the reasons why I wanted to start with camp was that was probably my first leadership moment, being the only deaf and hard of hearing child in our community and in the school, the only personality that I really seemed to have because of my situation was a person ‑‑ a very shy, quiet person. And when I got to camp for deaf and hard of hearing people, these children, this whole other personality came out of me that I did not even know existed. And I found out that I was outgoing, outrageously funny, apparently. Didn't know that.

[ Laughter ]

And a leader. And just like so full‑on involved and active with the cabin. And that part never existed prior to that.

So I do believe those child life experiences, like camp, can be the starting point for bringing out potential leaders.

How about some of our other high school programs? I think there's Loft or something? Is that what it's called, Loft? I know a little about that.

You'll need a microphone.

>> AUDIENCE MEMBER: I only know ‑‑ I'm not involved personally in the program. I only know from resources I receive from their program specifically, but they do have a summer camp that's...

>> Can we hold on for a moment? We want to move the interpreter placement to other side of the room for lighting purposes. Just one moment.

That other side of the room is fairly dark, so we're going to set up the interpreters on the other side.

Is that much better for everyone else in the room?

All right. Just one moment.

>> AUDIENCE MEMBER: So it's the AG Bell Association has a Loft program, and it's a summer program for ‑‑ I think it stands for Leaders of the Future in Training, I think is what it stands for, through the AG Bell Association. It's yearly. And they have amazing scholarship programs for children who are listening in spoken language communication modality. But there's a couple other camps that I know of. I don't know if you want me so share about those or just LOFT.

>> STEPHANIE OLSON: Any other programs out there?

>> AUDIENCE MEMBER: Hi. In Washington State there is a Deaf Youth Leadership. DYL... yes, Deaf Team Leadership. Both our kids have participated in that one. But as a family, we live really close to the Canadian border, so we went up to British Columbia on Hornby Island there's the Family Network for Deaf Children. So there's a family camp one week and then the kids can stay there and do just a kids camp.

As parents we got to do the same activities as the children, like high ropes course. And so when we're asking the kids... you can do it! You can do it! Well, we got to do high ropes. And that was amazing!

And so as a parent, we're asking our kids to do these things. Oh, you can do it... it's fine!

Think about it.

Anyway, it was a wonderful experience. I highly recommend it.

>> STEPHANIE OLSON: Okay, we're jumping around.

>> AUDIENCE MEMBER: Sorry, I just want to say because I'm from Vancouver, British Columbia, thank you for mentioning that, because I just made a note in my book as well to... and I'm here to learn more. I've met with Stephanie and Karen and they've both coming to BC and given excellent training and a wonderful foundation. So I'm just here to expand on that and learn more. I wrote it down because Family Network for Deaf Children and the Hornby Island camp you mentioned is still happening. If anybody is interested in more information you're welcome to get in touch with me and I can pass you on to the right people to connect with. And they're trying to expand and do more of those camps and more youth leadership types of programs in BC. So there might be opportunities for others.

>> STEPHANIE OLSON: Is time running away from us?

Maybe we... yeah, maybe one more.

Okay.

>> AUDIENCE MEMBER: Correct me if I'm wrong, but I think the National Association of the Deaf has a Junior Camp, like Junior NAD. Is that correct? Junior NAD, yeah, they have a camp in Georgia, along with Georgia Association of the Deaf. It's a junior camp. We can look into that. I had a group of deaf and hard of hearing kids go... without their phones. Without their iPads. For two weeks!

[chuckles]

Woo‑wee!

>> STEPHANIE OLSON: That's great. We all could use a camp like that. How about college training programs? Do you know of college training programs that have supportive classes or something on leadership for deaf and hard of hearing professionals out there?

You do know of one? Gallaudet. That's what we're trying to find out. Okay...

>> And NTID. Definitely.

>> STEPHANIE OLSON: Good, that's what we want to find out so everyone can know more about it. What did you say, Nan? The same one.

>> AUDIENCE MEMBER: NTID has several tracks.

>> STEPHANIE OLSON: We want this out here so people can be aware of what is out there.

Very good.

So we have a lot with our kids and youth. We have a little bit on the college level. Then we get to the adult professional part. And are there leadership training programs? There are?

Other leadership training programs for deaf and hard of hearing professionals?

That's what we're going to find out.

And do they need to be different? Do deaf and hard of hearing leaders training programs need to be different than other leadership training programs?

So what do you think? I saw some hands go up.

>> AUDIENCE MEMBER: I do have something to add. I just wanted to share briefly that a community‑based organization that I'm familiar with, we are located in Sacramento, and our area is Northern California, but we have two schools for the deaf in that area. Fremont and Riverside, and both have those programs and their activities. But at the same time, many in our community don't go to those two schools for the deaf, those residential schools. So they look at us to provide services and programs and events and activities like Silent Sleigh for if younger children. We have 400 deaf kids who come to Silent Sleigh to meet deaf Santa Clauses. We have high school, junior high, separate rooms for their activities, separately. You have to keep the young away from the older.

And also we just started a prom for deaf and hard of hearing students that are in mainstream schools and they don't go to state schools, so they are all in different counties, so they all come together to the deaf prom. Last year we had the first prom with over 100 kids coming to the prom.

And we encourage those events, and we do host those events and they already told us what they want us to host for next year.

So, we formed a committee and said, come on down, tell us what you want. And they are leading us. So we may be a little group, but we can lead to bigger things. And I know those kids will be our counselors at the camp in future, I know they will be.

>> STEPHANIE OLSON: Very good. Danielle.

>> AUDIENCE MEMBER: And I would like to add what you asked before about the college training, for early intervention, I'm familiar with Gallaudet. They have an Infant Family Certification Program. That program, it's possible to become a master's degree at Gallaudet. Secondly, they have an Early Childhood Education Program at Gallaudet as well.

So if deaf or hard of hearing leaders want to get a degree in those areas, please go to Gallaudet. Go for it!

>> STEPHANIE OLSON: That's wonderful. I was hoping that would come out so everybody would have an opportunity to hear about that. Very good.

One more. And then we've got to get moving.

>> AUDIENCE MEMBER: Hello again. I work for the state government. And all of that is wonderful. But ADA, Americans with Disabilities Act, is a little bit of a double‑edged sword. Because back in the day many deaf people worked where? In public services. And that has diminished, because they are now in the private sector. High tech. Medicine.

They have gone everywhere for their jobs.

So, if you want to develop leaders in the public sector, you can include early intervention. Maybe you can start young. Teach them about the benefits and value of public service. Which has gone by the wayside. Maybe state government, non‑profits, schools. Okay?

Thank you!

>> STEPHANIE OLSON: That's a good foundation for the next couple of slides.

We're going to be moving into the skills and qualities that make good leaders, either just regular leadership or deaf and hard of hearing leaders. We're not going to talk about 101 best leadership skills that you can find on the Internet. That's a lot. . That's a lot.

So you can Google and find all these good straits, but we want to pull in together here this afternoon and find out something a little bit more unique. And that is, what are the top five traits, the most important traits for effective deaf and hard of hearing leaders in our EHDI system. So we would like you to talk among yourselves at your table. And then when finished, we'll pull out one or two of those traits or qualities for a good leader in the system, deaf and hard of hearing leaders in the system, okay?

Thank you.

>> I'm going to bring you back, if I can. I know that was quick.

Flash, flash, flash... my pretend flashing lights.

All right. Can I just get a few report‑outs here about what were some of the characteristics? Specifically for deaf/hard of hearing leaders in EHDI systems. We're drilling pretty specific here, but what were some characteristics that you identified? Who would like to go first?

Right here. Jacob. Microphone coming.

>> AUDIENCE MEMBER: One that we identified important for a deaf and hard of hearing leader in the EHDI system, but in general as well, just patience. You know, going... working through difficulties in communication across different lines. I'm thinking about it from the perspective of a parent organization and deaf mentorship, being able to sort of work through that initial difficulties in how do we talk about this and... yeah, very important.

>> Patience is very important. And honestly I think most deaf and hard of hearing adults and individuals I know have been given a lot of patience, because that's life, right? It's constantly having to advocate and remind and educate. Yes, that's a good point. Thank you.

Other characteristics for deaf and hard of hearing leaders in EHDI?

>> AUDIENCE MEMBER: I would say that person would have to be willing to listen. And they must listen, of course, so that they can hear all perspectives on all sides of the coin. I know there are a lot of people that want good things to happen, but they're only focused on one side of what is happening. So I would like for them to know all perspectives.

And then the second thing about listening is also having that good balance as well.

Having those people who would like to take on too much responsibility but they are not effective in their leadership when that happens. So sometimes they have to learn to say no.

>> KAREN PUTZ: Yeah, those are really good points. Thank you for sharing that.

In the back of the room... yes?

>> AUDIENCE MEMBER: I have to tell you what happened at our table. We were discussing traits and someone having an open mind and an open heart as well. And, you know, living in the deaf world and also hearing world, having both of those worlds colliding and coming together and learning from one another and just being open in that space to share your experiences, to share what you have learned. And there was someone at the table. I'm trying to remember this person's name. What's your name?

>> Marie.

>> AUDIENCE MEMBER: Marie is table and one thing mentioned was keeping biases out of the way. Many are set and hold fast to the biases we have, but we have to make decisions to let go of the biases. It's okay to share our experiences. But also we want to make sure in sharing experiences we don't diminish the other individual.

I know that Karen mentioned that lollipop moment. That's another example as well that we should think about, you know, thinking about that step, making that first step for yourself. Feeling comfortable and confident in what you're doing and making that step forward. Because we all go to a variety of places and we take those steps. We don't want to stay stagnant sitting in one place. We want to keep moving forward. That's part of the discussion we had at our table.

>> KAREN PUTZ: Thank you. Excellent points. Harnessing your motivation to do the work but not letting your personal experience maybe influence others. Yeah, excellent points. Anita, I'm going to have you share too.

Microphone... here.

Right behind you.

>> ANITA: What you were saying about bias, I mentioned at the table over here that, as deaf and hard of hearing individuals, we need to understand that while we had that experience and understand that, we eat, sleep and breathe deaf. We have zero experience being the hearing parent of a deaf child. And it took me a while to learn that. And when the light bulb finally went off, then I became the learner. And my ability to work with families changed significantly when I realized that I had to respect where they were coming from, not where I was coming from.

>> KAREN PUTZ: Thank you, Anita. Appreciate that. I think we'll take one more just to keep us moving.

>> AUDIENCE MEMBER: My group discussed at the table, we talked about the importance of training. And when you're training those at colleges and universities and their counseling degrees or fields of study, we want to make sure they understand where the parents are coming from. And also having that ability to listen. Because realizing those parents are experiencing the grieving process, so we want to make sure that it's a critical skill that we all have that skill to actually listen to one another.

>> KAREN PUTZ: Thank you. As a parent who went through that grieving process, we each are individual in how long that takes and what path that might spark us to take. But having that support and guidance, and don't give up on us even when we might seem not to be making decisions as fast as you might have liked, it's all part of that process of understanding and sticking with us and being by our side. Honestly, I'm grateful for the deaf and hard of hearing adults that continue to be in my life and guide me.

All right, I'm going to give this over to Stephanie.

>> STEPHANIE OLSON: That's good. Very good.

So getting ready for this workshop, I did a little bit of research. And of course there isn't much out there, but that's okay. Because I'm hoping that someone in this room will want to take this one step further. Maybe some students at Gallaudet or RIT will say, hey, I'm going to do this for my next project.

And that was the perspectives from leaders ‑‑ from deaf leaders and interpreter leaders. And they had the two groups together, just because there weren't a lot of deaf and hard of hearing leaders at the time that they did this research project. And they were asking about characteristics, just like we were doing a few minutes ago. What do others value in you as a leader and experiences and the differences and similarities between deaf leaders and hearing/interpreter leaders. In case you're wondering a little more about interpreter leaders, it wasn't ‑‑ it was an interesting article to read, I've got a copy or you can look it up, because our interpreter leaders actually do a lot of advocacy work, and now that there are more and more deaf and hard of hearing leaders in the system, they can step back and we're moving forward.

So it's interesting. So... taking a look at this characteristics, what do others value in you as a leader? All 24 of the deaf leaders we mentioned respect value leaders, quality. And that is very important, but I like to think that we have come a little bit further in that respect now is what we have, but what we do with that is what we're working on in the system.

This, I think, came from years ago when there wasn't a whole lot of respect or value placed on deaf and hard of hearing leaders. We're already starting to see this shift a little bit.

What do others value in you as a leader, being involved in the community? How many of us here wear multiple hats?

Where you are involved in more than one system outside of your job and in your community?

Right. Yeah.

Just moving your hat back and forth. Yes, that's a lot of us.

Being a good listener, we talked about that. Very good. Very important.

Being responsible and being fair. Here is something interesting in this research that I found to be valuable and I think that we should be talking about a little bit more, especially in the EHDI system. One of the five themes, a higher percentage of interpreter leaders than deaf leaders reported a knowledge of how systems work as a valuable characteristic and being a good leader.

The deaf and hard of hearing leaders did not report that. And there was a little bit of discussion in the article about why that might have been, and one interpreter leader shared hearing leaders have had more access to resources and assistance than deaf leaders. And that's something that we have seen shifting in the last few years. For a while there was a lot more ‑‑ there was easier access to resources out there, and I think with technology and EHDI system and state systems are more open and embracing deaf and hard of hearing leaders, we're starting to see that knowledge of systems has increased.

And why is this so important? Because we are here at the EHDI conference. And if you become involved without truly knowing or understanding the systems and the families that you serve, you can actually do more harm than good.

Because sometimes our deaf and hard of hearing leaders truly believe, and rightfully so, that they're there to share their story, and their story should impact the systems. And that could be their communication, their technology, or their modality. But that isn't what is driving us to be a great leader. It's understanding the system as a whole that is very important. We need a system that honors and includes deaf and hard of hearing adults and their services, and we need adults who are trained for this work. We're more than a story. Someone brought that up, the importance of being trained.

Karen... confident leaders.

>> KAREN PUTZ: I want to talk a little bit about the traits of an effective leader within the EHDI system and beyond. The traits are, when we analyze them, really the three of us came up with this list.

Authentic was our first.

Authentic.

Really, be yourself. And don't apologize for who you are. Don't apologize for your background and your experiences. That is part of who you are. And families appreciate that authenticity.

And if you don't know something, you can help them find out and admitting that is wonderful.

Second trait is open minded.

In the EHDI system and beyond.

We need leaders who are open minded and are willing to listen to anyone's experience and learn from each other's experience.

When I set up a program in Illinois, the Hands & Voices program, I did some analysis on my experience, on my work with the families in early intervention.

But with my experience, I was lacking in cued speech experience. I had no experience with that. I had never met a family who used it. I had never sat down with a family who asked me about cued speech. So I realized that I needed to learn more on that particular topic area. So I went to a cued speech meeting. I tried to learn some cued speech. I worked with the family.

We got a board member who was involved in cued speech. And my world became larger. Because I really ‑‑ we needed well‑rounded leaders. And that means willing to learn and experience things that are not part of your natural world. And you go out and expand your mind and see things from many, many perspectives.

Because that's valuable to families. Especially in a ‑‑ that's valuable to families, especially in a system.

And sincerity. Sincerity.

You have good intentions as leaders in this system. You want to see the same things. All of us do, want the same things. We want success for the deaf and hard of hearing children, so that they become wonderful adults.

How we get there may be different. But we have the same goal in mind. We have the same goals.

So we want to see the families succeed and happy with their children and their children happy and their children feel good about themselves as they grow up.

And I think it's important to embrace diversity. Not just skin color but every kind of diversity. And respect people's diverse journeys. How they get there. How the families get there.

I would say we have room at the table for everybody. Absolutely everybody. The system is huge. The families are diverse. We need every single person. We need everyone to be involved.

Another trait would be leaders know what they believe in. They know what they stand for. And it's perfectly all right to push it.

What is not all right is to push your own agenda. But it's okay to know what you believe in.

You know, one size doesn't fit all. And that is one problem when you push your viewpoints on other people, if you think there's one way for everybody to handle something. So we need a system that embraces variety and supports families on their journey.

So no one falls through the cracks. And, remember, the academic system is changing. Technology is now involved. And everybody is always learning something new. And we need to keep that and learn from each other. Being positive is a great trait. Families need that positivity. During times when they may feel it's dark, they may feel that they can't reach the positivity. You can bring that positive attitude to that family. There's never been a better time.

Bring it to the system and then it gets better and better all the time. It's so much better than it was 20 or 30 years ago. So let's keep moving to this ‑‑ in a positive way.

Deaf and hard of hearing people can become anything nowadays. Anything that they want to be.

So we want to stay positive for our families.

And that last one, of course, is... grit.

Don't give up!

Roll those sleeves up and be willing to really pursue your goals. And go for it! Grit... staying with it. Persevere. That's so important in a leader. It cannot be overemphasized. And recognize the family's worth and their deaf and hard of hearing children's worth.

Oh, my goodness... I could have been over here. My goodness.

Your story is important. It's your story. It's yours. It's your journey. That is valuable. And families can learn from your journey, but let's understand that your story does not mean that it becomes their story. That family's story is unique. And that's important for all of us to remember. Your story is valuable and the family can learn from your journey, from your story, but that doesn't mean it becomes their story. Families need to understand that separation.

What happens between my story and your story, it doesn't mean your children will become like me. They will create their own story. My story created me.

They will learn and they will apply certain things that they learned from your story, but they will match their journey with their child.

For example, suppose a profoundly deaf leader came in to the system and that child was also profoundly deaf. Is there a value there? Yes!

You don't need to match the families perfectly. We just need to work together. You can have a deaf person who uses ASL go into a home to help a family that are profoundly deaf child who uses spoken language. There is value in everyone's experience. Their perspective, their sharing, it cannot be reduced to communication alone. There are many things to share. Please don't think that it's only about communication. It's the whole of the person, the Gestalt. It's not only about communication and you have to communicate the same way or else you don't have anything to share. That is not true. There is a whole person there, there's a whole journey. And you have a wealth of information to share with the families.

Can you see me here or am I better there because it's too dark over there?

Do you mind coming over here?

Thank you.

Sometimes leaders are nervous or feeling like maybe they're not good enough, or they have worries. And I have to a serious suggestion about our own self‑talk and how we can switch that to positive self‑talk, so that we can lead with positivity instead of from anxiety.

Sometimes we say , Oh, gosh, I'm not good enough to do this...

Let's switch that to... I know my story. I can speak of my story and share it with confidence. Instead of thinking badly about ourselves. Remember that your story has value. Suppose if I mess up... suppose if I say the wrong thingggg...

Or I don't mean to manipulate the family and I do something wrong...

It's okay. Think of it as all the knowledge I need, all my knowledge, all my experience, my story... it's enough. Know that.

And what you don't know, you will learn with the family. Suppose the family asks lots of questions and you don't know.

Let's be honest. Say "I don't know, let's learn it together."

That's enough.

I don't know enough... I think we just covered that.

And saying "I don't know," everyone is better than me, they're a better leader than me.

Or "Why did I agree to do this? It's making me sick to my stomach! "

Why don't we change that to, "My purpose is here to connect, to inspire, to help, and to share."

That's the purpose. That's a leadership part. Inspiring, connecting, sharing.

And that last one...

You are enough.

You Are Enough. As you are.

You are unique. There's no one in the world like you. No one. And you have something to share. And something to give to our families. And to the system. We all do.

When we were thinking about this workshop and about what families need, they really need 360 degrees of support. Not just one piece of the system they need support with but with every single piece of the system.

That means you are one part. Somebody else is another part. The family is involved.

And everybody has to work together.

The system itself really is there to support the family. And when you arrive home and analyze your state after this conference, you have to think about what is missing. What can you do to help make that system 360 degrees of support for our families?

Analyze it. What is missing in your state? And then work together with other stakeholders to figure out how to pull in the support. So a family that has a baby that is deaf and hard of hearing has that support system ready to shelter them 360 degrees around.

So the family can see that they have everything they need to support them on that child's journey with them.

So building that 360 degrees of support together is what you can do when you get home.

If, for example, cued speech is an area that is weak, you can bring in experts. Bring in families who use that to help others learn about it. Connect with deaf and hard of hearing leaders and people. You know they are a diverse group. We are a diverse group.

And suppose a family is different from you.

Bring in a variety of leaders. For example, I work with a family who questioned me incessantly and cochlear implants. I have no experience with CIs. I didn't have one. I don't have one. So what I said is, You know what, I can't be your expert on this, but let's learn about it together.

Every week we would do research and compare notes and then we brought in a friend who volunteered with a cochlear implant company and we asked them all kinds of questions. And felt we were satisfied, the family was ready to make a decision. They made their own decision based on the research that we did together.

You can always bring other experts in who can answer those questions. Many times I don't know the answer, and we don't know what we don't know. And when the family will ask me, I'll say, "I don't know, let's learn it together."

You have a question?

>> AUDIENCE MEMBER: I do want to add, when you talk about support for the family, in helping the parents as they make that decision, definitely if they decide to do something that you don't agree with, just be open to their choice and support them in their choice and support them in their decision and respect their decision.

Let them know that they're always welcome to ‑‑ welcome back no matter what is going on.

>> KAREN PUTZ: Maybe the family decision ‑‑ they make a decision you don't agree with. That's okay, because you're human. But it's important to keep the door open because it's their journey and it always is in process. Later, as the child grows up, and the time is right for maybe learning ASL, maybe they will remember you and they will come back to you and say, you know what, that door is open for them to walk through and get that information about ASL, and they will walk right on through it and come back to you. That's a very fine point. Thank you for making that.

And this question is crucial for us all to remember. It's important to be focused on the family, not ourselves. We have a belief system. We're human. We have our own opinions. But really the focus is always on the family. On their journey and their experience.

And as often as you can, ask yourself, am I focused on myself or the family?

And empowerment of the families to make their own decisions and follow their own journey is important. Many times families will say... What should I do? You're the expert. You're deaf. You're hard of hearing. Tell me what to do.

At that point... whew... [ whispering ]... it's tempting.

It's tempting to give them lots of advice.

But that's not the right thing to do. At that moment, what we need to do is empower them to make that decision and back up.

And I will ask and say, Well, let me ask you again some more questions. And get the family to understand and know that they are in power to make their own decision, that they can do it. That is your job as a leader. To guide the family back to their own empowerment.

Families need knowledge.

They need expertise. They need exposure to a variety of deaf and hard of hearing people to make a good decision. And, again, to review that 360 support, did they get it? If no, you can help fill in those gaps that they did not get for the family.

And value. Whew!

Are you adding value to the journey? Or are you becoming a negative drag on their journey? We have to ask ourselves that. It's really a hard question to face. Sometimes we make situations worse and we don't want that.

We have to ask ourselves... "are we helping in the right way or are we becoming a barrier?"

Yes, ma'am?

>> AUDIENCE MEMBER: When you made your comment, it made me think of something else I thought about. There was one family, it was a panel where we were discussing, and I was part of the panel as well. I talked about learning sign language and other individuals at residential schools for the deaf. And then there was one parent that actually asked me a question and said, you know, I really want to know your personal experience, because they wanted to talk about that personal pain that they had experienced.

And so I wanted to tell them to take that pain and turn it into something positive. And so as we were going long, the parent said, I wanted my child to learn American Sign Language, but my husband wanted our child to speak.

So that was a struggle within the family. And so I was thinking, you know, I'm responsible. How do I solve their issue that they're dealing with within their marriage? But then I realized I'm not an expert at counseling and this is not something I should do. But I suggested that they as a couple come to some sort of compromise. Maybe they could have the child learn to speak and also use sign language. Maybe they can provide both modalities for that child in that case.

And in that case the parents were both like, oh, I didn't realize that. So I thought I saved their marriage in that respect you know, helped them with those concerns they were having at that moment.

So I'm grateful that that happened.

>> KAREN PUTZ: And what happened with that couple?! Did they get divorced?

>> AUDIENCE MEMBER: Well, we'll have to go back to another panel again to see what happened, but I think they're okay.

>> KAREN PUTZ: And all the time, it always has... well, there are conflicts, because they're learning different things. They're experiencing new things. We see that all the time within families, that there are conflicts. But we still have to empower the family to make the decision themselves.

And I will explain more about the 360. A mom, her ‑‑ a friend of mine, her mom died in her 80s and my friend was deaf. And when I was chatting with the mom before she passed away, the mom had never learned sign. But the mom said, "My one regret, I should have listened to that expert a long time ago who told me not to do... I should have never listened to that expert who told me not to learn sign all those years ago."

And I share that story because you never want to be the person who tells a family something and then 40 or 50 years later they're bitter against advice that you provided. You want to empower them to make the decisions themselves. Don't make the decisions for them. You know, you make the decisions with the best knowledge you can. Those families then own it and don't go to their 80s regretting the decisions that were forced on them.

>> AUDIENCE MEMBER: Just to kind of get back to the value and thinking about our own agenda, I'm an audiologist at Children's Hospital Colorado. I'm also hard of hearing. And I think, you know, as a professional going into these appointments, we have our agenda what we need to get done in certain appointments, and it's the same thing, you know, oftentimes we find with kids it doesn't go the way you think it's going to go, right?

it's the same thing being a deaf hard of hearing professional in the EHDI system. It's okay to have a plan, but if you're going to go in with that plan and stick to it no matter what, you're going to end up not serving the family the best way you should.

And that can be as simple as ‑‑ especially at Children's, we see a lot of deaf/hard of hearing, but we see a lot of Deaf+, a lot of kids with multiple involvements, and you may be meeting the family at a time where, yes, communication is important, they want that experience meeting a deaf/hard of hearing adult but they may be dealing with other diagnoses. They may be dealing with a lack of resources. You need to be sort of willing to put your own agenda or plan and table it and meet the family where they're at and help them with getting the resources they need that day. So it's another thing to think about.

>> KAREN PUTZ: Meet the family where they are. Yes.

A little side conversation here...

>> SPEAKER: We do want to make time for a break. We've been sitting for a while. I know blood flow and oxygen is important for learning as adults. We have a panel, so we're going to move to that in a minute. But I wanted to take a moment and talk about this slide here. I'm going to pull aside for a moment and talk to the hearing folks in the room, the parent leaders in the room for a second as allies, as people that are in a position of support to deaf and hard of hearing leaders who are emerging.

Just wanted to remind us that we do not replace the value, the incredible value of a deaf or hard of hearing adult who could stand in and be the representative for a perspective on an advisory committee, whatever role they're going to play, we do not replace them. Correct?

There could be again that same situation where there is no one at the table yet

I would encourage to all look around and that opportunity to see there is not representation of deaf and hard of hearing adults, that it is our responsibility and duty to make sure that we include and we recruit and we get those deaf and hard of hearing leaders to the table and then we step back and we let them lead. I know sometimes we can be a little engage and parent leaders have risen up in the EHDI system. When I started 18+ years ago, there were no parents at EHDI conferences, let alone deaf and hard of hearing adults. And I am so grateful for the fact that not only have parent leaders risen up and become part of the system, but there are deaf and hard of hearing adults, a variety of deaf and hard of hearing adults who are finally here to speak for themselves. And that's where we need to go. But there are not enough. And we need to take our responsibility as parent leaders and hearing individuals to always be looking for that opportunity to put someone in place of someone who maybe does not have that personal experience.

I'm proud that a number of years ago, I was in the room, probably with these lovely ladies right here, where Hands & Voices had that same conversation about what can we do as parent leaders who have gotten to a certain place, to make sure that we also step in and make sure that there are deaf and hard of hearing adults in the room. And so Karen and Stephanie came on board and they became our co‑directors of Deaf and Hard of Hearing Infusion for that very reason. And I'm proud of the fact that program has been going... ladies, how many years? That was a long time ago. I don't think I had frown lines back then.

>> KAREN PUTZ: I don't remember.

>> SPEAKER: That's enough, time is now, get them in the room. I don't know if you realize this, but it was a parent that created and suggested ‑‑ or parents that created the track at EHDI for deaf and hard of hearing representation and tracks, that was parents looking around going, there's not a deaf and hard of hearing adult track... what the heck!?

And they actually said that this needs to happen here. So it was that change. And I think it was just two years ago.

So, again, that's our responsibility and that's the power of what we can do, as long as we remember our place, that we are there to help advance deaf and hard of hearing adults.

So we're used to this. I think we're used to doing representation of a diverse group, unilateral, where are the parents that sign, where the parents that cue, but we need the same thing with deaf and hard of hearing leadership. And not only as tokens in the system, we need to ensure that the deaf and hard of hearing leaders that are put in places are put in places of decision making, financial decisions, and policy. It is not enough to sit on an advisory committee and just have a say once a week about maybe what the agenda is. There needs to be decision making about funding, about policy, about system. And that's something we can do as parent leaders.

So I just want to take a moment and talk to my brethren, our peeps out there and parent peeps that's our responsibility.

So I preach, didn't I? So I'm going to move through... sorry, just had to get that out.

I feel better now!

[chuckles]

We're going to move through the slides pretty quickly, because I think we talked about respecting a family's journey, and really recognizing the diversity of the deaf and hard of hearing community that we serve, and I just want to remind us, I think it was a deaf woman ‑‑ again, all the really brilliant stuff comes from deaf people I'm sorry, that's just how that works.

So it was a deaf colleague of mine that we brought on board. Because, again, we need more deaf and hard of hearing in the system, who said "Talk to me about who we're serving." And when she heard that the largest group were unilateral kiddos and mild and... you know, that profoundly deaf was a smaller percentage, it didn't change what we were going to do. My son is profoundly deaf and he sure as heck needs a lot of things and communication access and interpreters and all that, but it also changed her perception. Oh, my gosh! I had no idea that unilateral was the largest group. So, again, just reinforcing that thought about diversity.

Again, just reinforcing that the journey is not ours.

Do you want to say a few words...

>> Are we going to break?

>> SPEAKER: We're going to take a break now. Because adult learners need a little rejuvenation to get our brains going, and we're going to have a panel after this. This is going to be a lot of fun. You're going to hear from some amazing individuals.

So take a break.

How about ten minutes? Where are we at for time?

So, you know, 10 still maybe... 15. She's going 15.

Okay, we, we'll...

10 minutes, but be back in 15 or I'm coming looking for you. How about that?

>> Thanks, guys!

>> AUDIENCE MEMBER: I just want to make a comment. I wanted to tell you a big thank you for ‑‑ thank you for supporting deaf and hard of hearing leaders, because I think many deaf and hard of hearing leaders out there are very capable, but they just experience so many barriers in getting there.

So I would like hearing people to support us as allies. Will that be ‑‑ will you bring more ‑‑ will you be bringing that up more as a way to ‑‑ how to support and be allies to deaf and hard of hearing leaders? I'm sorry, I ruined your break. I'm sorry!

[ Break ]

>> STEPHANIE OLSON: Okay, everybody. Come on in and we'll start our panel discussion.

We're going to start the panel discussion.

There we go. That feels better. We're better when there's a team, a team of people.

Thank you to the panelists for coming.

Thank you, Emily, for rushing in so quickly and coming to the panel. Because you just arrived, right?

Yes.

So thank you for being here.

We're going to start with the few questions and then we'll open it up and I'll take questions throughout this process because we have a panel of experts here. Leaders in the system to share their experiences, just like we have leaders in the system out here.

So this is part of the workshop where we wanted to be collaborative and exchange ideas and bring up questions that you might have.

So the first question we have the to tell us about your experience of becoming a leader and what helped your success. And we'll start with Anita, maybe give your name and tell us a little about who you are and then move into the question of your experience in becoming a leader and what helped you in that position.

>> ANITA: I'm wondering if everyone can see me from where I'm seated? Do I need to stand?

Okay.

I'm Anita Dowd. I'm from Kentucky. I work for the Kentucky Commission for the Deaf and Hard of Hearing, and I'm also the president of the Kentucky Chapter of Hands & Voices. I have two deaf daughters with hearing loss.

Now on I'm the National Council for Hands & Voices.

My mom always told me that I would be a good leader because I have a big mouth and I never learn to shut up, but putting that aside, I definitely try to stay in the background, you know, growing up I went to a mainstream school. Interpreting services were not provided at the school. I was not shy, I would say, but I did have fears that I would misunderstand information.

And so that's one of the defenses that I set up for myself.

My oldest daughter was five years old when we moved to Kansas from Kentucky.

So at home we used sign language. We spoke, we used whatever mode of communication we needed to do at the time. At that time we used Signed Exact English to communicate primarily. So when my daughter would come home from school, when we were trying to communicate, there was a lot of disruption in our communication. It wasn't as smooth because she learned SEE in school but I was using Case as the mode of sign language. So we had some communication difficulties trying to communicate. And so, of course, I had issues with school and I called together the IEP team and also suggested that they provide an interpreter and that interpreter should not use SEE. So we had a lot of meetings at that time. So I finally developed my tact over time. I was a parent that was really demanding at first saying I needed all these things to happen, but over time, after many hours, sleepless nights at the kitchen table looking through legal documents with highlighters, going through those documents. And so I learned, of course, what I could do in reference to the rights for my daughters.

And I think that actually led to me empowering myself at that moment with the information that I had.

And also arming myself with that information, I was better to ‑‑ better able to communicate with the school and also understanding the frustration of other families.

So the information I learned I then passed along that information to other families. And I'm learning about the IEPs, the LREs and all that. That's what led me to my passion for sharing leadership. Is that enough for now?

All right.

>> SPEAKER: Is this on?

Okay. We'll do this.

My name is Allison. I am an audiologist at the Children's Hospital Colorado. I have a wonderful fortune of working with Ms. Stephanie Olson over here. She's amazing, as we all know.

I recently transitioned into a pretty big leadership role within my job. I am now ‑‑ I have gone from a clinician to a management position within Children's. So this is a really timely topic for me because I'm still trying to figure out how to be a leader just at my job, as well as a deaf/hard of hearing mentor and leader as well.

I think for me, when I think about, as I become a leader, sort of going into this process, when we were talking earlier about the article that looked at what deaf people were looking for, deaf leaders, and the number‑one thing was being involved in a community.

And we think about leadership, my definition or core tenet of leadership is service to others. And those of us who are deaf/hard of hearing, particularly before newborn hearing screening, and that was identified later, I'm sure many of us were identified later, we thrived and survived because of our advocates, for those of us that served for us. So it makes a lot of sense that we would value that quality in our own leadership and as leaders ourselves. So when I'm going through the process, becoming more of a leader, I keep that tenet in my head, how can I be of service to you and to my team and to the families and to the children who are deaf/hard of hearing.

I think another area where I've gained a lot of experience is I recently became a court‑appointed special advocate. It's also known as a guardian ad litem through the child welfare court system.

And the training that I received has been pretty mind‑blowing and really changed my practice on how I better serve and empower families, as well as team members.

And I've been doing that for about two years now. And I think that has just looking beyond the scope of deaf/hard of hearing and looking at our community as a whole has made me a better person and leader as well.

So, that's my story about leadership.

>> SPEAKER: Good afternoon, I'm Nan Asher, I am the program consultant for the Michigan EHDI Program, and I've been in that position about eight years, and my journey to leadership was never intentional. I didn't grow up thinking, I'm going to be a hard of hearing leader and do all this wonderful stuff, but...

So my brother was born profoundly deaf and I was hard of hearing, and we were not diagnosed until we were much older. I was four during kindergarten round‑up and my brother was six. My mom tried for years to tell people he was deaf. No, he's a boy, he's not paying attention... all this other stuff. And he went through the first year of kindergarten and my mom was told he should be mentally institutionalized because he was mentally retarded. She did not reason to that. We moved to a new school and my mother didn't say anything, my brother completed kindergarten, mostly in the closet from misbehaving.

Three days he came home with a note pinned to his sweater, Mrs. Jones come to the classroom, we're waiting for you. She lugged my brother and baby sister. It was the teacher, principal and school audiologist told my mom, your son is profoundly deaf. And my mom cried out of relief. For four years she had been telling people and nobody listened, the doctor, none of that.

So he started school right away.

They found I was hard of hearing five months later through kindergarten round‑up. I had to have my hearing tested eight to ten times because they could not believe I had the loss I had because I was an expert lipreader and my mom used to dealing with the deaf son looked at us and that sort of stuff.

So I was in a hearing impaired program for about five years and we moved to a county that did not have a very good program. So I was mainstreamed at that point.

And when you are mainstreamed your number‑one goal is to fit in. You don't want to stick out or any of that. I did really well being mainstreamed, I was in the to be 7% of my class even though I had no accommodation whatsoever, and I do have a severe hearing loss. But where I got my leadership finally into was there was a group forming in a county called ‑‑ it was called Self‑help for Hard of hearing People.

I thought my brother needed it, but it ended up being me that needed pit when we first started this grew, we learned about other hard of hearing and how they got successful. Everybody in the group read a book about a deaf or hard of hearing author. There were quite a few out there. The book I chose was The Feel of Silence by Bonnie tucker, and she's an attorney in Arizona. And I read that book and that book made me mad. I was really angry about the author, because she goes on and on about being in denial of her hearing loss.

And I couldn't grasp that. Because here you are, you've been wearing hearing aids since you were two years old and done all this stuff and the reason for your divorce, how are you saying you're in denial?

And three months later during a mundane task, it finally hit me what she meant. She didn't mean she was in denial of her hearing loss. She was in denial that her hearing loss affected her, that she was different from hearing people, that hearing aids, all this technology does not mitigate it fully, that you are still hard of hearing, that you still have issues.

So once I understood that ‑‑ and the reason it bother me and didn't understand it, because I was doing the stadium thing. I had overcome my hearing loss, I didn't need help, I was doing great. But this was about the time where FMs were coming out, closed captioning was coming out, and my world just got a whole lot bigger and a lot more people, when I accepted that about myself, that I do things differently and people treat my differently because they have to get my attention, they can't talk behind my back, that sort of stuff. They can, but if they want me to know what I'm saying, they need to be in front of me.

Once I got through that, then I could really start making a difference not only in a lot of other hard of hearing and deaf people's lives but my own as well.

So that's kind of where I got there.

>> SPEAKER: I don't need the mic. I'm going to sign. I am Elle. I'm a manager, community systems in advocacy, and I had five programs, and one is the youth program at my agency.

That is called Armed. Adult role models in education for the deaf. And we recruit deaf and hard of hearing adults for that, teachers of the deaf, doctors, lawyers, any professional, blue collar workers to white collar workers to come to different schools. Here in Chicago we have over 30 schools with deaf and hard of hearing programs. So we recruit these role models to go to schools and meet the children, because they don't have role models to look up to. So we bring those deaf adults to their classroom so they see deaf adults who can explain their life experience and their job experiences and how they communicate with their bosses and their coworkers and how they advocate for what they need. And I was shy growing up. I never thought I could become a leader, but, wow, when I got involved in the deaf community and deaf culture during college... I got involved

And that made the difference when I joined different deaf organizations in college. And if I was the only one before that, when I was a deaf person always surrounded by hearing people,... and now I have three girls. The two oldest ones are deaf. And because I'm deaf myself, I know the struggles that they face. And because I work with deaf adults, I see their frustrations, their struggles as well.

So as a deaf person, and as a mom, I have perspectives with how parents can struggle. What do I do with my deaf child? I face those as well, even though I'm a deaf adult.

And so really by joining the EHDI system about two years ago, it really encouraged me to become involved in EHDI. Many years I would get encouraged to join by my manager. But I'm finally here.

I've been quiet until now, but I'm starting to get more and more involved. And I'm trying to bring more deaf and hard of hearing to the system. I don't know that it's recognized yet but as Karen Putz has said, she mentioned there are a few deaf mentors that are active in the state of Illinois but really only one is paid by the state. One. So we're trying to get that program back under the state system to get more deaf and hard of hearing mentors

We want therapists for hearing, physical therapists that are paid. Why aren't the deaf paid what the other therapists are paid? That's my journey in how I became a leader.

>> SPEAKER: Hello, I am Elle Wielding. I've been thinking a lot about this question. And what brought me to my childhood memories. I don't think I was born to be a leader.

I believed I was born to be in the community. And it was the community that led me to become a leader.

I was deaf at two and a half, and when diagnosed my mother went through that grieving time. I was in Seattle at the time. That's where I was born, Washington state. My parents brought me to different vents and I can remember seeing others that were like me, and I couldn't believe it. I was like all of these other people.

Without that experience I would not be who I am today. It's the community that brought me to this journey and where I am.

Going through college, at that time I knew I wanted to be a teacher. I majored in early childhood education, and as I was going through and I realized that that's not where my heart truly lied. My heart lied with families.

So I knew Gallaudet had a program that had early education centered for that 0‑5 age. That's where I dove in and developed my leadership from seeing the others.

The Benedicts, among others, Barbara, just amazing role models that I was able to see out there at Gallaudet. It really motivated me, and that's just bringing in the community.

So I expect all of you to bring in those people to the community and it will help with their journey as well.

That's how I got here.

>> SPEAKER: Now we would like to ask some panelists some questions. In the EHDI system, in the state system, how do they support deaf and hard of hearing people to become leaders? And how do families have access ‑‑ how do families access the deaf and hard of hearing leaders?

Open for any of the panelists to answer that question.

It's number 2 on the slide.

How does the state system support deaf and hard of hearing adult leadership and how do the families connect with them?

>> SPEAKER: I'll start.

First I will say that we do not have a deaf and hard of hearing program. That's one of the discussions that we had for quite some time right now, that we need to establish something.

And we do through my organization, the commission here in Kentucky, we provide leadership trainings for youth, and so we're hoping that the youth will stay in the state. Why does everyone leave Kentucky? Probably because it's a little boring there. As soon as they get the training, they head off and go somewhere else. But we hope that the youth we're training right now will actually stay in the state.

>> SPEAKER: I am a deaf and hard of hearing guide with Hands & Voices, and we look to increase the number of guides that we have available. And then the EHDI program in Kentucky is severely lacking. And so early intervention, oh, my God, I don't know exactly what to say.

They really aren't leading the families.

And so as a result of that, it's lucky that families find any sort of help that they need in our state. And so as a result of Hands & Voices, they are actually able to find some of the supports they need

So we want to make sure the families get what they need from Hands & Voices and also from the state commission.

And because really there's no one giving them that list of resources, and it's kind of sad what is actually happening in the state.

>> SPEAKER: I actually think Stephanie can answer this question a little better than I can, but I do want to say, in Colorado, for whatever reason, we have quite a few deaf/hard of hearing professionals just already in the system by accident or whatever. And so there are some families that do have ‑‑ that are sometimes identified by an audiologist who is deaf/hard of hearing and then their initial introduction into the early intervention system is by somebody who is deaf herself and then maybe assigned what is called a CHIP facilitator, a provider who also happens to be deaf/hard of hearing, and it's amazing when that happens. It doesn't always happen that way. I do want to give a shout‑out that we see that in our state, but I do know there's a more formalized program for deaf/hard of hearing leadership. But I don't know if there's anything in particular in our state going on. Stephanie, do you know?

>> STEPHANIE OLSON: There was a cooperative agreement with several agencies to offer role models to all of the families, and that cooperative agreement has since gone away, so Hands & Voices is trying to absorb that program.

>> SPEAKER: I also want to say that most of the families or all of the families that get identified through our hospital at Children's Hospital have the ability to meet Stephanie, our Deaf Family Consultant, so that's an amazing resource to have.

I'm also on the board of Hands & Voices, so I always think about getting that parent‑to‑parent support in right away and then a lot of times that is a natural way to introduce mentorship of other deaf/hard of hearing adults as well, a pretty good resource.

>> STEPHANIE OLSON: And I would add I think the big question that comes up, the clinical model, medical studying, which isn't always seen positively, is that the goal in the role that I have is not to make sure that the family you know, gets technology and this and this and that, but just to get all of the resources so that they can make that decision. There's sometimes an assumption that because you meet ‑‑ the first person you meet uses spoken language and ASL or ‑‑ or ASL, that's what the family will do, and that isn't the case when they get the variety of different professionals and diversity, then they can become empowered like Karen was talking about to make that decision. So this is where we're seeing a shift where we don't have to be the first one in the door to use spoken language or the first one in the door to use ASL in order for that family to make a decision, all of it will help the family make the decision. So...

>> NAN: Our state of Michigan Hands & Voices program have been working really hard the past year, so to do a deaf and hard of hearing mentorship for their parents, and the Hands & Voices program, they're also a member of the Michigan Coalition for Deaf and Hard of Hearing People, and that's an organization that is all volunteer and you have to be an organization that serves deaf or hard of hearing or deaf‑blind people in order to belong. And so by that connection they have a lot of connection to other agencies through the state for the Coalition to try to pull from, so...

>> SPEAKER: So the third state I worked this is New Mexico. First I was in Washington, D.C., then Utah. Now I'm in New Mexico. I've been in this field about 20 years now. It's unbelievable. Wow! Okay.

So, working with the state, right, as the parent family specialist in Seattle, and then I switched to teaching from preschool all the way through the years. A program in New Mexico where I am now. But I'm thinking New Mexico is a little unique in that we celebrate ‑‑ we will be celebrating our 25th anniversary soon and our shared reading and literacy program, and the deaf involvement in that.

So we have had those role models that have been developing. We also have a deaf mentoring program in New Mexico. New Mexico is a very rural state. Really everybody works at the school for the deaf. There is no other job opportunities. It's really just there. I think about 90% of the deaf and hard of hearing individuals that work in New Mexico are at the school. So we have a clear mecca of where all the deaf people are, where the opportunities are for jobs. And that is at the school. And we already have access to everything. At the moment that they enter the school, from birth, right? If your child fails the newborn screening, they're automatically sent to one of our statewide people within the school. And that leads them there for the rest of their schooling. So I think our system is pretty much established.

>> SPEAKER: We're almost out of time, so I want to get to the last question. What is the best advice, support or resources that have helped deaf and hard of hearing people become leaders in your state?

What advice do you have to share with our audience here?

>> STEPHANIE OLSON: And that can be for upcoming youth leaders, it can be advice for parents, advice for other deaf and hard of hearing professionals or systems. What advice do you have to help us get more involved in the systems?

>> SPEAKER: I think, for me, I think for one, you talked a little bit about owning your story and telling your story. So I think for myself, it was I had to think of my story, but also think of my identity beyond just being deaf/hard of hearing. If all you can think about is yourself as a deaf/hard of hearing person, it becomes very one‑sided. I mean, you're more than just your deafness or your hearing differences.

And I think you're better able to serve families. And also in a leadership role, if you look beyond yourself, it's just a deaf/hard of hearing person, and I think for me too you know, just look at other resources within leadership. There's a lot of lessons to be learned that can be applied to mentoring and establishing leaders who are deaf/hard of hearing.

I think for me, just understanding that I'm going through a leadership program through Children's Hospital Colorado right now and doing a program called Systems Thinking. And it's a way of looking at problems. And there's this idea of what we called a Wicked problem. And I think we're all familiar. Wicked problems are what keep us up at night. And so Systems Thinking is different mental models which we can engage in solving our Wicked problems. And this is at the heart of collaboration and empowerment. Because if we keep coming to the table with our own agenda or certain biases or preferences, we're not going to solve any of these "Wicked problems," and we have to look at things from a different perspective. And while the heart of advocacy and problem‑solving is emotion, we have to also be willing to take some of the emotion out of it to start creating solutions within our EHDI system.

And I think that's really what is going to help foster some of this deaf/hard of hearing leadership that we're looking for within our system.

>> STEPHANIE OLSON: I think the one bit of advice I would give to a deaf or hard of hearing person wanting to get into the EHDI system is figure out which position you want and then find out what you need to get in that position, what education, what experience, whatever, and then kind of work backward from there. So you have that.

So always have a goal in mind. Know your goal can change and you can make your ‑‑ you know, change your plans accordingly.

>> SPEAKER: I have something I would like to add. It's important for youth, new leaders, of course, there will be every person will face hurdles. But how you respond to those hurdles and obstacles is what is key.

We have a small community. We are a small community. We need to embrace diversity and inclusiveness, as well as inspire other people to be involved in our community.

So if, for example, we look at somebody and say, oh, they're young!

Don't give up. Because they might have, you know, other people have experience. Maybe a young person will learn a great deal from that person with a lot of experience.

And I also think it's very important to find that person who is willing to mentor or... you know what? Correct your mistakes.

But providing guidance and support while you're on your journey is crucial.

>> SPEAKER: I would like to definitely echo what was said earlier. Own Your Journey.

Respect the other family's journey.

We can't dictate what their journey is supposed to look like. Each person is different. Each child is different. Each family is different.

What may work for me may not work best for family.

Also I would like to add that we should encourage leaders to become leaders in the system.

Learn more about governmental policy and those types of things.

If you actually want to effect change, you need to learn about the system. So it's not easy to walk in and say, well, the ADA says all these things...

They don't really care about that. So they're already involved in the system. So you have to figure out how to navigate the system to actually work within the system.

>> SPEAKER: About two years ago, my boss sent me off to Gallaudet for recruiting people.

I was not a very successful recruiter. I went through, I tried to advertise what we do at the program. But really it was difficult to find people who had that passion to work in the education field.

Everybody wants to work with technology. That's definitely shifted. It's a big shift that has happened over the past 20 years.

I was speaking with one of my professors and I was telling them how my difficulties of trying to find new leadership. And they told me that going in and finding each people and recruiting them is very difficult.

You need to cultivate leaders. You need to grow them through their journey. And that has been what has been working for me. It's not my journey. Right?

It's not my journey on what I think their journey should be. It's that family's journey, right?

So what happens in New Mexico happens in New Mexico.

If I bring somebody else in who has new ideas, new energy from a different state, those that were born and raised in New Mexico are not going to understand that. It's not going to match the culture where we are.

New Mexico has a strong Navajo population. So, I realize the importance of culture and family and communication and all of that, the whole being, the whole child will dictate that journey.

>> SPEAKER: Can we open the floor for a short period of time to questions from the audience?

Yes?

I will be bringing you a microphone. Hang on.

>> AUDIENCE MEMBER: Thank you. Hi, I'm the EHDI coordinator in Idaho and we've been working with Hands & Voices to bring Guide By Your Side over the past couple years. We would like to expand that into having a deaf mentor program, and I was hoping that y'all could give me some, like, dos and don'ts or lessons learned. So I just don't want to mess it up in the first place you know.

>> SPEAKER: Folks...

>> STEPHANIE OLSON: You can go ahead. I just would like a little clarity. Dos and don'ts, I missed something. Dos and don'ts for what?

For starting a program? Got it.

All right

>> SPEAKER: Any one...

>> SPEAKER: I don't think any of us here have started a deaf mentoring program. You want to answer it?

>> SPEAKER: I just wanted to say, if you want to set up a mentoring program, first you have to start with recruiting. You need to recruit those individuals who understand what you want and what you need to do. You have to market what you're trying to do as well. Because a lot of individuals are not as familiar what you're trying to do. So you to get out and market the program to get those people in, and then once you get them in you can provide training. And some of them, of course, once they take those trainings and everything, they'll understand better, but in a lot of cases they don't understand at the beginning.

>> SPEAKER: You asked about deaf mentorship programs and dos and don'ts. We have a national institute there that provides training on a national level. So if you're interested in setting up a deaf mentorship program, I suggest contacting...

>> AUDIENCE MEMBER: [ off microphone ]

>> SPEAKER: Dr. Paula Pittman.

She is the one who founded the... she's from the organization, and she...

[chuckles]

Sky High University, and they have been running that research center for about 20‑25 years. And so they have a curriculum, evidence‑based curriculum that can provide a deaf mentorship program, and they can help you do it. They will guide you through the whole process, dealing with training for deaf and hard of hearing mentors. And if after you want to contact me, after this workshop, you want to contact me, I can give you Dr. Paula's information. Okay?

I'd like to clarify ‑‑ a clarification, please.

I heard "deaf mentor" specifically.

They must get a certification, is that right?

We need somebody to sign back there so folks can see what is going on.

Here we go...

Should I back up and start again?

Okay, I'm going to start again.

I would like some clarification. I've heard that deaf mentors, specifically, need a ‑‑ must go through a specific process to get certified. And I also know that some, quote, deaf mentors come into the home and take the kids and work with them as role models. But they never are involved with the parents. And then, in a third situation, I also know there's family mentors that come in the home and expose the family to a functional language models and do different things, so I'm hearing quite a variety of the definition of what a mentor is. And I'm wondering if we can get some clarification on that.

>> SPEAKER: I just wanted to quickly say that in Washington we did a needs assessment gap analysis, and setting up a deaf mentorship or deaf/hard of hearing guide program, totally two different things.

So in talking with your state, one of suggestions we made in our state is that state stakeholders get together and decide what type of program they want, whether that be all the programs or one or the other, but to have buy‑in from the stakeholders and have a clear understanding of what those programs are going to be doing. What are the outcomes?

Because that happens. There's a lot of clarification that needs to happen.

>> STEPHANIE OLSON: Thank you.

>> SPEAKER: We value that, because when we write the guidelines, we see that situation, it varies. We sat down and queried. We worked. We asked people different... and analyzed the different states and the systems they have already set up. And we wrote the guidelines. They're out there. They're on the website.

So if you go to handsandvoices.org, you will see the guidelines. We learned in the process, a deaf mentor, that brand by Sky High... that's their brand.

EHDI. Sorry.

No, Sky High.

>> INTERPRETER: Interpreter error. I was right the first time.

>> SPEAKER: That program has been around a long time. They have been teaching the purpose of ASL, but they have added...

The purpose, I think, it was set up to teach ASL, right? In the beginning. And then it expanded and added more curriculum and their duties expanded.

So nowadays, families still go to those trainings, and those programs, when the state brand uses a deaf mentor from Sky High, that's what they're called. That's the brand by Hands & Voices.

And that is not communication specific at all to what modalities they use.

For example, Minnesota has both. I think they're adding others too. And so there's quite a variety of different services that are provided.

>> SPEAKER: Isn't Sky High run by Utah, not Hands & Voices?

>> CANDACE: There was interpreter error. Just to be clear, Sky High is what we're talking about.

>> SPEAKER: It's not a Hands & Voices program, exactly right.

Any more questions?

You have one more.

>> SPEAKER: I just want to mention in California that some of us at the agency would use Sky High for their curriculum for deaf mentoring. And we're also in the process of actually developing our own deaf coaching curriculum.

Sky High, of course, their mentor and a term they use...

Talks about specific processes that are used.

But we are actually developing our own processes in the state to have more resources available that we can actually pull from and use.

The general idea is to have that Train the Trainer type of curriculum set. And then in that way, I know a long time ago, we had a grant in California, in Wilmot. And so the parents were involved in that process. There was a specific program that included parent involvement, but we noticed a lot of gaps along the way in that program. So with the newborn hearing screenings, the tests that they actually would receive, they realized that the baby was actually deaf but they were referred to a public health Department of Education center.

And so once the parents found out that information and found out that the child was deaf, we wanted to make sure that that gap was filled, that parents would have the support that they needed, whether the child be hearing or deaf, we wanted to make sure we provide what they needed. But that grant expired and we no longer have that grant.

And so that program is now kind of under the Department of Education and it's actually run by the parent program.

The Links program.

So we hope someday that program will be run statewide, but we want to make sure that we provide for those needs. The needs for a parent who can speak and parents who are deaf, to provide coaching and mentoring and access for those parents to provide what the family needs to provide services, well‑rounded services for them. We need to take advantage of what is actually available.

>> STEPHANIE OLSON: So that resource for guidelines is at the end of the slide, the PowerPoint, and there is some other resources, because we did talk about the Sky High program. Some states have the deaf mentor program with shared life experiences. And then there's the Guide program through Hands & Voices. And that partners with parents offering that support. So these programs can look a little bit different depending on your needs. And that's why I like what Christine said from Washington about the needs assessment. And there's information on that, the needs assessment to really get an understanding of what your state and families would benefit from, or a combination of.

So...

>> SPEAKER: Awesome. This slide wants to give you some... a lot of times in our field, we have boundaries and silos, and it's hard to communicate with each other. And we also want to get some standards going, so we can build what connections we have and not divide us.

So use what makes us joined.

And the power of your story is crucial.

>> STEPHANIE OLSON: And the panelists did a good job of addressing your story and then you did earlier today with listening, and I think the most important thing is that we always remember to welcome input before giving input. It's easy in our roles to forget about that.

>> SPEAKER: Really we hoped to have more time for this, but what is important is value. The value of this.

When you work directly with a family, you have to meet them where they are. And sometimes you can get off course and the family is really only thinking about right now. You've got to take the pulse of the family.

Yes, share the story that fits where they are now. Not the one that maybe they won't need to hear for years.

And we see a lot of times that... excuse me...

Many times there's that token, deaf or hard of hearing person representing every single person in the community.

No, one deaf or hard of hearing person cannot represent everyone. Diversity should be embraced and also celebrated. One person cannot represent all.

Look at us!

We're representing deaf and hard of hearing community, just the two of us? No!

Our job is not to represent. We just happen to be deaf, happen to be hard of hearing.

So we need to morph that perspective into something more valuable and more positive. Like she said, there's value to all of our stories. Not just one of us or the two of us. Everybody's story is valuable.

>> STEPHANIE OLSON: I want to add, we talk about deaf and hard of hearing families, but sometimes as professionals we don't do a good job listening to each other and we get caught up in what the person's style is or communication or technology, and that's not why we do what we do.

And I've been in the field long enough and I think several of us ‑‑ Emily said 20 years, and I think I'm on 30‑some, and there are many times that we criticize who we are. But that's not why we're doing this, to criticize. We need deaf and hard of hearing professionals to do a better job embracing one another.

>> SPEAKER: I want to go in the back. Excuse me.

You can head on back if you want, if it's easier to see.

We need to talk about the support of the journey. And if they don't feel supported, it makes it quite difficult for them to make a decision.

Being deaf or hard of hearing, we have to provide the support without bias. Often those misunderstandings are around bias..

Bias means to manipulate. If, for example, I get ‑‑ if I put on my ASL hat and someone says... "huh... how can you wear an ASL hat, T‑shirt and you work for Hands & Voices? Why would you wear that ASL T‑shirt? That's a bias! "

It's not a bias.

If I wore... "all families should use ASL" shirt, that's a bias. That intention by wearing that T‑shirt is manipulating.

But I can celebrate my use of ASL. I go to many conferences, cued speech conferences. People used to say... [ gasp ]...

No, you tell them this field is one where everyone should be welcome. If I show up, it doesn't mean that I'm biased. It means there is a difference.

There is a difference.

>> STEPHANIE OLSON: So the last topic of conversation, two to three minutes, if you could just quickly find out in your table what is meaningful involvement. What does that mean in the system? So that we don't have just a token representation, one deaf leader for our state and we call that good. That's not good. We need more active involvement and meaningful involvement.

>> SPEAKER: And then we'll continue the discussion?

>> STEPHANIE OLSON: Two to three minutes, if you can find out what meaningful involvement means at your table.

You can write it on a sticky note and then we can collect them and share. There should be sticky notes on your table. Somebody just jot down a few.

>> SPEAKER: One thing, those sticky notes, we will use them to write an article. So your input is crucial.

Because there's your opportunity to effect change in the system. I want to go back one little bit. Back a slide.

We talked about what was meaningful involvement and what it looked like.

I also want you to talk about situations in the system and how to fix and how to improve them. Put those down on the sticky note.

And how can we change the system?

So think about that and put it all down.

And we will collect them. Please, feel free... go for it!

>> SPEAKER: Sticky notes, anyone?

Sticky notes?

>> SPEAKER: I think I'm going to bring us back. I think that was one of the shortest table discussions on the planet. If we can bring your attention back up here.

I know we gave you a lot to think about in a very short time.

If you think of a few more things and you've got the sticky notes still, feel free to keep writing them down. If you have a delayed idea... (chuckling) you know how to get ahold of the three of us.

Our email collectively is FL3@handsandvoices.org.

If you have delayed response about meaningful involvement or some of the questions Karen talked about, please keep talking with us.

So I appreciate the discussion today and, really, I am honored, when I looked out and I see individuals in this room and the experience and the years of advocacy and work that has been done by those in this room, it's inspiring.

My son is 23, going to be 24. Like I said, his youth is gone. He's now an adult. But like I mentioned, he has gotten here because of all the people who invested time like yourselves in the system to make a difference.

And I am so aware of how much effort goes into that. Often for little pay and a lot of hours.

So first of all, thank you.

But I am going to ask you for a little help. I'm hoping that today in this discussion we've all come to that same place, that same agreement that there is no time to waste. Please don't let any more kiddos get to adulthood without that opportunity for both involvement of deaf and hard of hearing adults from a very early age to help them shape their identity, help them feel better about themselves, but completely confident that who they are right now is good enough and actually pretty damn good too.

So let's all share that vision as we leave this room today.

And let's all share that same vision that we have a role and responsibility to ensure that there are more and more deaf and hard of hearing adults at places where decisions are being made for the future of deaf and hard of hearing children.

Because we can't let any more kids wait out there while we're figuring it out.

So, this is where the call to action comes in.

How can you make a difference in your sphere of influence? What can you do when you leave this room that will make a difference about that call to action?

What can we each actually individually do? And what can we each individually do to cultivate new leaders within this EHDI system so that when we come next year, and the next year, this room is busting, and there are so many deaf and hard of hearing people at this conference that every interpreter across the U.S. and territories is working that weekend because we don't have enough people to provide all the access that is needed, right? Let's bust the system. It will be kind of fun (chuckling).

So please join me in that. Because, really, it would be great to see.

I did want to leave you with a few resources. I hope you have all seen the JCIH, the Joint Commission on Infant Hearing on the position and supplement back in 2013 where it has goals around insisting ‑‑ this has been around since 2013, guys, five, six years now, where it said in there, a recommendation of a group of people who got together, a really diverse group of people at that, got together and agreed there needs to be deaf and hard of hearing involvement in the system and families need to have access to deaf and hard of hearing adults. It's already in there. Six years later, what are we doing about that? How do we make sure it happens everywhere? It shouldn't matter if the kid is born in Minnesota or Guam or Arkansas, that should be consistent across the country, right? How are we going to do that?

There is a great presentation, I think, this was by Kristy Yoshiana.

This is a terrible summary, but if a child and family had an opportunity to look around and everyone they met, everywhere they went, there was a deaf or hard of hearing adult, the audiologist, the early interventionist, the speech language path, the deaf mentor, if there were all these people that just... boom! There they were!

What a difference that would make if our kid thought that every single person in that family, every single person they came in contact with could be deaf or hard of hearing, no barriers, right?

The NCHAM, National Center for Hearing Assessment and Management, has had a learning community and there have been resources developed. That link is up here and you have information about that.

And then there's two pieces I want to share with you developed through the FL3 project. There's the link. You can get to it from the Hands & Voices website, go straight to FL3 website, but that goes back to this idea about tips for meaningful participation by parents and adults who are deaf and hard of hearing. This is specifically for advisory committees and quality employment committees, but there's gems in there, guys, that can be applied to other arenas too. But there's been input with deaf and hard of hearing adults that led the effort.

And there's needs assessment report done by the FL3 project and wonderful gems in trying to dig into why do families not access deaf and hard of hearing adults? Why? if they're offered, why are they not doing it? There are good gems in that document as well.

There are the deaf and hard of hearing guidelines we referred to earlier. And that's going to answer your question to a bit, Ryan, about, you know, some key elements and themes around you know, getting a stakeholder group together to find what it is you're looking for. Is it a deaf mentor? Is it deaf/hard of hearing guides? I would argue for both. What are the steps needed to have a quality program? And I want to address Jonelle's question because she got cut off when we went to the break. I want to address your question. I didn't want to lose you because you made a good point. You wanted more information about being allies, how hearing individuals, how parent leaders can be allies with deaf and hard of hearing adults.

This is not definitive, but I did write an article on the topic and I would be happy to share that, post that and distribute it around. Because it really kind of speaks to the same core elements about backing it up and letting deaf and hard of hearing leaders lead.

So there's just a few resources for you.

And then...

Oh, and there's the guidelines. Sorry, I forgot that other slide.

All right. So, I just want to, again, thank you all so much for spending this afternoon. You could have been a lot of different places. You could have done a lot of different things. But to bring your wisdom and brain trust into this room to talk about this issue means a lot to me as a mother. Because really you are the ones that are going to make a difference. You are the ones that have been working in this for a long time. And I'm asking for you to stick in it a little longer, because we've got a whole bunch of new kids coming through the pipeline, and every single one of them is worth the effort. And it's going to take all of you to continue.

>> SPEAKER: I missed your name.

>> SPEAKER: Candace Lindell Davis. Minnesota, but I'm with Hands & Voices headquarters.

>> SPEAKER: Thank you for coming and sharing.

>> SPEAKER: Anything else, ladies?

>> SPEAKER: Time is up. Time is up. Thank you so much for coming. Please do fill out your evaluations. Because those provide feedback, important feedback for EHDI. So go ahead and fill those out, please!

Thank you so much for coming this afternoon.

Thank you very much!

>> Thank you, interpreters.

Thank you, captionist!