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SUNDAY, FEBRUARY 26, 2017

10:00 A.M. EST

NATIONAL EHDI MEETING

INSIDE, OUTSIDE, UPSIDE DOWN

INFUSING THE EHDI SYSTEM WITH DEAF AND HARD OF HEARING PARTNERS AND PARENTS

HANOVER D

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>> All right! Y'all are here for a presentation called Inside, Outside, Upside Down.

Everyone is going to introduce themselves. If you have any questions or anything, I will be in the back, as far as needing an evaluation sheet or anything like that. Thank you very much.

>> Thank you, everybody, for coming. We are so glad you came to join us on this butte beautiful afternoon in Atlanta. We are so happy that one of our presenters literally just walked in the room a few minutes ago. Flew in. She made it! So we are very, very happy.

We are going to pretty much follow the Power Point that we posted on the EHDI website. There have been a few changes. There will be a break after about an hour. We actually have two of our presenters that are going to have to leave and come back for other presentations or meetings. That pretty much, I think, is how we all are in the EHDI and early intervention system. We wear many hats. And we go where we need to go, and we try to do as much as we can.

Bear with us with having a little bit of a shuffling around, if we need to do that

Inside, Outside, Upside Down, wait a minute. Where is the ...

Sorry, right there. Not my computer

We took the title from the well-loved book of Inside, Outside, Upside Down, and it is appropriate for early intervention because we all know that repetition is great for little kids. I love it because Small Bear goes on this adventure and only 15 pictures and 66 words, Small Bear gets in a box that get dollied up on to a truck and he gets taken to town. The box falls off the truck. Small Bear climbs out and he runs home and says mama, mama, I went to town, Inside, Outside, Upside Down. When I used to read that to my kids, I was worried that mama didn't even know that Small Bear was missing for a little bit

But sometimes it feels like we are inside and we are doing great work. Sometimes we feel like we are on the outside trying to get in. Sometimes systems and programs and people trained, you feel like you're inside up and you have to right yourself up again and get going. We are going to find out the many different views and perspectives of deaf and hard of hearing and strengthening it with deaf and hard of hearing mentors, guides, people and parents

One of the big debates with this book that I founding is the spelling and the pronunciation of Jan Bernenstain's last name. Who knew! Welcome to Inside, Outside, Upside Down. We will introduce ourselves.

Yes. So, I kind of said this. We have been involved as parents and deaf and hard of hearing, professionals, many different committees and task forces and in the EHDI system. Just a few minutes ago a couple of us were talking about our first EHDI. For some of you this might be your first EHDI. If there's some acronyms or terms that you are not sure of, please raise your hand and shout out and ask us what that means. That is the best way to get in and start becoming more aware.

And we seem to be doing a good job of making up -- not making up, but creating more and more abbreviations

Okay. I will first present Nan.

>> NAN ASHER: I'm from the Michigan EHDI program, and I am on the stakeholder board for a long time before I started working with EHDI. I am a subcontracted, I'm rented out to the State of Michigan began. It has been very different being on the inside as opposed to being on the outside, totally. Even advisory was actually different from being a staff member.

>> KAREN HOPKINS: Hi, I'm Karen Hopkins from Maine. I'm the director of Early Child and Family Services in Maine, serving birth through age 5. So somebody wanted the interpreter here?

>> (Speaker away from microphone.)

>> KAREN HOPKINS: Okay. That's me when I was five. That was when I was diagnosed with moderate hearing level. My hearing loss progressed over time to now profound. I was born in northern Maine with no services. My parents had no services. I didn't meet another deaf person until I was 18, when I hit the campus at Gallaudet University and changed my life.

You are going to hear a little bit about that from all of us. My job in Maine is services to birth to age five. The early childhood program and what else? I just flew in. I'm catching my breath.

>> KAREN PUTZ: Hi, I'm Karen Putz from Illinois. I became deaf at the age of 18 while barefoot waterskiing. In my family, we are the only family in the United States with a really rare mitochondrial gene in my family. We were all born with normal hearing and one by one have lost our hearing. Gone through the give generations. Founder of Illinois Hands & Voices back when we had the fourth chapter. We go back a long way with the organization. Currently on staff and share the staff with Stephanie in Deaf and Hard of Hearing infusion. Of course, the word infusion really confuses a lot of people. Today we hope we leave here, you will have a very clear idea of exactly what infusion means in the system.

I am a mom of three deaf and hard of hearing kids who are -- they are not kids anymore. They are 23, 21, and 19.

I have been working as a deaf mentor in early intervention since 2003. One of the first -- first deaf mentors trained in the system. The first kid in the family I had is now 18 and in college. So I'm feeling old.

(Chuckles.)

Let's see. Does that cover it all? I think that's it.

>> MELINDA MEYERS: Hi, I'm Melinda Meyers. And I'm from Maine. I was born Deaf. My family didn't know until I was three years old. That's when I was diagnosed. And they were looking, they went to another doctor for a second opinion. I was born prematurely. They believed that is the cause of the deafness, although they didn't diagnose it until I was three. My hearing has decreased over time. And I have become profoundly deaf when I was 38. It was a slow progression. I had a whole journey in my life.

I worked in early intervention -- well, my first job was as a developmental therapist. I didn't work with the EI system but I was self employed, contracting out. And realized there was a definite need for EI, parents didn't know about the system. They didn't know about deaf mentors or the Deaf adults or the community. I decided to partner up with the EI system in the state of Maine and figure out how we might make those services more accessible to people.

The Maine center for deaf and hard of hearing, MeCDHH is the program that runs it. And I have been representing kind of the Deaf community. And then we decided to have a Deaf mentor program and have been running that eight years, reaching out to Deaf people all over the state to teach ASL to hearing families all over the state and currently I'm an ASL parent infant program. That's 0 to 5 set, preschool basically. I have done that for many years as well.

And real realizing there are still needs out there. Getting involved in some of the other committees. Trying to develop a collaboration with the Deaf community. Set up forums, which happens every so often with different political groups trying to really bridge the gaps out there in our communities. Hands & Voices has been one of our partners more recently. We have just blossomed. That program has grown. Deaf people in the community are very excited about getting involved. People are excited about getting trained. That's where we are and why I'm here today.

>> LISA KOVACS: Hi, everyone, I'm Lisa Kovacs, the director of programs for Hands & Voices. I have been with Hands & Voices for 14 years now. I'm pleased to be here as bringing the parent perspective today with this fantastic group of deaf and hard of hearing adult presenters.

My introduction into Hands & Voices is I helped cofound the chapter in Indiana back in 2004. And in 2009 I got involved as the Indiana Guide By Your Side coordinator. That was a tremendous experience. I, for five years was like a first point of contact for families, right after learning of their child's hearing condition I would contact those families. In Indiana we diagnose about 250 kids a year. That was a tremendous opportunity to be able to see beyond my own journey and learn about a lot of other families' journeys.

In 2014 I became the director of Guide By Your Side for Hands & Voices headquarters. Then in 2016, if I have my dates right, I became the director of programs for Hands & Voices. I oversee our Guide By Your Side programs. We have 21 of those across the U.S. and Canada. Then also ASTRA, our educational advocacy program, newest program. We have six of those. It's just a year old. We have six right now in the United States. We've trained actually in eight states. So we anticipate lots of growth there.

My involvement in the EHDI system started, of course, with my son Anthony, who is 16 now, going to be 17 in June. Which is amazing to me.

He was born in 2000. In Indiana in 2000 they had just passed the newborn hearing screening mandate. We feel as a family very fortunate that we were able to benefit from that. From there I have been involved on our EHDI Advisory Committee. I've done NICHQ improvement work, great for me. I'm sitting on the American Academy of Pediatrics EHDI program on the leadership team and also the quality improvement team. When you see me sneak out of here in a few minute it's because I am going to do a presentation with the group of regional network liaisons who are pediatricians, ENTs, and we are doing a session on getting beyond pathologizing deafness and looking beyond the ears.

(Laughter.)

So I will be out for 20 minutes, once again providing the parent perspective with that.

And like I said, of course, this all just got started because of my son. He likes to remind me I wouldn't have a job if it wasn't for him.

(Laughter.)

>> Thank you, Lisa. I'm very grateful to the parents ...

Thank you. I'm very grateful to the parents and having Lisa at the table with us. I remember the first EHDI conference that I went to. There were probably just two or three deaf and hard of hearing adults. The reason why I got there was because the parents looked around and said wait a minute, we are talking about our kids, our children and we don't have any deaf and hard of hearing people to help support and guide us. This is growing tremendously. And I loved that we worked together in a system where we continue to honor parents, deaf and hard of hearing people, professionals, and the early interventionists that are here.

One of the things that comes up, though, is the emerging vocabulary technology. Some things in this presentation may not ring true or speak true to you. And we can have conversations about that. But we want to keep moving forward with the terminology. A lot of times we need to meet parents or people where they are comfortable and let them grow and get there.

An example of this is when we talk about hearing levels, hearing conditions, hearing loss, there are many different ways to refer to that. And diagnose, identify, is the right way? We want to get there. Like I said, we want to honor families, our parents and using the language and terminology and bringing this to all the appointments and visits with the family will help them get there.

I was identified at the age of 3 with a profound hearing loss. I have a picture at the bottom here that I use a lot with my presentations. I was the first born child, first child for my mom and dad. Of course, they are looking at me with loving eyes and just thrilled that I'm there.

But it was three years before I was identified. And my mom kept telling professionals there wasn't something not quite right. I wasn't speaking, not talking yet. I am very visually attuned to her. When I found this photo, I looked at it. It's beautiful and I love seeing my parents here. It speaks to me so deeply.

And I did wonder about those three years that I went without services.

So I asked my mom. I said mom, look at this. I was I was hoping we would have the heart felt conversation and the moment to talk about my hearing. A little bit of her journey as a parent. She looked at that photo and she said I don't know what I was thinking when I picked out that couch! That sofa!

(Laughter.)

>> STEPHANIE OLSON: And the lamp, oh, my gosh, that lamp is so ugly, but that was the style, the early American style.

I'm like okay, mom. We tried to move forward. Interestingly enough, she doesn't really remember.

She doesn't remember other than the shock that I hadn't been hearing. Many years to come with wrapping what she knew around the overwhelming sense and feeling of grief and that's why I started getting more involved because I don't want our families around parents to have years and years of working through that grief. I don't want to hurry it up by any means, but the reason why it took my mom so long is that there weren't any resources available. There weren't any other deaf and hard of hearing for her to identify with. She did meet one who later became one of my mom's very dearest friends. Did you know that they never had a conversation about hearing at all? And what the possibilities were for me? And I do believe that it is because of the times. It was so important to focus on being normal rather than identifying and embracing deaf and hard of hearing. That's what we are going to move to today. I worked in early intervention, Hands & Voices, and the Colorado board. I'm currently involved with working at children's hospital in a unique position where I connect with families shortly after the family has, their baby is identified. And what that looks like, all of the options and the possibilities and the hopes and the dreams that are there for that family. It is a very unique position. As you know, in a hospital everything has to be billable. And families are not billed for any time that they spend with me. I'm very fortunate where there's a grant that covers that. So we can offer this service to families.

That is the foundation for today. If we can start embedding, infusing, as Karen said, deaf and hard of hearing people in the beginning of the journey, families can grow with confidence that their child is going to have their own journey as well.

So our passion is to move beyond asking deaf and hard of hearing people and parents to come and help at certain times or to sit on a committee at a certain time. I'm grateful for that in the beginning, but we want to move beyond that. We are getting there, where if the family sees that we are infused in all levels of the system, it becomes normal to see that their child too is infused at every part of the process, the services, and the goals that we have with the family service plan and IEPs. We want to move from personal to professional, going beyond volunteering to talk with the family to being a professional in the system, improving all outcomes and to work with all the partners at the federal level, international, to make improvements.

Whether we agree or disagree with the philosophies, we need to be involved at every level. And for our children to be receiving this possibility of services, opportunities to connect with deaf and hard of hearing individuals in a timely manner.

And these are kind of, this is just a reminder of the goals for this session that we have today, in case you wondered why you signed up for this presentation. We are looking at cohesiveness instead of dividing, how we can work together instead of separating, sorting out all of this, how we can bring us together.

>> LISA KOVACS: Okay. It's a little bit hard to get back there.

Very quickly we'll talk about the history. I mean, EHDI goes back a long way. Families go back even longer. We have been having deaf and hard of hearing children since the beginning of time. And surprisingly, the services have changed and changed and changed. But so have the families and so have the children.

And Stephanie, myself, and we were involved years ago. We share a long history with EHDI and the system.

What we are hoping to do here today is to talk a little bit about that, our own stories and working through it. Our stories matter. Each of you here in the room, you have a story. You have a reason for being in this room, a reason for being woven into the system. We want to be able to share that today and hopefully learn from each other, we will recognize that we learn from each other, to explore this process together.

You may see something very different in and that little piece may help somebody else in the system. And recognize that we share a common goal here. We are all here because we want to provide the very best in family support, no matter where they are in their journey and no matter what their choices, their experiences, where they are coming from in this.

So really quickly I'm going to tell you a little bit about the Hands & Voices philosophy and our vision. A lot of times when people look at Hands & Voices they are thinking to bring it down to communication modes and methodologies. I assure you, we are far more than just that. Sometimes we have been told we are too much hands, we are too much voices. We are a combination of both. We will explore that a little bit further in this process.

But briefly, the mission that we have here, we are parent-driven. This is a very important component. We are for and by parents. That's number one. We work in collaboration with professionals, deaf and hard of hearing adults, and others in a team. Primarily we are parent-driven. 51 percent of our board involvement is by parents.

Our foundation is that we have, we work without biases against communication modes or methodologies. That is very important. When you look at the idea of supporting families, it's a holistic approach. Communication is one part of it, but it is not the all.

The vision, I'll read it word-for-word. It's important.

We envision a world where children who are deaf and hard of hearing have every opportunity to achieve their full potential. That's what we are about. We are about maximizing what a deaf and hard of hearing child can do no matter where the parent is on the journey. It is really simple. What works for your child is what makes the choice right. That's our motto.

Oh, yes? Okay, we are going to do a communication check, yes.

We need to figure out a better way to ...

(Pause.)

(Laughter.)

>> (Speaker away from microphone.)

>> This is what access to communication looks like, where we stop, pause, take a check and see if everybody can see and do what they need to do. This is actually so beautiful. My hope and dream is that this becomes natural for us, not just at EHDI but at home, in the schools, in the job force, everywhere. Where we just pause a minute from what we are doing and see if we can make it even better.

So thank you. Christine, you're in charge of catching our interpreter.

So that was a little bit about Hands & Voices. And we want to go a little bit now into the EHDI system. We are just going to touch on this briefly. Most of us have been involved in the EHDI system for awhile. Is there anybody new to the EHDI system today?

Oh, good! Look at that! Round of applause for new people. That is so wonderful. Wonderful. Oh, excellent. So please, do raise your hand and ask questions. We love it. We love it.

So this was a little tricky to find a good mission for EHDI because there is some stuff out there, but it also looks different at the state level. And that's how every state operates and takes care of the early intervention.

But we have the basic and common values starting with the universal newborn hearing screening prompt and appropriate early intervention. I think this is a great opportunity today to keep talking about vocabulary. A lot of people are looking at can we move from early intervention to early involvement? So be thinking about take for your systems.

Providers and training, enhancing skills. Monitoring and evaluation. We are going to be talking a lot about that in the months to come, with some changes, how we can properly monitor, evaluate and assess. That's how we can continue our funding.

Research and tracking. Very important. We need more of that. It's hard sometimes to get research on how a family improves or gets better after their early intervention or early involvement process, but it is there. We just need more of it.

Any of you are who passionate about research, this is a beautiful time to get involved.

Legislation. We are heavily involved with that. Financing, money for programs, that's always a big, big question, concern, roadblock, or opportunity for more programs and parent support. Looking at the 1, 3, 6 model.

EHDI does recognize that early intervention is very important. EHDI involvement in deaf and hard of hearing is very important also.

They used terminology, deaf mentors, deaf guides, role models, partners. I also like that they talk about using deaf and hard of hearing professionals. We need to reach out for that.

So a few years ago at one of the EHDI conferences there was a group of people, deaf and hard of hearing people who got together to establish the learning community. And you can find this in the NCHAM, early intervention EHDI Web site. The link if you want to dig into it a little bit more, if you're looking for a foundation for that in your community.

Here is another term, deaf and hard of hearing involvement. It captures abroad range of service delivery models. This might be a good term for you to use in your state programs.

And we use a variety of communication modalities and assistive devices. All of it is good, with the hope that we can meet and reach every family. There are some programs that do a beautiful job of bringing ASL into the family home and increasing that language. That is wonderful. We want that. We need that. But we also have families with children who might have unilateral hearing loss or mild hearing loss. The dynamics of how parents are going to provide services for their adults, we want to honor that.

This is an example, hard to see, but these are some of the deaf and hard of hearing programs where professionals and deaf and hard of hearing models are being used in NCHAM. This is old. Some of these don't exist. The purpose of this is to give you the opportunity to go in, see what is in there, and expand upon that. Maybe it's time to delete and update information.

I like this because I think some of us in some states feel like there aren't enough of us. We don't exist. We need more. And we have that foundation. How are we going to create and get more programs?

Anybody recognize anything up here that you've done or you have been involved with that is no longer ... it's hard to see. You can't see, right, right. There are a few of them, the Minnesota program, the Minnesota deaf mentor program that I track. There's a variety. Arizona school for the deaf. There are some contact people. I would guess that they changed the name, educational center. Karen will talk about that in a little bit.

Then going back to the research. EHDI with deaf and hard of hearing individuals woven into the fabric of the EHDI system at every level, what Christie Yoshinaga Itano has been working on. There's a good chance here, if you haven't been able to familiarize yourself and add this into your state system, please do.

You can leave that for a moment. Sign language will be provided by professionals who have native or fluent skills and are trained to teach families and young children.

The development and implementation of EHDI systems. We talked about that.

And I love the last one, goal 11, all children who are deaf and hard of hearing and their families have access to support, mentorship and guidance from individuals who are deaf and hard of hearing. We want meaningful interaction. Picnics, going to the pumpkin pot, signing Santa, that's all wonderful and those are great ways to incorporate the family's sense of community and connection. But we want to take it way beyond that.

One of the things that I'm very adamant about with my job in the work that I do is that this is a decision that is made by people, a team of people and families, in that a professional doesn't decide when is the right time for a family to connect with deaf and hard of hearing guides or partners or mentors. Sometimes the families are not fully aware of how meaningful those interactions will be until much later. But we can't wait. And we have professionals that still will decide, you know what? Let's give the family so many visits and then we'll bring in a mentor. That's something that needs to be assure decision between families and the deaf and hard of hearing guides.

Additional research from the book Turning the Tide. Nan has it. Just to increase your awareness of what's out there.

And it is small. You want to glance at it? Read it? You want me to ...

I'll go through. One is from Paula. She is here. Maybe she can add to it. Children from families who received deaf mentor services made greater language gains, have considerably larger vocabularies and scored higher on measures of communication, language, and English syntax than similarly situated children without deaf mentor services.

And that is from 1998. I know we have a more current resource, but we are talking about the impact that people in this system can have on the language and the social/emotional development, academic access, family sections. Anybody want to add to anything? Paula, you want to add anything? No? No? Okay.

Anybody else?

Effective programs. I remember the days when this was done voluntarily by me, if I have the time. This is what happened is that I received an email to visit with a deaf and hard of hearing family. I would find a babysitter for my three kids at home, pay X amount of dollars, be gone half the day because I live out of the city. Meet with the family. Come home and while it was wonderful, it wasn't a consistent and effective way to do this.

So we moved forward in Colorado and I think many other states have, where we do need a written description. We need appropriate expectations, policies and procedures, a strength based program, strong role models, strong families and a coordinator for the project. Training and awareness of biases, and follow-up reports on effectiveness.

We need to be in touch with each other in our states to find out what is working and what is not working so well.

The concept of training and awareness of biases is very interesting because I know and I am confident in what worked for me and the way that I was raised. When families are using parent guides or meeting with other parents, it is very possible for a parent in that position to tell their story without influencing the parents.

When I tell my story, that assumed bias is already in place because the family can see and hear and know that there is a deaf and hard of hearing person, but she is not fighting. She is speaking. The assumption is made that's the path I went down. Maybe I don't embrace or accept sign language, and that's not true.

Within our own community we have to be careful in how we tell our story with the way that we were raised or the way we grew up and why we went in one direction or another without influencing families.

We will talk more about that. But one of the ways that we do that, we have a level recognition program in Hands & Voices that is required training and there is a GBYS stands for Guide By Your Side training. And we also take part, we are Hands & Voices, an introduction to Guide By Your Side, supporting families without bias.

We have two additional trainings, which is the role of the deaf and hard of hearing guide and working with the parents because as I said earlier, we were able to get into this system because of some of the work that the parents had done before us. Not always, but in some of the systems.

This is so important. I had the opportunity to train a group of people in British Columbia. The training was wonderful. It was open. It was very diverse. It was incredible. Wonderful people.

And then a few months later after I got home I received some emails. Some of the people that were in that training, deaf and hard of hearing guides, were trying to figure out how to balance and tell their story and how to better understand some of else's story. It's a very unique walk that we have, and the training that needs to be continuous.

So Hands & Voices guides will share the uncut version of their own story. And use that as an opportunity to learn from one another.

We work with the parent guides, as I mentioned a few minutes ago, to understand the different roles that they play, and how they are part of the system. Protocols on how to cross-refer and work as a team. That is going to be the secret to what you will be doing in the future. And then it is very important to understand the billing, program policies, et cetera, to go up.

We have Mindy coming up.

>> MELINDA MEYERS: So where should I stand in where is it better to see me? Can you see me -- I think Paula should be closer to the Power Point? Somebody can do the slides for me if I stand here? I'm going to be signing. I want to make sure I am going to be visible. Let me try different places.

I can do it from here, can't I? Yeah.

No, that's not going to work. Let me try over here. I am not going to stand where the interpreter was. I would like to be on this side, if I may.

Okay. So this slide, as you can see, it starts with a question. What connections do deaf and hard of hearing adults have that other experts may not have? What can we bring to the table? Resources clearly is one of them. Not only EI resources but ASL resources as well.

There may be things that the other professionals are not aware of. When a deaf person comes into the picture they can share those resources and the EI professionals can add that to their repertoire and toolkit. We are on the same page sharing information and resources so we can better support families.

There is also the piece, initially on YouTube nowadays there are more and more young people using social media. And with sign language. There are tons of videos out there. They are wonderful. You can learn sign language on YouTube.

So when you meet, you have an EI professional and a deaf individual coming into the family's life, they can make sure that those resources are being shared freely and the family is getting needs met. The other piece is a social identification piece. So you have somebody who identifies as deaf, somebody who identifies as hard of hearing and in the community we say okay, well, that person is part of our community. I mean, they can call themselves hard of hearing, of course, but that's part of our global community and they are welcome into it.

Hard of hearing people sometimes feel like they are straddling the fence. They are not sure what their identity is. So the ability to meet with people from the Deaf community, to talk about the feeling of pride and self worth and feeling really quite happy with who you are as a person, and as a deaf person. When families see that, when parents see proud deaf adults they realize the sky is the limit for their own child. If they see somebody struggling with that identity, they imagine that their own child is going to struggle as well. That has implications for their sense of self worth and self-esteem. It is important that the Deaf community, sometimes kids tell their parents I'm deaf and I'm proud. Often they are more passive. By bringing a deaf adult into the picture early on, we can convey those experiences, the social, emotional developmental part which is equally crucial to all the other developmental parts.

And then parents may be more willing to learn sign language rather than putting it off or procrastinating or something. They might feel like this is really a path that they can walk with their child and support their child, if they've got a partnership between an EI professional and a deaf individual in their setting.

We really can get the sense that ASL is a beautiful language and it is the primary language of the Deaf community and it is worthwhile.

Peer to peer networking is something that we can bring as well as members of the deaf community. We are looking at the services for birth to 5. And preschool. Parents are coming and trying to figure out what they should do. They are not really sure. They are being asked to make decisions and to put a communication plan and language plan into place. And that early visual communication is key to those later learnings.

If parents can see other children playing with their own child and realize that there are opportunities to take advantage of, I have had people come to me and say Melinda, you are oh he right, my child doesn't know sign language and I don't know sign language, I thought it wasn't going to work. We went to a play group and it was beneficial. That is something we encourage. We make those connections across the communities, both for ASL development and for social/emotional development and when they are pre-K or K ready. That peer to peer networking is very important.

When a deaf child is isolated with other hearing children in the classroom we guarantee there are going to be struggles. They are going to need support. That support, you know, can come from a transition specialist, can come from various professionals in that child's life. But it is important that we identify that those needs real and then that person can develop a sense of pride, dignity and growth. They are fine exactly as they are. When parents know that, when children know that, they need support from the adult Deaf community to get there.

We talked about the field of EI professionals, the EI specialists, SLP, managers, they all have their meetings. There is a deaf guide or deaf ASL instructor or ASL parent advisor, people who have a particular certificate can join those teams.

Everybody has their area of expertise. So in the field of ASL development, ASL development, an EI professional may not know those benchmarks. And the presence of a deaf adult can encourage people to continue to enhance their knowledge, to share further resources with the family, to add it to the EI toolkit so that all sides are represented.

Absent that, I think that deaf and hard of hearing people have to be involved on every team having to do with deaf and hard of hearing children because they bring so much to the table.

And with the Hands & Voices, for example, you know, this is an organization and deaf people are welcome to join. In Maine, the Deaf community didn't know about Hands & Voices. We only established our chapter maybe two years ago. We wanted to get deaf people to come, be involved. We had to have a deaf community forum, bring people in, network in an informal way. We hosted events where people would meet each other and kind of Suss it out, what was going on and mingle. And parents, you know, if there was an interpreter they felt like they could ask questions and the deaf person could answer about their work, their life, all that sort of sharing what happened in an open forum. They asked a lot of questions about our own journeys as Deaf people, what our childhood and identity was like. Of course, everyone, everything is individual. You can't compare one child to another child. Everyone has their own journey, but the factually background is a factor. The educational background is going to be a factor. What age they were identified, what sorts of resources they had access to. All of these are factors in people's journeys. We are able to share some of those life stories.

Then there's the cultural community involvement. That was the point of this Deaf forum. We invited the community to come in and meet parents to bridge those gaps because for many parents that are, the first Deaf person they met is their child. It is important that they need Deaf adults. We talked about Deaf power back in the day. Now we have more of a concept of collaboration. Early intervention, Deaf education specialists working together to be more of an open, collaborative approach. That works best rather than a siloed approach.

So people are stepping up to the plate, getting involved, going to events and helping parents navigate the journeys for their own children. Breaking the ice. You can have a parent learning day event. Obviously there are different models of how you can do it in your particular communities. It is important that parents and Deaf community members have a place to come together to get to know each other.

And as I mentioned we are a real life model for families and the EI team. They are trying to explore what the possibilities or for this particular child. What their communication plans should be. Should we look at the cochlear implants? Should we look at hearing aids? There's audiology, there's politics, there's the education piece of it, meaning access to education. What rights exist for the deaf and hard of hearing child in our current system? And so forth.

I think we can help instantiate those visions and ideals because we are a real person. We can see this is exactly what my life journey was like and it is important that deaf adults be involved because we are perhaps a picture of what their child may be.

And there are so many commonalities between Deaf and hearing people. So many similarities. They can see that they have hope for their deaf children.

There may just be a few of us, but the families need us. We need to get out there and represent and show that ASL is a viable option in terms of all of the communications options. Some states have a bilingual approach and some have a bilingual/bimodal approach. There are a lot of approaches, but the key is to be open minded and open to that conversation.

I think I said all of this already, actually.

Hmm ... oh, I added this top bullet because I'm one of the group of Deaf individuals. We've talked about audiology. And some of the issues therein. Cognitive -- I can't spell it.

Binaural and unilateral. Talking about the different kinds of deafness. People get interested in the medical situation, what is your level of hearing? What kind of hearing loss do you have? My friends talk about it being bilateral and having very different experiences even so. One having a hearing aid early, one having a hearing aid late in life, one never being aided not realizing benefit from it at all, it wasn't worth it. People look for an easy answer. There is no easy answer. The answer is talk to deaf community members and realize whatever it says on a piece of paper about your hearing loss does not actually indicate what kind of auditory access you may have in life, aided or unaided. You can't compare people's experiences. They are very individual even if the numbers look the same.

The other thing is talking about our own personal experiences and the positive perspective that we can bring to that. A lot of families, you know, working with deaf adults wonder what might happen for their children. Here I am, or here is another deaf person is saying I have this wonderful job, I get to meet and support families, support my own family financially with this job. It is very positive. And with that experience families then can have more hope for the lifecycle of their own child.

Then, of course, having families get together with other families, preschool program. It depends on what services your state provides, but it is important when parents are making the choice about what preschool to put their child into, it is important that if they see their child learning, growing in sign language and wondering if that's positive or not positive, if they have deaf community members there to present them that this is basically an entree into a unique, interesting world. There can be families that never met a deaf adult and it is important that they network with each other to share experiences with all of the EI team.

Yeah, we talked about being role models. Can't stress that enough.

The reason I put that there specifically, I'm in the northeast. We have deaf adults who use cued speech. That was the methodology at some point in their history. Then they got married. One person got married to an ASL user and they were a cued speech user. There are some families who want to start with cued speech.

And because of this person's experience, they can advise the family about that.

And the key for us is to be open, to talk to families. They are going to go on a journey. They may change boats over time but we are in the same boat with them as they navigate this journey. Children end up making their own choices.

Is there a question?

>> (Speaker away from microphone.)

>> MELINDA MEYERS: Okay.

(Laughter.)

>> So I can't actually. I'm not an expert on cued speech.

>> I was going to say there's a cued speech table in the exhibit ham and there is a guy who is really good with that. That will get us out of our timeline here.

>> We have 26 hand shapes that represent phonics. It's a way of showing the language on the hands in the English language.

>> (Speaker away from microphone.)

>> MELINDA MEYERS: Another question?

>> (Speaker away from microphone.)

>> Wait, wait, wait. There is no way that CART can get that. You have to use the microphone at the back, please.

>> AUDIENCE: I'm penny, I'm vice-president of the national cued speech association. And I would be happy to speak to anybody afterwards about cued speech.

I'm also a Louisiana Guide By Your Side parent guide.

>> MELINDA MEYERS: Thank you so much. Thanks.

Last bullet point about focusing on access. Okay, imagine that we have a deaf and hard of hearing child and their families may not even know the needs that they have all together. So the family is cooking and the child is playing. Where is the quality family time in that equation? So we encourage parents to basically narrate their day and have true engagement, turn taking, communication happening in the home. Which they may not even realize is a need.

Simple logistical things like having a video phone or having an alerting system in the house, visual alerting systems, communication access and other kinds of access for emergency.

One family, for example, they were not understanding their child. They couldn't communicate with their child. The child was getting very, very frustrated. They used an iPad and the child found what the child was looking for and they wanted to play a particular game or whatever it was they were doing. They were able to communicate that way using the iPad for communication access.

And then they can play with their hearing siblings. The deaf child didn't want to be left out when hearing siblings were playing. The deaf person came into that situation and shared technological resources that might enhance communication access at home.

So again, I am from the northeast region. I've gathered information from the northeast. I talked to people broadly, but when deaf parents have a child and their child is deaf, there may be a bit of grieving because they know what it was like to grow up as a deaf person. They know the particular kinds of oppressions this child might experience. They may have some mixed feelings. They may not. They may be completely thrilled. This child is healthy, normal, fantastic and happy to have a child who is going to understand what my life is like and vice versa.

Now, it is harder for hearing parents. They go through a longer grieving process and that's okay. That's why EI is there who help parents do the grieving process and give them the resources they need to emotionally support those parents. And to give them the resources about how to connect with their deaf child. For example, eye contact being very important and to kind of set up slightly different modalities of behavior than hearing parents might have been expecting to engage in if they had a hearing child.

Putting a child in a high chair and making sure the child can see the parent at all times so they can narrate their day as they are cooking, whatever. And the EI professional can give those kinds of tips to help the parent connect to their child.

It is a bonding issue.

So as I said, both sets of parents may have a grieving process. There may be the question about speech D. Deaf parents have a child. At some point, maybe this child is a CODA. So a hearing child. Some of them have family members may be living in the house and, of course, the environment is mostly comprised of hearing people. So their language development develops on target.

But there are some who may not have a whole lot of hearing individuals in their lives. They use sign language at home because their parents use sign language. Maybe they live in a rural area and it is a small communities and deaf parents aren't sure how to support their child's speech language development. So they might have moments of grieving about that. I might not be the right parent for this child because I can't teach them to talk, for example.

And there are CODAs who have gotten speech therapy for short periods of time to catch them up. I have two hearing children. They are grown now, of course. I remember the doctor expressing concern that my child was going to be deaf. This is while I was still pregnant. My husband is deaf. And so -- I said my husband was not born deaf. My husband was born hearing. He became deaf later. It is not a genetic link. So you know, each deaf adult experience is quite unique. The etiology of their deafness is different. So they thought, you know, there might be behavior issues. Sometimes there are behavior issues that hearing children test boundaries with their deaf parents. And some deaf parents may not teach their children full ASL. That's an issue for some of our mixed families, just as in the other direction.

In the IFSP, during those meetings, you know, parents tend to -- they know what they know, but they are not sure if maybe their child is developing on target. You know, this one doesn't seem to be hearing, or this one doesn't seem to be developing speech. What is going on here?

Whereas deaf parents if they find out their child is deaf they pretty much know. We are going to choose this for your language plan and this for your development plan and choose this school for you. They know what the options are in a way that hearing parents just don't know.

And of course, deaf parents, having grown up in the Deaf community are very familiar with deaf culture and the choices to be made therein.

And deaf parents are ready to communicate with their children from day one. And it takes a little bit more effort for hearing parents who don't have that experience. We are there to support them through that effort, through that journey and relieve their burden a little bit. You can be yourself with your child. Maybe you are going to learn ASL or maybe another language or use more visual modes of communication so your child knows what is going on and you can accept your Deaf child.

So often times Deaf adults will be asked what their experience was like growing up in a hearing family. No experience, no one experience is like another. Communication access is not necessarily one experience. It goes up and down. It depends between siblings. It can be different.

Everybody experiences, though, similar family issues like sibling rivalry, et cetera, et cetera.

And the importance is having that communication access and full exposure to language. So experiencing activities like going to the Deaf club and being involved in a culture helps a child grow up and feel more comfortable in their identity whereas Deaf children who have hearing parents, it often is a more difficult process. Developing the proficiency in sign language, for instance, may take longer. I often get asked, how did you become such a good signer? I encourage parents to learn ASL weekly. If they want to improve their skills and become better signers as hearing parents, they have to work at it.

Okay. So, first, Nan is going to talk about the Deaf plus and what the sign is for Deaf plus and what sign is being chosen. You know, many people may read Deaf plus and misunderstand what we are talking about. But what we mean is in addition to, okay? So we use this sign because we want to talk about disability, but in a positive way. In an empowering way. Some people sign Deaf like the sign plus, the math sign plus and that works as well.

>> NAN ASHER: Thank you, Mindy. You did a great job here. Deaf plus, about 30 to 40 percent of children who have hearing loss have another disability. So it is very important to include them. What a lot of these families find is that in the early years the other disability usually takes precedence. Many times when they finally get that all orchestrated out and figured out and move on, with the hearing loss, the deafness, the hard of hearingness is with that child for life. So they gradually transition into that. We find out later, older parents because they were dealing with some of the other disabilities, we want to make sure we include that in there. There's other families that don't fit in our typical EHDI box. Michigan we have a lot of migrant workers there. On the west side they pick the fruit and move with the season. Then in Dearborn, southeast Michigan we have the larger Arabic community in the nation. So we have to have guides that know Spanish and Arabic so we can service all our communities.

And I'm sure other states have their own languages and things that they have to be aware of. Make sure you have parents and professional, deaf and hard of hearing professionals who deal with those cultural instances too. That's really important.

The families across the hearing level spectrum. The EHDI we serve everybody from mild unilateral hearing loss to problem found bilateral loss. We have a wide spectrum in there. We want to make sure we meet all of those needs in there as well. We also have deaf parents with deaf plus children with other disabilities. I personally know several in Michigan.

Then the deaf parents have to learn about the other disabilities that they are not familiar with, though they can handle the deafness part of their child with no problem at all. It's interesting how we can fold them into parent engagement in there. There's a lot of lesbian, gay, transexual families. We need to include them and make them feel welcome into our EHDI program.

And then teen parents. I usually drag in the grandparents along with that. We need to be inclusive and accepting of all these different families and not be judgmental and try to create more barriers than they are already facing.

So I want you guys to think a little bit about this. What insights, connections and insights that deaf and hard of hearing adults may have to help with EHDI and other experts in Hands & Voices. A the look of times the families may have other objectives than other professionals. We need to honor that, understand that, and maybe flesh it out. They may have other ideas that may not be realistic and try to figure that out and help bring them together there.

So did anybody have any comments on these types of families that you have experienced or you had ideas or things that worked for you that you might want to share?

We have a microphone we can pass around.

Lisa, can you do that?

>> LISA KOVACS: Anybody? No?

>> NAN ASHER: Okay. One of the other things -- I did see a hand. She is the facilitator for the room. Okay.

No?

One of the things that our Michigan EHDI conferences is for many families and many professionals even, the first time they see what true access looks like where we have interpreters and CART. A lot of families are not exposed to that. They may hear about it. Until you actually experience it, you don't know what the CART is, the captioning going along up top here. It is important in Michigan to have that available so when the parents go to the school and they are asking for this, for a middle school or high schooler, they can talk coherently and explain it better and tell why it is so important for their child. It is important that people know what that looks like, there.

Any other ideas?

No? You have a question? All right.

I can't see here.

Okay. Then how does our personal history and experience impact our system? More discussion on there?

>> LISA KOVACS: This is the time for you guys to participate! In case you missed that. So ideas from you about how does your personal history, you personally impact systems?

>> We have a brave one.

>> AUDIENCE: Just making sure the interpreter can see me. I'm Stacey Abrams, a family mentor for the Arizona school for the deaf. My parents are hearing. You know, I have a strong connection to families with deaf children because of my personal experience. Having hearing parents and growing up in a small town, in Arkansas, you know, what if I met a deaf family that lived in the town. The parents had no idea. They didn't even know that there were services provided for families with deaf children. So they came knocking on our door. That was our first experience with another deaf family.

So my parents got the opportunity to ask them lots of questions and see different perspectives from other deaf people. Because not every deaf person has the same experience. My, they gave my mother a lot of information about where to find services and support in the state of Arkansas, in her local community.

But my parents they realized that they had to have different expectations for their two children because my other sibling is also deaf too. And that we could grow up to be successful adults.

So with my family, with our families I try to look back and remember how important it was for my parents to meet deaf adults when I was younger. Because of that, I believe we have a very strong impact on how deaf children grow up.

Excuse me, interrupting.

It had a strong impact on how me and my sibling were raised and helped us to become the people that we are today. It was all based on that experience that my parents had with a deaf family. So we share that with other hearing families that we work with, to impact them as well.

>> LISA KOVACS: Thank you for that great example. Anyone else?

>> That was the next slide with the partial one? You had your hand up?

Okay.

>> Thank you. I'm parent of a 24-year-old Deaf son. I also have been involved, gosh, since 2004 with programs that provide deaf and hard of hearing adult involvement for families in one way or another. I think one of the important things to keep in mind too when we are supporting families is that you have parents, especially with newborn parent support too but people who have spent time in the journey enough to get different perspectives. You can't read different perspectives or experiences from the book or the Internet easily. You have to put in the time to go out there and meet other individuals. That's when you start realizing: Oh, everybody's story is different, right? And so I think one of the most important things is to encourage families to be curious and not to be afraid to ask questions. That's how I learned along the way very early on, just dove right into the Deaf community, but by talking to people who were hard of hearing and were raised without sign language, by talking to people that had a profound hearing loss but spoke beautifully and the next person was raised orally but didn't speak so great and had to use sign language to communicate -- not had to, but preferred to use sign language to communicate.

You start to see by your own personal experiences and you can internalize that truly everybody is different and on a different journey and we are supporting them to get to the ideal outcomes for their child. It doesn't matter what path they take.

I think time is important, too, and exposure. And being curious.

>> So normalizing hearing loss.

>> I like that. Thank you for bringing that up. In addition to that, allowing parents and deaf and hard of hearing guides to change their minds and opinions and beliefs. Sometimes we hear -- I'll use me as an example. I said I would never, ever get a cochlear implant. And I don't know what happened, but years down the road it was something that I wanted to explore and look into and investigate. And I think we put our guides in to boxes based on how we move in the world. We forget to allow for changes. I have had deaf and hard of hearing guides that have said they grew up oral and they became beautifully fluent in ASL and that became their language.

We need to always be mindful and allow for that flexibility in our families, providers, and in our own selves as well.

Anything else we want to add to that before we take a break for everybody? I was thinking about our interpreters, but I think we all need to stand up and move. Anything else you want to add real quick in terms of how your experiences impact the families or the systems?

Maybe think about it. If you think about something when you come back we'll touch on it. We'll take a ten-minute break. We should come back just 2:55.

(Break.)

>> Okay. I'm going to give you a 60-second warning and we are going to get started.

(Pause.)

>> LISA KOVACS: Okay. We are going to spend the next few minutes just talking a little bit about the evolution of parent involvement in EHDI systems. I know that primarily this session is focusing on deaf and hard of hearing involvement in EHDI systems, but I think that there are some things that we can learn about parent involvement and also I think that there's a lot of similarities when we talk about either infusing parents or deaf and hard of hearing adults in EHDI systems.

So first of all, I thought I would talk a little bit about my own consumer experience and how that influenced my ability to be a parent leader. And I want to encourage you to think about deaf and hard of hearing adults as the consumer of EHDI systems, and how that might influence their ability to be a great deaf and hard of hearing adult leader in EHDI systems. Of course, the journey started in 2000 for myself as a parent leader when my son referred on his NBHS. That was my first introduction, going through the whole process of newborn hearing screening, both positive and some challenging experiences with that.

There was going through the diagnostic process and how that influenced me. Looking at my experience in the medical home, working with different medical providers. Early intervention, and as parents, you know, as soon as we work our tail also off to learn everything we need to to learn about early intervention, gosh darn it, school starts and we have to learn about navigating the education system and so then it was learning how to be a good IEP team member, myself as a parent leader.

Then becoming an advocate for other families. And then my son is now joining, he's on his journey. He's on the uphill swing to join the troops of deaf and hard of hearing adult leaders out there. So my next job as a parent leader was to be a role model and teacher for my son because ultimately he was going to take over this responsibility.

We have to become transition experts as parents, learning about getting our kids where they need to be either into the workforce or into post-secondary education. That's a whole nother learning process.

And lastly, we start stepping into this position. I'm about halfway there now with my son, who has really taken on his own identity, his own wishes, dreams, decisions. I'm now the observer and supporter of him as he transitions into, like I said, the group of deaf and hard of hearing adult leaders in this world.

So we think about parent involvement. I remember the days. I remember the days when parent involvement and specifically in EHDI systems, came on the horizon. I feel fortunate enough that it was during my time. I remember initially it was, parents were asked to be at the table. They were a stakeholder. It was a check box. Check! Parents were here.

They didn't necessarily really want to hear from parents. But they were being told they really should have a parent at the table.

A lot of times in my experience, in the very early days I would look around the room. I have four children. And they were all really young. I was paying lots of money for a babysitter so I could go sit at this meeting in the middle of the day, not conducive of my schedule, paying lots of money for a babysitter and I was not being paid. I looked around the table and thought hmm, everybody else here is being paid to participate in this. Those were like the really early days.

Then all of a sudden we started seeing this evolution of what parent involvement, parent engagement really looked like. So like I said, in the beginning parents were kind of seen but not really heard. Typically as volunteers. Then all of a sudden there started being this requirement that parents be involved. And with that requirement came paid positions so they were actually being paid to be at the table. A lot of different organizations recognized this. NICHQ started requiring that if states were going to bring a team to do quality improvement there must be a parent on that team.

Pepnet which, for Deaf education, they had a requirement that a parent must be on the state team when they came. The joint commission on infant hearing has been such a champion for us about parent involvement and, of course, deaf and hard of hearing involvement too. They were a huge champion for deaf and hard of hearing involvement.

Of course, requirements on Advisory Committees. And over the course of this time we started seeing parents in leadership roles. I know parents within our system now the chair of their EHDI Advisory Committee. I can think of two states in particular that have a Hands & Voices parents leader as chair of their Advisory Committee. I'm Co-chair of the Department of Education special education council as a parent. And the other chair is a parent as well.

We are starting to see parents in leadership roles.

So if you think about this evolution, we started and it was kind of seen but not heard. Now we are seeing lots of parents even in leadership positions and in paid positions within the system.

So I just want to bring to all of our attention, and I know lots of you in this room are familiar with this. There were two maternal child health bureau HRSA grants or cooperative agreements that just came out. I believe this is historical. So the first time ever the renewal of the EHDI state grants had a requirement in it that 100 percent of the EHDI programs must develop partnerships and a memorandum of understanding with a family-based organization that are supports families of deaf and hard of hearing children. 25 percent of their budget must go towards that. Now there's the requirement for paid positions.

The other cooperative agreement that I'm really pleased to announce is a new cooperative agreement from the maternal child health bureau of the family leadership and language and learning. This is a new technical assistance center for those family-based organizations in the 59 states and territories and Hands & Voices was awarded to be the national technical assistance center.

I would like to talk to you about the goals of that. This may be some new information to you. So the first goal, there are five program goals. The first is involving EHDI systems and the family-based organizations that they are funding and what that partnership looks like. It says 100 percent of state EHDI systems will develop partnerships with identified statewide family-based organizations that provide family to family support to families of deaf and hard of hearing children.

The second program goal is that to increase by 30 percent from baseline the number of families who have increased knowledge, skills, ability and self efficacy to serve as leaders. Training parents to be leaders. It is not just picking, you know, the parent that you met off the street but actually providing them with training on how to be a leader in EHDI systems.

The third objective, increase by 50 percent from baseline the number of families who have the opportunity for family to family support by the end of the three years. And the last two, my favorite. Increase by 50 percent from baseline the number of families with opportunities for knowledge, literacy and social development for their children by the end of the three-year period.

So the system is recognizing what we all know, all of us either deaf and hard of hearing adults or families that language, literacy, and social development is what this is all about. Lastly, to increase by 30 percent from baseline the number of families who are offered support by Deaf mentors. This is huge. It's a requirement.

So that's why, you know, part of the presentation today is we want to talk about, we know there's some really awesome Deaf mentor programs out there. There are not enough. How are we going to increase those in our states and territories?

The family leadership and language and learning. I keep having to look at my paper because we fell into that acronym world and we used the acronym FL3.

We are running a little bit behind. I want to get to our other deaf and hard of hearing presenters. I'll skip a couple of my slides.

Something else I want to talk about is we look at parent leaders in the system. We know that originally parent leaders come into this because of their own child. I can tell you 14 years ago when I was sitting at the Indiana school for the deaf listening to a presentation by Hands & Voices I had a five-year-old, a seven-year-old, a five-year-old and twin three-year-olds. The leader said if we had anybody in the room who is interested in starting a Hands & Voices chapter, we could get one going. Myself and a Deaf adult raised our hands. My brain was saying: Put your hand down! Are you crazy?

Honestly, I didn't do it to come and speak at an EHDI conference or to sit at an IEP table with other families. I selfishly did it for my own tell, I'm here to tell you.

Through the evolution of 14 years of parent involvement, I've gotten interested in being ab parent leader now in EHDI systems. That was not my initial intention.

We see parent leaders evolving to want to do parent to parent.

Then we have leaders who themselves want to get involved in the system.

So one of our programs is Guide By Your Side. I think just by the faces in the room, lots of you are familiar with Guide By Your Side. I don't want to take a lot of time talking about this. We do have 21 programs currently. We are anticipating with the new EHDI state grants, we have six that I know of, states that contacted us, state chapters that will be adding additional Guide By Your Side programs. This is our parent to parent support program where we have a formalized training program, where we train parents of children who are deaf and hard of hearing to be matched with other families. With Guide By Your Side we also have deaf and hard of hearing guides, okay? Where some deaf and hard of hearing programs are deaf mentor programs, with deaf mentor programs we have deaf and hard of hearing guides. We look for diversity of life experiences, like Chris mentioned before the break, where families have the opportunity to meet a variety of deaf and hard of hearing adults and those who are accessing their world through different lived experiences.

When we think about parents' ability to participate in systems and when we think about training that we provide to parents, start thinking about how we provide training to deaf and hard of hearing adults to be infused in the system, we want to look at what do we need to do to ensure that they have the ability to share their insights and information about their experiences in ways that others can learn from? And that was a learning curve for me as a parent. Initially I only knew my own story. As time went on and I got to meet lots of other families I was able to share not just a story that represented my son but stories that represented many, many other families and doing it in a way that I knew would be conducive so that others in the EHDI system would be will and open to listen.

Also families, you have to be able to represent families with different viewpoints. Hands & Voices was my window of opportunity to be able to meet families that were having different lived experiences than my family was having, but the amazing thing was we were having very similar outcomes for our families and for our kids. So Hands & Voices is a wonderful opportunity to do that. And one of my last words leaving the room of pediatricians, I said to them, some of them raised their hand. Over the course of practice they've only met maybe five families who have deaf and hard of hearing kids. I said you are at a conference where it is filled with parents and deaf and hard of hearing adults. Break out of your comfort zone. Go to a session that is being presented by a parent or a deaf and hard of hearing adult and continue to learn. That variety of experiences is so important.

When we think about parent leaders or deaf and hard of hearing adult leaders, they have to be able to have training to meet individuals or families that are different than their own. We have to be able to respect the perspectives and viewpoints of others, speak comfortably in the group and really want to be true partners in this work.

So I contribute to the EHDI email express that is a monthly article. There's a partner partnership section. I write an article for it each month. Many times it's about different resources. I submitted an article about Rachel Coleman's new signing program that is accessible to families now for free, families 0 to 3. If you don't know about it, it's out there.

But last month I submitted an article because I was just kind of thinking about my journey with EHDI and I'm on a quality improvement team. One of the things that the pediatric practices talk a about across the KT is getting a check box on the electronic medical records to talk about talking to parents about newborn hearing screening.

I'm happy that that discussion is happening. As I reflected on this, I wrote that universal newborn hearing screening, parent concerns, management of risk factors for hearing loss are not just a check box on an electronic medical records. Trying to remind them that their job is not done. It is something that we need to try to remember to discuss with families on routine visits. These factors can greatly impact the outcomes of children like my son.

I want to remind them it's all about the child and the child outcomes, not just that they now have an electronic box on the medical record.

How do we at Hands & Voices look and identify parent leaders? We see parents who demonstrate a desire to want to help others. Once again, we are here to talk about deaf or hard of hearing involvement. How do you start recognizing deaf and hard of hearing to infuse the system, ability to see beyond their own story, ability to share insights and experiences in ways that others can learn from. Understanding of the common challenges faced by families.

Ability to speak with candor. Motivation to impact and improve the system. And, you know, a solution maker. Not somebody who wants to come and complain, but come with true solutions. Be willing to work as a team. Then you also have to ensure that they have the capacity to engage and maintain involvement.

Then once we train the parents or the deaf or hard of hearing adults how to be part of the system, we have to do some training with the professionals part of the system. What does that look like? I'll tell you the new FL3 cooperative agreement has the opportunity for us to reach out to professionals and do some training. We want to make sure that they articulate to families, deaf and hard of hearing adults the value of their experience. Coming from the professional. I can't imagine if I sat down at my first meeting I was asked to take that seat and put the hat on as a parent, if the professional across from me said we value your experience and want to hear from you. That would have made a big difference. I see that now. I see that happening a lot. This is just if you are a professional in the room, think about that. Just taking a few minutes to say we value your perspective.

Explain what you'll do with the information that they share. And then share an example of how parent or deaf or hard of hearing experiences or stories you have heard from those individuals has changed your work or practice. Then, of course, you want to make sure that these partners have easy access. And obviously that is communication access, but I mean once again when that meeting is at noon, you know, on Wednesday afternoon because it works for everybody else's schedule, if you really want to get parents and deaf and hard of hearing partners at the table you need to talk, maybe think about how you are going to provide them with access to that meeting if they can't either be there in person, you might need to change the time, you might have to offer virtual opportunities. But think in those terms.

So can we give our interpreter some applause for standing on this chair? Oh, my goodness! Wow! I feel like I need to stand on the chair because I'm so short.

Examples of Hands & Voices parent involvement at different levels. Looking at local and state levels, special education advisory councils, state EHDI advisory boards, parents participating in legislative efforts, parents coauthoring or authoring publications, local early intervention councils, inducing ourselves where it starts at the American academy of pediatrics.

Speakers at conferences and workshops, and engaging ourselves in quality improvement efforts. Once again when you are thinking about how are you going to begin to infuse deaf and hard of hearing into adults into your systems, there are so many opportunities for including deaf and hard of hearing adults.

So I'm going to close with, you know, of course I'm not trying to work myself out of a job. I hope I get to be a parent leader in the system a long time. Now there is this experience that I'm having is transitioning of leadership from the parent to young deaf and hard of hearing adult involvement. It has to be some intentional effort with our kids. There have been things that we've done along the journey as parents, my husband and I, to intentionally give my son opportunities to become a leader himself. So those things have been getting him on panels where he is a presenter as a young little individual, deaf and hard of hearing individual and groups of parents.

Putting him in I call it sandwiched, the best experience ever for him has been that he has had deaf or hard of hearing adults himself and he has mentored younger people. I believe he has equally gained leadership skills by having both, by having mentors above him and being a mentor to others.

Leadership opportunities, signing him up for different leadership camps he can go to so he can develop leadership skills. He recently was asked to present to remote technologies through a zoom meeting to an audiology course of students. That was really, they came with all their questions. You know, I did absolutely no prep of him. I was sitting next to him but not on camera. And yeah, it was pretty interesting how he answered some of the questions.

(Laughter.)

>> LISA KOVACS: Once again, these are just examples of opportunities to start thinking about our young deaf and hard of hearing adults and how we can start building skills in them for them to be leaders and assistants in the future.

Here are some great Hands & Voices young deaf and hard of hearing adults. In our minds in Hands & Voices in the perfect world some of the Hands & Voices kids and early intervention kids will lead EHDI in the next generation. Thank you.

(Applause.)

>> NAN ASHER: Thank you. Okay. Well, we talk about Inside, Outside, Upside Down, that sort of stuff. My story, I was on the EHDI Advisory Board before it was called and Advisory Board. It was still called the stakeholder meetings in the early 2000s. I was one of the hard of hearing representatives. It was a bunch of agencies that represented the deaf and hard of hearing. Yes, the division of deaf and hard of hearing. I was part of the Michigan association of deaf and hard of hearing. Even though we were deaf and hard of hearing, it was our agency that was being represented on the stakeholders.

Later on we got in there. Then we changed it from agency's perspective to individuals. I became a hard of hearing representative instead of representing an agency that served deaf and hard of hearing. That's kind of what was in there.

So once I was outside that, once I moved inside because now I'm a contract worker within the State of Michigan began, I'm one of the few who don't work with the families when they are newly identified. I do a lot of follow-up. I go to the doctor's office explaining about EHDI and explain why we don't wait until they are five years old, the kids. There are a lot of comments from doctors on that. I think it was beneficial for them to see a hard of hearing person functioning, you know, trying to encourage and why it wasn't just look at me, but some of their own bias. Are you really finding deaf and hard of hearing children, babies? Yes. And one of my favorites is, I know they don't leave the hospital until they pass the newborn screening. I know it doesn't work that way. I said if they had newborn screening rules like that all those years ago, my brother and I would still be in the hospital.

(Laughter.)

>> NAN ASHER: I'm required to make phone callers to be parent and making sure, the baby didn't pass the screening. I have technology in my office that helps me, I have Bluetooth that works with my, because my cube is on the other side of the kitchen and there's a lot of noise, a lot of conversations. That helps me do that.

And then one of the first things I help to do is to approve a guide book that was going on for early on. There was a paragraph in there talking about learning sign language. And they said in this guide book it said deaf people feel that the best way to learn sign language is from native learners ... I'm like, it's not all deaf people. All people think that their language is not learned from a book. You want to use native speakers. It took weeks for them to learn that perspective. It was not only deaf only. It was people on the other side.

Turning it upside down, I didn't limit my role. I spear he had haded the midwife project. We had midwives doing newborn hearing screening with ABR equipment and I was given freedom to do that. That was good. I talked earlier about the conferences in family members and what access looks like with ter CART and interpreters. And I also support Hands & Voices as a deaf and hard of hearing family but I don't do stuff with the families. I go to the picnics and meet some of the families there. And occasionally I get called from parents of older children. I'm also on the advisory administrative or camp Chris William which is a camp for kids age 11 to 17. I talk to the parents of the older deaf kids not newborn, the really young ones on there.

And then now in EHDI looking out, I have a totally different perspective on that from what I had before when I was on the outside looking in. We have a miss Mitch Greene KT, she spearheaded legislation with Senator Zorn about getting hearing aid coverage for all children in Michigan. It has been stalled until 2020 because of the Affordable Care Act benefits. If you are familiar with that, every five years they go over what is minimally required by all insurances. If the legislature without it being labeled as an essential benefit, the State of Michigan began would be on the hook to pay for all that. It's still in process on there.

The other is a Deaf child Bill of Rights and the lead-K bill. You are familiar with that. Our EHDI was never invited to the lead K, but as part of the coalition, on the hearing loss association, as an advocate I got involved in that. The lead K is so different from the lead K in other states that the legislators are changing their name. They are not even calling it lead K. What is really important in Michigan is that parents' choice is paramount on that. They are not going to let that be just ASL or just aural. It is going to be both and heavily focused towards the parents, which is as it should be on there.

One of my concerns with the way the lead K was written, I did not think would benefit as many people as they wanted to benefit. Outside looking in, you see that 95 percent of the babies are screened. In Michigan it's close to 98 percent of babies are being screened. It is easy to assume 90 percent of the babies being screened, they are being identified. We all know loss to fault that is not what happens. When you are outside, you don't necessarily know what that means. We identified 175 babies in 2014, because 2015 we are still working on the numbers now.

With our birth rate it should be closer to 300 baby, the loss to follow-up we are still missing a lot of babies not being identified. Lead K is to get kids ready for kindergarten. If they are not identified until 4 or 5, they are not ready for kindergarten. That's my concern on that.

Early on enrollment, it took us a lot of time to get their data because we are under HIPAA privacy and they are under FRBA. Now we get aggregate data and we find that 50 percent of deaf and hard of hearing babies who are identified are getting early on services and you know, why is that? We don't know. Is it because many of them have mild losses and the parents don't think it's a concern or the doctors don't or to unilateral? We have a lot more education to do on that. That is the other reason I didn't think that lead K would go where it should go.

Any questions real quick before I sit down?

>> Do I need to stand up? Move, switch? Hi, I'm back. As I said when I introduced myself I was raised in northern Maine, the only deaf person that I knew or my parents knew. It wasn't until high school that my best friend and I were sitting in the bedroom one day and she said Karen, I found the perfect college for you. You did? Tell me. She found Gallaudet University and said you've got to go to this place. I had no idea what it was, never heard of it. So that spring break she convinced my parents to drive from northern Maine all the way to D.C. We got in the car. We drove the whole way down. We learned the ABCs in ASL. That's all we did for 15 hours. And this best friend changed my life.

When I got to Gallaudet, I said oh, my goodness! What is this place? Who are these people? Who am I? And I had a huge identity crisis all in a matter of minutes. She tells me now, she said I watched you that day and watched your face change and watched your life changed. It really, really did. I was there for the four years, undergrad in elementary education. The whole time I was there I remember looking around saying these people are like me and they are not like me, and how cool is that? So I started talking to more and more Deaf people. I started searching Deaf people. As many Deaf people as I could find at Gallaudet University, at home and anywhere in between Maine, D.C., everywhere else.

I realized that Deaf people like hearing people are different. There are no two Deaf people alike in the same way that hearing people are not alike. We tend to categorize people. I thought you know what? I have to go home to Maine and fix this problem.

No way can there be any more Deaf babies up in northern Maine that don't meet other Deaf babies or parents like my mom who hadn't met other parents. Something has to change.

So I said I'm going to go in this box and I'm going to go in strong and do it.

So I wasn't back to Maine and I realized that it is much better when you are inside than when you are outside. But what I had to learn was I had to be what I say sneaky and really I wasn't sneaky but I had to be subtle. I had to be super, super nice to people. I had to smile a whole lot. And I had to just kind of be everywhere. I had to show up everywhere where there are Deaf people. I had to show up everywhere there were parents, where there were hearing people in hour power, as I say, and just be there. I wasn't on any commits or councils. I was just there. They are public meetings so I started showing up everywhere. When they had public comments, I started popping up and saying where are the Deaf people? Where are the Deaf people who talk? Where are they? People were looking at me like: I don't know, you're always here. So we kept going and going and I kept showing up. I just realized that the more I was around, I found Deaf people but I had to really hunt for them in Maine. They were on a little island, the school for the Deaf in main is on a 100-acre island, outside of physical mouth. I said I'm going to work there and meet these Deaf people, but I had to hunt for them. I said that's horrible that Deaf adults in Maine had to hunt for other Deaf adults and Deaf children had to hunt for other Deaf children. If you lived in the right area, you got what you needed.

We started maybe -- now what did I do?

To back up a little bit, when we first started, I introduced, like I said I just got off the plane. I had to breathe. There was a picture of me as a five-year-old. There is another picture of baton twirlers. If I could find that I would bring it back, but I would lose my way so I won't. There were 15 little girls holding batons with their hands up. One girl in the back. And her hand was down. Guess whose hand was down? Me.

When I came back from Gallaudet I started talking to my mom and looking through family pictures. There were a lot of those pictures. People were doing something and I was doing the opposite or I was on the outside with no access, trying to get in. The more I started thinking about that, I thought oh, what is wrong with this picture? I'm doing the opposite of everybody else. I didn't have access. Working on access was really important. When I started getting together with more deaf and hard of hearing adults, Mindy being one, we started looking at who we were as Deaf people and realized that we never talked about our hearing levels. And we never really talked about our communication modalities. We just were. And there was one day at back to school for the Deaf with a bunch of Deaf staff and I got together and we found our audiograms and put them all out. They were really shocked I was the most Deaf one in the whole group.

And then there were other Deaf adults who had audio grams that were 40 or 50DBs and they were ASL only and when I was at Gallaudet I started signing too. That was an aha moment. As adults you don't talk about hearing levels or communication modality. You just are. You are Deaf adults together. How cool is that?

Another aha, we have to get these Deaf kids together and not talk about modality. We have to get parents together and not talk about modality and stop talking about the audiogram and all that and just be together. That's something that we made a goal in Maine was to get more and more Deaf children together.

One things we did, as director of early intervention, I said now I can do something because I'm a director, whatever that means. When you're a director, you have a little bit more say in what happens in your state. That became a goal for me, to be a director. I started to see that all the directors could make things happen. As director I met with the other director, the Department of Education director. And said we've got to fix this system. So over five years, in a little meeting room in our state capital, we wrote a memorandum of understanding. I said it took us five years. It was not easy. It took us a lot of work, a lot of interacting a lot, analyzing best practices in education, best practices in early intervention and best practices in Deaf education, Deaf 01, Deaf culture, all that Deaf stuff, trying to bring that to the table in every meeting we had.

We wrote it. It became a legal document. I will tell you a little bit about that as we go on.

We had a lot of support from our Maine EHDI program. We added a parent consultant through grant funding. The parent consultant calls every new family that has a baby who is Deaf and Hard of Hearing. We added a parent coordinator and they call every doctor or audiologist. We spearhead from several ways.

We added a Deaf mentor program and Hands & Voices. That's something I called in the EHDI conference in 2006, I think it was. I started feeling that I had to go to the conferences nationally to learn more. One conference I was at where I met Lee Anne Seiver when there were very few deaf and hard of hearing adults here. I went to the table. There would be a table here in the vendor booth. I encourage you to talk to them. I said what is this Hands & Voices thing? They started talking to me about it and I said I'm hooked. How can I do it. She said you can't do it. You are not a parent of a deaf child. You need a parent. I said okay.

Back to main I go. I found a parent and we teamed up. It was Janet and Lee Anne that day that taught me that I couldn't do it alone. It is that team of parents and deaf adults that is magic. That was very cool.

So this is our four-pronged approach that we have to supporting families, which took a long time to develop but it has been fun. The Maine EHDI has the follow-up coordinator, the Guide By Your Side, early intervention and deaf role models.

So our goal with all those people involved was to develop one family centered early intervention process for families who have deaf and hard of hearing children in Maine. That sounds simple. It was not simple. But we are pretty much there which is exciting. No matter where you live in Maine, if you live up on the tip of Maine near Canada or on the corner on the eastern-most point of the United States or way up in the mountains or down by New Hampshire, you get the same process, no matter where you are.

And this is where we began. We are getting these little, little babies now in Maine. Nationally everybody is, but it has been such an honor to start with these families. This is one of the moms I worked with about ten years ago now. When I walked in the door she said you're Deaf. Things are going to be okay. After she realized that I drove there myself. I had a husband, I had a job, I had a baby. Yeah, okay. But that mom taught me a lot. She taught me that early on these families needed to meet deaf and hard of hearing adults. They needed to meet people like me. They needed to meet people that didn't talk or people who used cued speech, they needed to meet everybody, that mom taught me.

In Maine and a lot of places early intervention needs to be a process. All too often we help families make quick decisions. I say help when sometimes I don't think we help them at all. We have a check box that says pig one. Pick a modality. Pig one, pick a therapist. Pick one, pick a program. What does that do to families? It by passes the whole process that they have to take. Healing, the new mom. Mindy was talking about new moms, hearing moms, deaf and hard of hearing moms. They are all moms of little babies. They have a lot of feelings. They are grieving, processing. They have a lot of expectations, questions. We give them information. Sometimes they get a lot of opinions, right or wrong, from everybody under the sun.

We have to build respect for them. And we have to have a lot of dialogue.

We have to build trust and ha importance and hopefully, hopefully we will build a great collaboration and come to decisions with this family. It can't be my decision. It has to be their decision.

I love this. I use it all the time. So we developed what we call our six visit process. In that when babies are referred to early intervention in Maine, we now have early childhood consultants, parent consultants, every state calls it something different.

At every of the nine sites around the State. One of my staff is embedded there. We have the same process throughout the State. In the sixth visit families are going to learn about their communication options. They are going to learn about technology options. They are going to learn about those hearing levels they have to learn about. They are going to learn about other things that families need to know to make decisions, but we are going to do it in this way. We are going to slow things down. What we've found is that it takes about six visits to get through that in a way that is family-centered, slow, mindful.

The most important, families lead that. Too often the early intervention workers show up with their toy bag and their goals and their checklist and assessments and families are way back here. We took a step and said we will let the families lead those visits and we are going to change things.

This quote was one that keeps coming up for me. The concept of informed choice reflects the fundamental belief that families need comprehensive, meaningful, relevant and evidence-based information from professionals in order to make decisions that are most appropriate for their child.

What word stands out for you there? Anybody have a big aha!

Fourth line down?

Fifth line down, sorry.

>> (Speaker away from microphone.)

>> Yes, what about parents, what about deaf and hard of hearing adults? What we did in that process in that MOU I talked about, we built in professionals. You have to have them. They are professionals. They are early interventionists. We also built in deaf and hard of hearing adults and we also built in families. So now every family in Maine, they get their professional, but they also get the opportunity to meet a deaf and hard of hearing adult within the first six visits of the early intervention process and they meet another deaf and hard of hearing parent, a parent of a deaf and hard of hearing child within the first six visits. That's really early. But what a difference we are seeing. And what we are seeing is the professional diminishes and they are on the back burner and the deaf and hard of hearing adult and families are the ones leading our process, which is real, really great. The professional is doing the legal end of things. They are guiding the process and making sure the plan gets written and making sure all those things that have to happen with an IFSP and early intervention happens. They are the specialist, so they are involved. But we have these other two people who are involved as well.

Families meet a variety of professionals. We have one professional that leads the way for early intervention, which is a primary service provider. In our state we have that model which is routines based. And then in addition to that in the sixth visit we have other professionals coming in. We have a listening and spoken language specialist come in, a cued speech specialist come in, we have a American Sign Language specialist come in. We have Mindy come in, a Deaf adult. We have another Deaf adult come in and a parent come in.

Families through the guidance of that one person are meeting all these other people, but they are doing it in a way that is family centered, not in a way that they go to the School of the Deaf one day and the LSLS school one day. Everybody is coming through the home but in one process. Everybody gets the same supported message. I think what used to happen in Maine a lot, a family would go to one program and they would tell the family what they wanted the family to hear. And they would go to another family and they tell the family what they want them to hear.

But when you bring everybody together it's much more balanced.

The other thing that we found in this was by bringing all these people together, in a way that was meaningful, we were able to take away some of the bias. We were able to take away some of the cornering of parents that was happening in our state an happens everywhere. We built what we call a community of practice. All these providers now contract with the Maine educational center for the deaf and hard of hearing. Every one of them. The cued speech specialist, American Sign Language specialist, listening and spoken language specialist. They all contract with us and then we send them out. We have one group of professionals working with us instead of all these different camps, which has really been beautiful. We meet all the tile together. We have had Stephanie come to kind of kick start us a few years ago. She was there for our first meeting. She said you're putting all these people in a room together? I said I am, let's do it. We did it. It was very cool. Since then we meet all the time. We're seeing my staff from the school for the Deaf interacting with listening and spoken language specialists having lunch together. It doesn't happen often. Everybody has a perspective and something to bring to the table. The families want it all. They want as much as they can together. By bringing one team together it has been nice.

I'll ask Mindy to share ... want to share about that, Mindy? These are just some of the ways in Maine that we make sure, other ways that we make sure families have interactions with deaf and hard of hearing adults. I talked about the Deaf role models. Mindy does the toddler infant programmer with the IFSP, the service that happens for all families that want it, free of charge. She has ASL for families program that happens statewide through distance technology and also goes to homes as well.

The Deaf mentor perhaps, Hands & Voices events, Mindy mentioned those. Those have been magic, just magic. We had one a few weeks ago. We brought in this animal guy, he had snakes, birds and strange exotic animals. Somebody said bring the animal guy. We did that and put it out there on Facebook, sent out fliers. Our cafeteria, very, very big room, it was completely full of families and children and deaf and hard of hearing adults.

And I was probably one of the only ones in the room who said wow, that's a cuer, that's LSLS kid, that's a deaf and hard of hearing adult, nobody was talking about modalities. Everybody had access, CART, F.M., we had interpreters, we had it all. That piece was taken away. If you can take away the access, kids and families can just be kids and families. So that was cool.

How are we learning from parents? Consultants, I talked about our guides. We have parents coming to the infant program and talk about experiences. As Lisa talks about, we have parents on every board, everywhere, in Hands & Voices events. This is a picture from our conference last year. We have an annual conference. The parents love it. One thing that we did, every presentation had a parent and a professional. There was not one presentation that a P did alone. That was really powerful for the parents to see other parents up there and as Lisa talked about, that was great, but there was nothing done just by a professional. We had Deaf presenters as well.

What we've added is because a lot of the parents and a lot of the deaf and hard of hearing adults that we were bringing in had never worked in a home or never worked with other families, we wanted a really simple way to start. So we called this strength-based connections and started with something that anybody can talk about. But it is putting the family you are talking to in the driver's seat and you are asking them about their baby. You are not going in with your agenda. Tell me about your baby, tell me about your family. Who gives you support. What are your interests? What are your jobs? That seems sim I am, but for parents who have never been to homes, it was a guide, something to talk about. Parent to parent, they go off and they were talking about everything. Same with deaf and hard of hearing adults. This is something that is typical to everybody. What do you do? What are your hobbies? We see Deaf adults making connections with families because they about both like to ski, something like that. Take away the modality discussions and just talk about life.

These are our Deaf mentors who came to be Maine and trained our folks throughout the State.

Our two-pronged Deaf role moldings and the family training I talked about.

Mindy, can you talk briefly about parent and infant?

>> MELINDA MEYERS: I'll speak a little bit about our parent infant toddler program. So once parents decide that they want to join the group it occurs over eight weeks. We have one every quarter with a break in the wintertime because we want to be mindful of parents who have to drive in the weather and everything. So they meet for two and a half hours we are session. And so that's how our eight-week quarter system goes. Parents come to socialize with one another. The babies come so they can socialize and play with one another. Parents get an excellent opportunity to see their children communicating with other deaf and hard of hearing children. So after that two and a half hours, the play group is finished. They -- we then have an ASL class for parents who are interested. It is only a half hour class. It doesn't take long or take a lot of time but gives them an opportunity for them to increase their ASL skills.

So the parent, infant, toddler program consists of Deaf and hearing teams that work together. Rather than just kind of focusing on issues like, is the child learning sign language? What are they doing? We focus on how the babies are doing and parents can communicate kind of what stage they are in in their child's development. And what questions they may have. And this is great because parents may look at another parent and say: Oh, my gosh, you're going through a similar situation as me. Or it helped me. And deaf parents are also part of this team. It gives hearing parents a model to look at that is very beneficial for them.

When an EI professional or consultant comes to meet with the parents they will sit with them and ask them what their needs are. And we'll ask how can we help you, the parent? It is not up to me to decide what is best for their child. It is up to me to be able to match their needs.

So using Hands & Voices as an example, we post information on Facebook. The parents will see that and make connections on their own with information that we provide. They can share it with others, or you may ask a parent what did you do this summer? They'll say oh, I met with another family and we went to the beach together and hung out. We are noticing that parents are making their own connections because of that and that's nice.

>> KAREN: Thank you. Stephanie reminded me, she wanted me to tell you about a presentence preschool program. This is early intervention, but we have a bimodal preschool program in our school. Two classrooms, one is all in American Sign Language and the other the language of instruction is all in spoken language. There is a doorway between the two. The kids go back and forth. If families choose that program.

When we started that program there were lots of reasons why we did. We were hearing from families that they wanted more spoken language. The numbers were dwindling, like many schools for the Deaf. We were ready to close. The older kids programs, numbers getting smaller and smaller. We got together and said we have to add spoken language or we are going to shut down. We came up with the program, ensuring that access was given in both rooms. And that we had Deaf adults everywhere, Deaf consult adults that talked or signed. The ASL is all Deaf adults in there and Deaf children. We also have hearing children.

When we started to talk about this it became a real crisis, if you will, at our school. It was hard. We were a Deaf ASL school for the Deaf. All of a sudden we were talking about bringing in spoken language. So what we started to do is do a lot of training, a lot of talking, a lot of counseling amongst ourselves, supporting each other. It took us a few years to get to the point of this program. I would still say we will never be finished. It's an evolving program.

One thing I did with the Deaf staff who were struggling with it, especially with the spoken language room, I would set them up and explain what the teacher was going to be saying, what they were going to see. They would go in without an interpreter. The first time there was a Deaf man teacher who was very angry that we were adding this to our school. I said I want you to see the kids. Watch them go back and forth. He said you're not going to give me an interpreter? I said you always have access, but just for five minutes, I want you to just watch the kids.

So he went in. Sat in the back corner of the room and watched the kids float back and forth. And he said Karen, they are happy! I said you're right, they are happy. The kids were fine. They had access in both rooms. They were happy.

And for him that was a big aha moment. I think a lot of deaf and hard of hearing adults who had traumatic experiences growing up with speech therapy or not having good access, they weren't happy. For our Deaf community members who were adults they want to assure that kids are happy. They want to assure that kids make progress and have language and literacy. He saw that was happening.

So I encourage you to really look at kids' faces. Watch them. Watch their progress. Are they happy? If they are not happy, something is wrong.

And that's the same for early intervention all the way up. So make sure you are watching your kids.

I love this. It is Helen Keller. We can do so much if we all work together. If we work separately, we can't. Hopefully we can big one big community of practice together.

About the preschool program we are doing a presentation tomorrow on that if you are interested in learning more about how we set that up. But we can do a lot together.

I actually have to scoot out because I'm doing a 4:30 session on EHDI 101. But it is very nice to see you all. If you have questions, you can't catch me now, but you can catch me over the next few days. Thank you.

(Applause.)

>> We are going to pass out a logic medal for everybody. We are kind of running low on time. We were going to spend 20 minute on this. I think it is better if you take these home. Think about it. When you look at these logic medals, think about where you want to end up. Start at the end and work your way back. Use this as a map. Hopefully you are thinking about EHDI deaf and hard of hearing, adding EHDI deaf and hard of hearing people into your Hands & Voices system, the early involvement system. And we want you to share those ideas when you come back, how you are going to incorporate that.

Start with where you are looking as a long-term goal and before that, your impulses, your ideas, brainstorm with that one and then we will continue the presentations once that is all passed out.

>> LISA KOVACS: While we are passing these out, we would love some of your feedback about thinking about this logic model, thinking about who needs to be on your team. If you are in a state or territory that really needs to improve your deaf or hard of hearing involvement in your EHDI system. We would love to hear from you who you know think needs to be on that team to advocate to death deaf or hard of hearing adults involved in the EHDI system and what might you consider on your logic model? What steps might need to be taken. Any piece of that. Let's hear from a couple volunteers.

Come on, somebody.

>> AUDIENCE: I just want to -- whoops? Can you hear me? I think parents are critical. Parents are critical. There is a Senate Bill that is being presented again tomorrow, Senate Bill 206 presented and organized by parents. But on the Advisory Committee the parents got together, doctors, therapists, people from the state agencies, everyone that is important in trying to get hearing aids for children paid for by insurance.

But I think, I just found out it was tomorrow. I just want to say that all the legislation, I think that is going on now, all of it that I know of has been started by parents. I just can't say how important it was.

>> LISA KOVACS: Maybe my question was too big for some of you guys. Let's talk about who your stakeholders might be who might be good advocates in your EHDI system in order to improve deaf and hard of hearing involvement. Who might you seek out as stakeholders to begin to improve your deaf or hard of hearing involvement in your EHDI system?

>> AUDIENCE: I'm thinking West Virginia association for the deaf? West Virginia association for the deaf? That's West Virginia?

>> LISA KOVACS: Great, one stakeholder. Who might be other stakeholders who would be good advocates to help us?

I am reading lips. Parents? Okay, who else?

What was that? Just for CART?

>> Healthcare providers.

>> LISA KOVACS: Great. I saw a hand. Where was the hand? Yes?

>> AUDIENCE: I think the HLAA could be a great partner, depending on the area.

>> LISA KOVACS: Great. Anyone else?

School for the deaf? Early intervention? Great! So as you think about this logic model, going home and planning, we want to know that next year when we come back to EHDI, we have more Deaf mentor programs, more Deaf adults infused in EHDI systems. We want to see improvement. In three numbers we need to improve by 30 percent the number of families who are offered Deaf mentor services for their families. We have to go home and we have to do action.

The first step of action is, who do you need to add to your team? All right! I'm going to turn this over to Karen.

>> KAREN HOPKINS: Okay, everybody, we are in the home stretch. You can open your eyes now.

This is the part where I'm going to challenge you to go back home and take some action. The whole EHDI system is turning upside down to go out. What are the gaps in the services in your state? Start thinking about how we can make a difference, have a different perspective and bring the services to a whole new level. This is my family here. For 1sts we were upside down. Is the perfect picture for this. One of the biggest questions we get here at Hands & Voices is how can you possibly provide support without bias? We all have a bias, right? How in the world can we deliver services to the system without sharing that bias? Let me explain really quickly. When we think about bias, at Hands & Voices we have the definition of bias as you having an outcome for the family that may not be what the family wants. It may be an outcome that you personally are manipulating. That's when we start going into this bias thing.

Now, there are two little kids here. I mentioned the family. They are now 13. So it's quite awhile ago. This was when early intervention was still pretty much in the infancy. Deaf mentors were not around or a common thing in the system. And I was one of the early Deaf mentors.

Well, with this family, Byron David and Maya. Maya was born deaf and had other disabilities at the time. The mom wanted to explore cochlear implants. I don't have a cochlear implant. So how can a Deaf mentor help a family when they personally don't have the experience?

How do we not cross over into bias with that? Suppose I personally was against cochlear implants? How can I serve a family? We come across that all the time. And when you don't have experience, one of the things you can do is learn with the family, have a completely open mind with the family. And say you know what? I have very little experience with cochlear implants. Let's explore it together. You roll up your sleeves and you work with the family. And you find resources for them. And you go with them on visits. Maybe you support them on the day of the surgery. Those are different ways out of the box ways that deaf and hard of hearing adults or anyone in the system can support a family when you personally don't have the expertise or the knowledge or the experience.

Go in with an open mind and learn with the family. Help them find the resources they need to make decisions that they are comfortable with.

In that case with this family, that's exactly what we did. We learned together. And today they are doing very, very well, both kids. So that was just an example there that you can take back with you.

Don't discount any person on your team because of lack of experience or knowledge or where they are coming from.

As a Deaf mentor I'm always asked different questions by families. It's kind of funny sometimes where the questions come from or what the parents are thinking of. And one of the beautiful things about being a Deaf -- I prefer the word Deaf guide. I say that I was trained as a Deaf mentor but I prefer the words Deaf guide.

Often we bring a perspective that almost nobody else on the team has. They have access to stories that they team may not have.

And some of these questions come up, you know, can my child learn another language? I get that frequently from families where English is a second language in the home. Surprisingly, in the education system the typical feeling for families that English has to be first. That tends to be the message that families get especially with deaf and hard of hearing children. I do the opposite. I believe that whatever the language is in the home, parents own it. Expose your child to it. We have come up with different creative ways to do that with families where English is the second language in the home.

Another question, can my child ever fly a plane if they are deaf or hard of hearing? There are over 200 pilots out there who are deaf or hard of hearing. Yes, you can fly a plane. With the use of technology, we have one student learning to become a commercial pilot, has bilateral cochlear implants. We are breaking the barriers every day of what deaf and hard of hearing adults can do.

Can my child serve in the military? The answer is yes and no. We are working today to change that, but there are deaf and hard of hearing in the military in noncombat positions.

Can my child scuba dive? For some with implants, there may be restrictions. For others, another way of looking at it, you can have complete conversations under water.

Finally, can my child ... the answer is, let's find out. Explore with the family. If you don't know an answer, explore it together with the family. You do not have to come to a family knowing all the answers. And when you don't know them, pull in other people, resources in the community so you can find answers together.

One of my team questioned why we had a firefighter in an early intervention slide. And I have to laugh. There is a story behind this. In one of the parent connection meetings that we had, in Hands & Voices, a mom stood up and she said: Last night my child, before we went to bed, said to me "mom, I want to be a firefighter." the mom started to cry at that moment and she said I just looked at him and I nodded. But I know he can't be a firefighter.

She started bawling at that point. I looked at her and said why not? She looked at me like I had grown horns. The kid is hard of hearing. He has hearing aids. You can't be a firefighter if you are deaf or hard of hearing!

Why not? Turns out two towns over from where this mom lives is a full-time firefighter who uses ASL. So when I explained that to the mom, all of a sudden the whole paradigm of her child's future literally flipped 180 at that moment. That is the value of knowing deaf and hard of hearing adults in the EHDI system. Because when you know possibilities, you know hope for your child and for that family.

Now, this firefighter up here happens to be a second generation firefighter who is Deaf, who is also a fire chief in Pennsylvania. I want you to sit there for a minute and digest that. A fire chief. Doesn't that change everything that you have known about deaf and hard of hearing adults? All of a sudden when you work with a family that has this little baby, it's like whoa, wait a minute! That changes the whole paradigm of what we do in this system. There are Deaf pilots, Deaf engineers, there are Deaf doctors. You will be meeting a Deaf pediatrician who will be giving the keynote. Do not miss that keynote.

It changes the whole paradigm of this entire system. Okay? And I have another picture here of someone who is a Deaf doctor. There are over 200. There is actually an organization of deaf and hard of hearing doctors, pediatricians, nurses, dentists, pharmacists. Lee Woodruff is the wife of Bob Woodruff on who is an ABC reporter. They have a child who -- twins, actually. Twin girls. They were in London when she noticed one of her little girls just wasn't keeping up. Her twin was far ahead in language and everything. She wasn't responding.

Took her to the pediatrician and the pediatrician gave her the news: Your daughter is deaf. And so Lee said to herself: Deaf! Her first thought was, who is going to take a Deaf girl to the prom? That was her first thought when she held her baby going home. Over the years she met deaf and hard of hearing adults. She had heard through an EHDI system, and her child is now a teenager. And Lee wrote in her book -- I love this -- in the long ago days I saw a daughter with a disability. Now she sees a beautiful engaging daughter with a different ability, one that blessed her with extra gifts and special perception. So she shifted the whole paradigm and started to see the gifts of a different ability.

What about this final thought from a parent. I'm going to read it: What we really want and really need as parents is opportunities to contact other families with deaf children, help make regular contact with parents who are deaf and hard of hearing, information that is accurate, honest, unbiased and fair.

We kneeled early support from our early interventionists on make the decisions that are right for us and our child.

Now, I personally have three deaf and hard of hearing kids. And I think we skipped this slide here, didn't we? Yeah, I believe we did. Those two kids we didn't have early intervention. They were diagnosed when they were 2 and 4. With my third child, he was two and a half. I already had two deaf and hard of hearing kids. Two and a half years old, my child now, he passed the newborn hearing screening that we paid for. We thought okay, he's hearing. 2 and 1. Two and a half years old he was not developing speech, he was not using ASL. I began to think, oh, he may have autism. He was very, very, very shy, could not make eye contact with anyone.

So I thought to myself, no problem, a little early intervention will fix this kid right up. So get on the phone, I ordered some speech therapy services.

The speech therapist who was a mom of two Deaf kids arrived at the front door. And I'm sitting there playing with my son. She knocks on the door. I look up. He does not. She diagnosed him right through the front door.

(Laughter.)

>> KAREN HOPKINS: She signed to me and said he's Deaf. I'm like, you could have hit me over the head with a two-by-four. Hello! Five generations of deafness in my family, two kids that are deaf and hard of hearing and I still as a parent missed it in my own child.

And I may be the only parent in North America who has received a diagnosis from a front door.

(Laughter.)

>> KAREN HOPKIINS: So we are going to wrap this up. I want to share something with you. I just got this this morning, and it wasn't for me. It's from a parent who sent a text and I think this text is probably the most valuable things that you guys are going to take with you and walk out that door with because it is feedback from a parent.

The parent said: Eleven years ago you helped a scared mama get through some tough times of hearing loss diagnosis with a newborn son. Although it has been so long and we are miles apart I think of you often as inspiration. As a successful woman and mother. I'm just sending you my appreciation. I hope you know that you have touched my life and I'm sure many others.

This was a text from a mom sent to Stephanie this morning. I think it says more than anything about the powerful impact of deaf and hard of hearing adults in the EHDI system. So I hope that you guys today, I know you sat through three hours of a lot of stuff. But I hope you today walk out that door, go home, and make an impact on your system and your state, and touch many lives of parents with deaf and hard of hearing kids.

Thank you.

(Applause.)

>> KAREN HOPKINS: Thank you. We have time for some questions or comments if anybody has anything. Nan will bring the microphone and I speak for the rest of the team as well, I hope you take what you learned today back home and think about cohesiveness and collaboration and that we move forward in saving all the parents, the access to communication, all modalities equally.

Any questions or comments before we wrap up and get some fresh air?

>> LISA KOVACS: Anybody want a mic?

Come on, you have been here awhile. Okay.

>> AUDIENCE: I just want to thank you so much for this presentation. It is very eye opening to me as a parent guide. I really enjoyed listening to the collaboration of the Deaf role models along with the parent guides, the whole early intervention process that Karen expressed.

I really want to move forward in initiating that in my state. So thank you.

>> Any other comments or questions from the floor?

Okay!

>> AUDIENCE: I just wanted to say that I have been a witness to the power of having a Deaf adult professional be one of the first contacts for a newly identified family of a baby or toddler with hearing loss.

I am fortunate to work in a state where I am allowed to be one of the first contacts for newly identified families. And I am also fortunate to work in a state where I have families who have had the opportunity to -- to meet another Deaf professional at the hospital before they meet with me. They tell me that having met that Deaf professional at the hospital or even having met me first has really reassured them of knowing that everything will be okay. It is not the end of the world. And that there is support out there. And they can see that a lot of their fears have been or are going to be dispelled. Having seen us in person and so there is a lot of power in having Deaf adults on board with these new families.

>> Thank you. Another comment?

>> AUDIENCE: Hi, there. I can remember when our kids were first identified and I didn't know what Deaf looked like. My brother had a friend who was Deaf. He had a lot of behavior issues. This is back in the '70s.

And that was my picture. And so I sought out adults to have a conversation with them and in some of those same stories, it came up from them as well. And then I started getting involved with our state EHDI and I was one to come to the meeting, volunteer, all that.

I kept on saying where are the parents? And gosh, you know, today I'm sitting here and I'm listening to the stories and I'm seeing the examples of what is possible for parents and for Deaf adults. And for the families who are coming up through the system. You guys keep raising the bar. I want to appreciate all of your work and everybody here in the room as well because we keep raising the bar because it's our kids.

Anyway, thank you.

>> AUDIENCE: So this is my first EHDI conference. It has been very, very exciting. I'm actually brand new to this entire journey. So I have a ten month old son. He was identified about five months ago so this was really great to kind of hear what all can be beneficial to me. What you guys said is exactly how I feel. I know I'm going to go home and look for someone who is going to be able to help my young son and us. I see the important part is for us. So thank you.

(Voice cracking.)

>> Thank you. Any other questions? I think we are ... I thought that was a hand, okay.

All right! I want to thank you all for coming. I appreciate all your attention the last couple hours.

(Applause.)

(The session concluded at 4:30 p.m. EST.)

(CART provider signing off.)

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