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NCHAM
INTRODUCTION OF FAMILY SUPPORT/ROLE OF FAMILIES IN THE EHDI SYSTEM-(ADOBE 4.1)
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WILLIAM EISERMAN: Introduction of family support and the role of families in the EHDI system. We will be starting at the top of the hour in about eight minutes. For now get your volume adjusted to your liking using your headset or speaker volume adjustments and you should be set to go. once again you are in the right place for today's webinar that will be starting in just a few minutes. Today's webinar is entitled introduction a family support and the role of families in the EHDI system. We are going to get started here in just a few minutes.

And yes, that is my fan in the background, which I will turn off. That must be better. I'm sorry about that. It is summertime. [Laughter]

Janet, are you still with me?

JANET DESGEORGES: This is Janet. I am here and ready to go.

WILLIAM EISERMAN: excellent, thank you. Yes if only fans had a mute button, but they don't. [Laughter] it's all good.

While you get adjusted and settled in for today's webinar, be aware that today's webinar is going to be recorded and posted on infant hearing.org in the next couple of days. So if you think of others that are joining us live today that would benefit from today's webinar, be aware that they can access it on our website in just a couple days and of course you can also go back and review it yourself if you need a second run. Through it. We all like hearing Janet speak. So a second run is very likely.

While we get ready for today's webinar if you would take just a moment to tell us what perspective you bring to today's webinar. You may need to scroll down to find the role that best fits you. And you have to pick just one. So think of what is the primary role that brings you to today's webinar. It's always nice for our speakers to have an idea of who is out there. So thank you for responding to that. And we will just get started here in just a minute or two. All right. I'm going to initiate recording of the meeting and we will get started.

[Audio recording for this meeting has begun.]

WILLIAM EISERMAN: good morning everyone I would like to welcome you to today's webinar, which is a learning series for newcomers to the early hearing detection and intervention or EHDI system. My name is Will Eiserman and I'm the Associate Director for the National Center for Hearing Assessment and Management also known as NCHAM at Utah State University. NCHAM serves as the national technical resource Center sometimes referred to as the NTRC for EHDI providing opportunities like this one for you to learn more about different aspects of the EHDI system and implementing EHDI that might enhance the outcomes for children and families.

Today's session is one of four that will review some basic information about key components of the EHDI system with a key eye on newcomers to EHDI. Across the four sessions you will have the opportunity to learn about the history of EHDI including the EHDI act of 2017 that establishes EHDI as a national system and the key components of the EHDI system and the various stakeholders and funders. In a session that was provided yesterday as a part of this series and that will be available for viewing in the next couple of days on infant hearing.org, we had an interesting to audiology for non-audiologists, within and supporting the EHDI system so you can find that on infant hearing.org anytime.

The third session in the series will focus on the mos recent developments to expand the focus of EHDI to include the identification of children up to three years of age, and today's session will be an introduction to family support and the role of families in the EHDI system and before we get started I just want to give a shout out to our captioner here, thank you for your services today. That's a real person who is doing our captioning for us today and we so much appreciate the talent and time devoted to that so that we can make our learning opportunities like this one as accessible as possible.

Once our presenter has wrapped up her comments for today I will open up a Q&A box into which you can type in your questions or comments for her to respond to, and she most likely will. So without any further delay I would like to introduce to you Janet DesGeorges from hands and voices.

JANET DESGEORGES: hello everyone it's a thrill for me to be here with you today to talk about one of my favorite topics. As part of getting acquainted with the EHDI system for those of you new to working in this field one of the topics you will often hear referenced is the idea of family engagement, family support, and the role of families in the EHDI system.

If you are coming from another health, part of the health system and are new to EHDI as well I want you to know out the gate we are really proud of the meaningful involvement of families in the both development, implementation and evaluation of the EHDI system so that is what we are going to be exploring today.

If you think about the definitions themselves you may be sitting there thinking anything, definition anything is sort of like a passive recipient, like you know, compliance with recommended treatment. You might have heard that in the patient world. Although way to parents ruling the EHDI system world. All right I'm sure none of you thought of that as a definition. That's mine, but let's explore this today.

As we get started let me give you a little context about who I am and the organization that I'm a part of. my husband Joe and I are the proud parents of three daughters all now young adults. Our younger daughter Sarah is deaf hard of hearing. She is the reason I came into this story and purpose in my own life. I am a cofounder and the executive director of hands and voices. We are a parent driven organization that is dedicated to the support and advocacy and providing resources to families who have children who are deaf and hard of hearing. Our motto is what works for your child is what makes the choice right. I'm going to pause here in this presentation in talking about families, and talk about one of the main pillars of who we are at hands and voices in terms of our belief that families are in the best position to identify and help coach their children who are deaf or hard of hearing through their life's journey whether it is decisions we have to make regarding language and communication modality to education placement, to our own child's sense of identity of who they are as a deaf or hard of hearing person, that is our role and responsibility as parents.

Of course, in another presentation if I were able to talk about this longer we would talk about the evolution of the transition of the decision-making process for our deaf and hard of hearing children as they move and grow in making the decisions that are best for them.

But that is a little bit of who we are. You can see a map here. If you go to hands and voices.org you can check on your state and see where our chapters are. I'm going to expand the conversation a little bit and talk about one of the programs we have at hands and voices called the family leadership in language and learning. Our motto there is where love, language and learning thrive.

I want to share four-minute a little bit about the FL3 center, family leadership language and learning. The goal of the center is to increase family engagement and leadership, to support families in EHDI and think about the outcome of that which is to optimize the language, literacy, cognitive social and emotional development of our children who are deaf or hard of hearing. So you can see today's conversation that I will be sharing with you is right in the wheelhouse of what we do at hands and voices and particular at the FL3 center in terms of providing technical assistance, education and training opportunities around family engagement and support. We have a goal to increase the number of parents who are participating in the EHDI systems or training opportunities. We have an objective that we are working on in terms of ensuring that there is diversity and inclusion of families from underrepresented populations.

And as well, to make sure that resources that are developed for families don't just get put on a shelf and never used but to make sure they are out there being utilized by families.

So the goals for the session today, I'm going to start with a story and end with a story. I may have some stories in between. In fact, as you are thinking about your role here in the EHDI system and thinking about getting input and feedback from family is one of the most powerful ways you can think about whether the system is working or not is through the power of stories to invite families to share their stories. Do invite families who are currently going through the system and find out how things are working for them.

In fact if you had heard me speak on this topic20 years ago I would probably open with the same comment. Which is systems can be created, processes through bureaucratic organizational political and even collaborative processes between institutions you can create a system for a family. But unless the system works from the families perspective, then I would argue that that system is not successful. So as you think about the goals of the EHDI system being screening by one month, identification by three months and entry into early intervention by six months, those pillars of measurement in terms of being able to sit back and say we have successfully accomplished that, are only true if at the end those are the foundational pieces that help the family create a successful journey for their child. And I will tell you a little bit more about that. In the stories that I tell.

I'm going to share just a little bit of theory and data. We will describe five areas of support that families should have available to them as they move through the one, three, six system. We will look at the strategies of incorporating family engagement at three levels. I'm going to close with a case study that is a true story of a family I know that I often think of when I think of now that is how the EHDI some should work. And then I will leave some time for questions and comments from the audience.

So let's start with the story. I am as I mentioned I'm the mother of a daughter who is deaf/hard of hearing I often tell stories of the very beginning of our story and end with some great summary moments in our lives and as a family in terms of thinking about the success of our daughter and what led to that in her life. But actually today I'm going to just share a little bit of a middle-of-the-road story. You're going to say what does this have to do with EHDI. Just stick with me four-minute. Actually yesterday I was... On the Internet and I found the link of a young man who was telling his story. He is deaf. He was talking about in middle school when he left his families home and a mainstream educational setting and went to the first time to a deaf school. He tells a very powerful story of for the first time in his life having some access to some communication that prior to this in his life he had not and one of his stories was the amazement at realizing that televisions had close captioning. He loves movies and TV and this was something that transport his life in a very short period of time.

As he moved, as he went home one weekend back with his family he asked his mom could they please turn on the closed captioning. And she said no. And he didn't go into a lot of why she said no, but as I was sitting and reflecting on that I was kind of shocked. I was like wait what? why wouldn't she? but rather than thinking in a judgmental way about this particular mom, I began to think about my own life experience and what led to me as a hearing person the empowerment of understanding the life journey of my child who is deaf or hard of hearing. I thought about some of the advocacy and empowerment I felt as a parent going into the school system and talking about accessibility for my daughter. From the time she woke up in the morning till when she went to bed at night. So it was not school services, it was me understanding that captioning was going to be something as a part of our hearing families life with a deaf child. That my daughter needed to learn to wake herself up in the morning just like my hearing daughters who had hearing alarms, she needed a vibrating shaker alarm.

All of the idea that in our family we would not have a rule that, we would say never say never mind. If one of my daughters strategy to get communication was to say what did you say? And I was thinking about where the empowerment, where that came from for me as a parent it came from the foundational experiences when our daughter was first identified. And if we think that the EHDI system of making sure babies are screened identified and entered into early intervention is a marker success, I want you to know they are, those are all evidence-based moments in a family's journey life. But it has to lead to something. It has to lead to the ability of families to understand this unique journey. To be able to make good decisions for our kids so that they have access, they have strong language, they have good self-identity, self-esteem, that they have, are surrounded by the ability to make friends towards a successful life.

And so as we think about family engagement today remember it is not just the experience of the mom who will talk about the screening results and the hospital room. That families talk about over and over that they did not follow up after their baby failed a screen because the only thing they really remembered was someone saying to them it's probably just fluid in the ears.

I have thought, for those of you who have not yet been to the national EHDI conference it's a fantastic opportunity toa and I jokingly told other parents before, we should all make T-shirts that say on the T-shirt I was told it was just fluid in the ears or it turned out it was not just fluid in the ears. Listen I know that these systems and how we help families through them can be complex. But it is really important that we get this right because it really is the foundational, the foundation for what is to come in a family's journey in raising their child successfully.

Let's move through it now and think about some of the theory behind family engagement. It's pretty simple. It's not brain science. But when I came across this idea in and theory about coproduction I really liked it.

Coproduction can be viewed as not viewed, as a product delivered but better conceived as a service. Services are always co-perceived as by service professionals and service users. In terms of thinking about, when I talked about in the beginning getting to a system that really works for families is through the critical engagement of the families at tables where decisions are being made. If you think about not just the ability to... In this introductory talk I just want, I'm stumbling here because there's a lot of content here that can be explored. I encourage you to go look at the hands and voices website. We have all kinds of webinars on the topic. In fact we did a whole presentation on coproduction theory. But just to say that it's really important that we think about including families in the development of a system, meaningfully integrated so we are not just responding or reacting to it.

I recently heard a family talk about being asked to review a letter that was going to be sent out to families around failing the newborn hearing screening. And she remarked to me, I really wish that they had included the parent support in the development of this from the outset, rather than having to go in and react and respond to a letter that just had so many triggers for me as a parent right out the gate. I know we can do better than this and I'm happy to respond and give input after the fact. But ultimately if we as collaborators and parents and professionals and deaf and hard of hearing adults collaborate with perspectives from the beginning of the aspects of the system it will be a better system for family.

Thinking about, I wanted to share this slide with you, but really what I want you to do is click on the link and go to the FL3 national needs assessment we developed in 2018. There's all kinds of rich information that will help you understand where we are at currently in the system and where we are making progress towards. But in 2018 when families were asked what types of support they received , so now we are thinking about families who are going through the EHDI system did they receive this information or not, you can just look at this chart. And I would say that the fact that there are only three items here that even make the 50% mark is we all have better, more work to do. Down the left side of the column are some of the supports that families receive getting connected to early intervention, offer to participate in parent activities connected with other families and the list goes down. Help getting a hearing test. If only 34% of the families are reporting that, we know that even in thinking about how can we better support families any EHDI system we all have some work to do. Look down at the bottom of the list. Families help getting connected to a deaf or hard of hearing role model and I will talk about that in a minute when we talk about where families need to get their support from.

In fact here we are. Let's think for a minute about where families get the support that they need. When we think about support it is, there's different ways to kind of look at what supports are needed, but in general families thinking about comprehensive information about language and communication choices, information about, that the information needs to come from coordinated, trusted support and resources. That families need to get that from other families so let's look at these areas.

Families in a really good system you would say that families would move through the early intervention, the early days by ensuring that there's touch points in all these areas.

Up on the far left parent to parent support. Hands and voices in the FL3 center I shared with you at the beginning a map of our hands and voices chapter. If you go to the FL3 section of the website and scroll to support for families there are all kinds of family-based organizations that provide support to families and there is a really comprehensive list behind the chapters that we support and also learn from any EHDI system beyond the hands and voices chapters. It's really important for families to be able to get connected to parent to parent support. I had a dad one day call here at the hands and voices office, and he had a question, he had two twin sons, baby boys, that one of his sons had just been through the diagnostic process and he called our parent support organization because he did not trust the equipment that had been used. So I was able to talk a little bit but one of the things we as parents, parent to parent support providers do is get families to other places on the mechanism of who can answer best the questions that get asked of us. And so I was talking to him a little bit. I was actually, my office space was shared with some other professionals who I could quickly say, who can I get this dad connected to to talk to an audiologist who can maybe talk through the technological aspects of the equipment. It was a little bit out of my wheelhouse of knowledge. So I was connecting him to other places and spaces on this chart. We were chatting. I was kind of wrapping things up and there was a pause and he said well... You know in his voice kind of cracked and he said you know what I really want to know is will my son be able to play soccer. He was thinking about the context of the hearing person of what we take for granted in our world and our lives and begin to wonder how would that work for a deaf person. Those are some of the early questions we as parents struggle with. And I jokingly want to say to the dad, well you know it depends on your genetic makeup. Are you athletic? because having been a parent of course deaf kids can play soccer but I understood where the dad was at. I understood that what he was trying to make context to was living in a hearing world and how that would be adapted or what we could do. So I talked and shared with him a lot of stories about families of DEF hard of hearing kids and all kinds of sports and athletics, of athletes who had been to the Olympics and I was able to answer the questions at that moment but there's something a parent support and connections that we often say when you're in a trusting safe space it's the first place you can start asking the questions you are afraid to ask.

Moving to where families find support, adults who are deaf or hard of hearing. I will always start this conversation when I talk about the role of deaf and hard of hearing adults in the lives of families who are deaf/hard of hearing I always say my daughter would not be where she is today without the influence and input of deaf and hard of hearing adults with the lived experience of this and their impact on my life as a parent in terms of making good decisions for my daughter. When I say me making decisions I would like to stop here and acknowledge that my husband had a little something to do with this. We as parents are finding our way in terms of making decisions but I can't even begin to describe what it means to be able to meet a deaf or hard of hearing adult that somehow is able to touch your soul at the beginning of the experience, to look beyond the often narrow path of the medical part of this and begin to expand the holistic nature of being deaf as a positive thing. So that is really important for families and the EHDI system has and continues to build supports in place so that families have access to adults who are deaf or hard of hearing.

Obviously in the bottom right corner here professionals thinking about, these are often the individuals that the family first encounters hospital experience or the homebirth experience being screened diagnostic into early intervention. I will tell you I often call early intervention provider the lifeline in the first year of my daughter's identification and her ability and knowledge and being able to understand that besides just her professional point of view. She put me in the position to meet other deaf adults, to meet other parents.

And also in terms of her support, and being able to go through the process of decision-making around communication. It is not a one-time one moment decision for us as parents, in terms of making good decisions for our kids, for technology, communication, the use of visual and auditory inputs. That professional is so important in our family's life.

You will see at the bottom, families also come to the EHDI system not as a blank slate. They come into this already with existing communities, family, friends, neighborhoods, places of worship. Those are important spaces and places that families also, where they have been receiving support, continue that. And also families are often the conduit back to existing communities with the information they are learning about deafness. And then of course families get information and support through websites, apps, videos. You can see the list there.

It is funny because sometimes there's some conversations and systems about what I would consider gatekeeping of information. I know that sounds negative. I don't necessarily mean that in a negative way. It can be. But I think the professionals often have good radar about how much information to give families or not. Especially in the beginning if families are overwhelmed. I always say if you don't know how much information to give a family, ask them do you want more information? Is this too much information?

Do not make assumptions about the amount of information given to your families. In fact if you correlate the amount of information to emotional steadiness, I can tell you that some of the information that was given to me helped me get through the emotional state of being. So there is no magic bullet about how much or how little information to get families. It is individualized and I think the best ways to ask families, do you need more information, you want more information, how would you like the information delivered? you can see just through this graph when we as a system give some time and attention to make sure the families are supported from all of these entities, we are going to be creating a really good system of support.

Now let's just move to a different chart for a couple minutes. Thinking about family engagement, or family, the role of families. It is funny because you may find yourself in a situation where you are discussing this as a committee and maybe there hasn't been real clarity about what we are talking about here when we talk about family involvement. Are we talking about the recipient of the system that in terms of parents for their own child. Parents, the core and the center of the successful journey is parents lead center involved and directed for their own child. We know the statistics are true. You can look at the statistics and education. The number one indicator of successful outcomes in education is the direct involvement of parents. We understand that you can build a system that has all the components in place for the family to get through them with quality support, in a timely manner all the JCIH recommended things but at the end of the day parent engagement and involvement in their own child is going to be the number one indicator toward success.

As you go out of the circle often families, as they have moved through their own family they begin to understand and know the power of parent to parent for each other. I know there are a few parents on the call today who are actually here as part of the system to provide parent to parent support for each other. We know that families can often be engaged in the direct support. And in the outer circle thinking about parent participation through advocacy in the system. This is where you as newbies any EHDI system may begin to interact on committees or learning communities and begin to be in touch with families who are there as part of collaborators in the system back to the coproduction theory. So remember there are different layers and levels of parent engagement.

Now I am going to kind of end with a story here and we will open it up to questions and answers if you want.

I sometimes call this the story of the EHDI story in a perfect world. There was components of the story there were organized and planned to the system and some just through fate or destiny. This is the story of Michael and Eva they gave me permission to share their story at one point a long time ago. I should check in with them and see how they are doing. I did hear from them a couple years ago. They are doing great. Anyway there baby was born, screened right away, failed the newborn hearing screening before they left the hospital they were given appointments for diagnostic follow-up within two weeks. They had the diagnostic follow-up. They went. There son was identified with a hearing loss. Michael and, Michael went back to his job that day and Eva, the mom went home and Michael happen to be working in a company where there was a dad there who was part of Hans invoices. He could see that Michael was really upset and they chatted for a few minutes and he gave Michael the phone number for Hans invoices. Michael called our offices that they, the day of identification and we had a wonderful conversation that they and he had some immediate questions and we were able to get him some resources and information.

One comment he made is, you know my wife is really taking this differently than I am. She is really, she seems to be in real denial. And it was interesting because supporting that and thinking about, and that is again the process and evolution for families to come to terms with this, to accept the diagnosis, to begin to embrace the journey is a journey of joy. We are all present in that day. I did not see it, interesting in the story was the opportunity at an audiology clinic where there was parent to parent support in the audiology office, I did not see them for about a month but all of a sudden when we were doing some parent to parent support, the audiology clinic I was working with understood the holistic nature of this that it was not just a medical experience but they wanted to ensure that his family was going through a multidisciplinary clinic they had opportunity to meet another parity and a deaf hard of hearing adult. Michael and Eva came walking through the door with the baby and I could see the demeanor in their body language. They were parents of a living, a joyful experience of having a new baby. It was so different in just a one-month period of time. Just their sense already of what it is, they had gone through the systems faster than one, three, six. And they said you know what, and they talked a little bit about being connected to early intervention. He was already in early intervention and he said you know what, you know the moment in this past month where we knew that Ben would be okay? and I can tell you internally I was saying Lisa Hans invoices and say when you talk to another parent. He said the service coordinator came into their home to talk about the services in the state and she was deaf. She was a deaf professional. And he said once we interacted with her and she was not there as a quote role model she does happen to be integrated into the system with EHDI and was deaf herself and she said when we saw and met and talked with her and saw who she was, we knew Ben was going to be okay. I love that story, the family met the timelines. They were integrated into making sure that through kismet and through the system they had access to deaf or hard of hearing adults. They had access to another parent. They were getting the information and resources that they need. They came to a medical facility where that facilities systemically had created also the opportunity for the holistic aspect of the experience to take place. Wherever you are at, in whatever state or territory, whatever, if you are new to this you will be learning, unfolding how things work. I would just challenge and ask you today to always keep in mind the family's story, to keep in mind what can I as a professional or other deaf or other hard of hearing person do to ensure the integrity of the system so that at the end of the day families emerge out of this foundational experience understanding the nature of access needs of our kids. Understanding the social and emotional component. Understanding the ability to let go as a parent and let our children lead the way as they grow. There is so much we can do in the EHDI system to create a foundational experience through personal interaction of well-trained qualified professionals through access to deaf and hard of hearing adults, through access to the parent to parent connections. It is a system that I think we are doing a really good job at. There's room for improvement. Wherever you are at in the system I just want to thank you for... You being here. I hope that you never leave the system and I hope that you are always here for the right reasons.

So here are some resources that are available. And I'm going to go ahead and stop now. And William is going to open up the Q&A and I will take a shot at answering any of your questions. Thank you.

WILLIAM EISERMAN: thank you Janet. I have open up the Q&A on the left and if you have anything in mind you can type it there. We have a couple to begin with. Janet, you described your daughter as deaf/ hard of hearing can you clarify what you mean by using both terms for your daughter? it seems that not everyone may be using those terms in exactly the same way.

JANET DESGEORGES: this is Janet. This is a great question. I love the question. I think I have written some articles on the question. The reason I referred to my daughter as deaf/ and hard of hearing is that is how she identifies herself , and that is how she labels herself. And over the years as a parent, in the beginning I used a different terminology to describe Sarah at different times and in different contexts. Audiologically she's moderately [indiscernible] I would say she's halfway deaf in her right ear small the deaf and big D Deaf, if you're not familiar with that type of terminology, I encourage you to go to some good deaf community resources who have different articles and things. Typically capital D Deaf refers to members of those who self identify as part of Deaf community and culture.

So in terms of why I call my daughter certain words over the years, deaf or hard of hearing depended on the circumstance honestly. Sometimes in advocacy and education I would use terminology because we would tend to get, sort of people who do not know the experience because they think a child can speak or articulate the S sounds and think they are receiving all the information and almost dismiss sometimes kids with mild unilateral or moderate hearing loss as if they don't have needs. So we have used different terminology.

But from a pretty young age, our daughter used different words for herself. There were times when she considered herself a D Deaf individual, other times hard of hearing. I always like to say sometimes we call her deaf. Sometimes we call her hard of hearing but most of the time we just call her Sarah.

WILLIAM EISERMAN: the next question read thank you, Janet, this is Tarrant [guy] from Minnesota and I was wondering if you have points to offer to give new audiologists or ENTs to buy into the family support system

JANET DESGEORGES: this is Janet. Another good question. Next question? [laughter] just kidding. I think it depends on the context in terms of influencing systems, stakeholders and understanding the importance of the parent to parent connection. You do it through a variety of ways. Talking about it, talking about the power that it has held in your own life. Also being a parent to parent support organization that follows through and says what, does what they say they are going to do becomes an organization of trust, a follow-through for us at Hans and voices. That word would get back to the professionals that might be hesitating to give, to hand off the referral to hand-to-hand support and words get back that parents were supported well, that they were supported to their own unique needs and desire for information. And I think that is one of the things that overtime build trust. Also then it is not just about whether the professional trust, the parent groups or parent organizations but sometimes there is some work for us as parents to help professionals understand that we are not there to take their place. We are not there to do the work of early intervention providers or do the work of audiologists. There are some times when there is crossover support that happens but to just keep saying that out loud and again that we are not here to replace you. In fact most of us as parents really value the work that professionals held in our own children's success stories. Sometimes professionals are part of challenging part of the stories but nevertheless we need to just keep talking about. There's also some good, there's some really good outcome and research now that shows about the impact of parent to parent support, components and so I think we can do it through data, through story, through just being there, through follow-through. I just I don't know what else to say except that it is both a short-term and a long-term game, knocking, you know what I'm saying. And ever to ensure that the system stakeholders truly value and understand that as important as it is to make sure a baby is screened correctly, just as importantly is the parent to parent component in the system I would argue.

WILLIAM EISERMAN: the next question is circling back again to terminology. This question is, this is actually a combination of two questions. Isn't it incorrect to use the term hearing-impaired and can you also clarify, is hard of hearing typically referring to a lesser hearing ability than the term deaf?

JANET DESGEORGES: this is Janet, yeah, so hearing-impaired, I was in a meeting once where somebody called it hearing disability. There's some individualized, I talk a little bit about my own daughters preference for words. But I would say that there's some terminology the changes over time. But I think we need to listen to a broad audience of people in terms of saying hearing-impaired is a typical example. There's definitely a negative connotation I think of the word impaired. I personally do not use the term hearing-impaired what I'm talking about the deaf/hard of hearing experience. I know there are some people who do not use hard of hearing. They prefer every category of deafness around the ability to hear or hearing not would just be called deaf. But hard of hearing is something that I use, but I would say in general the answer to the first question, hearing-impaired is typically a word that I would say systemically is a word we are moving away from. I think that or hard of hearing is better I think again it's always better to ask families their preference.

Let me say this. Defying me to family and they have a newly identified child, and they are using terminology hearing-impaired I'm not going to go start wordsmithing or correcting them. I figure that is an evolution. I might model word usage. I don't think we should go out and start wordsmithing parents vocabularies that they are using, I think that typically evolves over time and an understanding of that. But then to answer the second part of your question, if you are not an audiologist ask an audiologist. They are really good at describing degrees of hearing loss but yes in general hard of hearing is typically when you're thinking about it from an audiological point of view people often call kids with up to mild moderate hard of hearing and be on that, deaf. But let me tell you when I as a parent talk about evolution of thought I wanted to keep meeting deaf people who had my daughter's degree of hearing loss in the beginning. And there were a lot of deaf adults that had my daughter's audiogram that describes themselves as deaf. D Deaf. So I don't think you can describe or automatically categorize word usage with for instance are of the audiological perspective but you will get different perspectives a new thing, in the EHDI system is a great thing to ask the question to other stakeholders and asked deaf or hard of hearing adults about the perspective about word usage, ask other professionals you work with about word usage.

WILLIAM EISERMAN: the next question is a natural for the next question and it reads the largest group of children identified by the EHDI system have mild or moderate hearing loss. How does family support as well as family engagement differ depending on the type or degree of hearing loss of a given child?

JANET DESGEORGES: to think that depending on the degree of hearing loss a child has is in some ways an entrée card or not to whether or not families should be involved, and I'm not responding directly how this question was asked... I'm processing the thought here in terms of, I'm thinking a little bit about parent to parent support over the years, as we have had events and families come walking through the door and I can't tell you how many times I have met families who have kids with unilateral mild hearing loss that will begin the conversation or the meeting with, I'm not sure this meeting is for me. I'm not sure whether I should be here. My child only has blank. Degree of hearing loss, even in the research in terms of impact, of emotional response when families find out they have a deaf or hard of hearing children the intensity of the emotional experience, the research has shown that's true for kids with unilateral, all the way to profound. So, and thinking about families involvement and engagement in the EHDI system we want to make sure that when we talk about diversity and inclusion we should make sure that not just according to statistics, but that the voice of families who have kids with unilateral and mild and moderate hearing loss, while their needs may be uniquely different from kids with profound hearing loss, your question is exactly targeting the diversity of our system. It needs to work for families regardless of degree of hearing loss. And so... I think we actually do need to do a better job in terms of looking around the room when we have families who are representing other families to say do we have a good diversity of families that have kids with unilateral all the way to profound? because I just think that creates a nice, a nice diversity within EHDI system and parent voice.

I will say that as parent representatives and parent leadership, development, one of our goals at the FL3 Center is to ensure that families who are representing families because there's no way you can have it repaired and every experience at the table but what we have to do as parents is be able to have the stories of other families in our hearts that we have the ability to represent all families across that, so while I may not be able to explicitly be able to tell you what it feels like to have a child with unilateral hearing loss, I have met hundreds of families with kids with unilateral hearing loss and I know, I know that our stories are both similar and unique.

So I think it is important for us make sure that we have broad spectrum of family stories involved in the EHDI system as well as family leaders who can represent not their own, not just their own life experience but those of all families across all degrees of hearing loss.

WILLIAM EISERMAN: thinking about diversity the next question is can you talk about serving different cultures and the need for cultural humility and the difference in how parents may respond to their child's diagnosis?

JANET DESGEORGES: it is both similar and unique. There's something about the experience of deafness as an anchor across cultures I'm actually part of a parent group, and international parent group with families from 28 countries around the world, and I can't tell you about this experience of sitting with a family from Africa or India or Croatia where there's some sort of boundary of all of us being in a similar culture together and that we share a common experience of deafness.

I wanted to start by saying that now let's talk a little bit about what your question is, which there are some unique aspects to culture, diversity of language from underrepresented populations that are unique, and our system should be giving some unique considerations and supports and services to. It is an area of work we need to do in the EHDI system and in fact we are really thrilled that hands and voice is part of the FL3 project over the next three years is to create a diversity and inclusion plan to share with state EHDI systems and other parent support organizations to create meaningful goals and objectives where we can as a systems this is where and how the unique cultural aspects of the process are incorporated into the system.

So an example of that would be a family who might come from a culture where disability is seen as a curse. And so you have to think about how does a family who might come from that cultural aspect move into a positive framework of the deafness experience. I heard this great story once at a conference once at the school for the deaf where I was struggling to get Spanish-speaking families meaningfully integrated into the deaf culture experience. And they talked about how the group of Spanish-speaking families could come to the school and do an evening of celebrating their culture, their Spanish culture, their food, their language, their dance, rather than trying to convince a Spanish-speaking family that they needed to embrace deaf culture and community. They, the school embrace the culture of that family. And once the bridge was established, the families that had come from there, that had struggle with deafness is kind of a positive force were able to sort of move in a space of trust toward then beginning to understand deafness as its own culture and community. That is one example but it goes across not just modalities, but the experiences of families who are Spanish-speaking who are going to audiology appointments and making sure that they have good accessibility that... The foreign language translators are translating or interpreting the true information that is coming and not making subjective decisions about what families should hear or not. I think that there's training on our side as parent to parent supporters and professionals in the system to engage and learn more and when you talk about cultural humility.

We are actually in the process of hiring a consultant here who has the lived experience of this because I'm probably not the best person to talk about it, but as a person in the system that wants to grow and build supports for families, yeah, I think it is definitely important.

WILLIAM EISERMAN: the next question is during times like this with Covid, families can't necessarily connect with other families or deaf adults in particular it's not ideal but do you know of any video recording available online of a panel discussion for example with deaf adults sharing their own experiences?

JANET DESGEORGES: this is Janet. Yeah. It is a great question and first of all I want to send you to a document that is on our website... I want to say it's on the front page but we may have moved it. You can certainly email me and ask for it. It is a systemic, it is a guide book for systems to look at how to meaningfully integrate and create opportunity for families to connect to deaf and hard of hearing adults. One of the areas is through videos. In fact I think sometimes parents will report they are a little nervous about meeting a deaf or hard of hearing adult for the first time so sometimes watching a video helps them through sort of the initial nervousness. And at hands and voices we have a beautiful collection of videos done by a wide variety of deaf and hard of hearing adults. You can find that on the FL3 website. If you go to the hands and voices.org and click on FL three, there's a whole section on their exploring deaf and hard of hearing adults. There is all kinds of videos, stories and things like that. I'm sure there's other organizations as well. I know there's... I think it is a hands and voices chapter out of Canada actually that has just recently put together a fantastic montage of deaf and hard of hearing role models. Possibly in your state, in your school for the deaf there may be deaf and hard of hearing role model programs that incorporate the use of videos as well. I don't, some states have skyhigh role model programs. They may utilize videos as well.

WILLIAM EISERMAN: two more questions then we will wrap it up. Thank you everybody for all the excellent questions and Janet, for your amazing responses. The next question is, I loved your story about Eva and Michael meeting a deaf service coordinator and being so inspired. To be honest, our experience meeting a deaf adult was supposed to have that effect, but the adult we were introduced to was struggling kind of angry about their experiences and left us worried, more worried than we were before. How can we support the potential of meeting deaf adults without having this experience repeated?

JANET DESGEORGES: I... Could replace the term deaf/ and hard of hearing adult experience also with the parent to parent support experience. I would argue both for parent to parent support and deaf/ hard of hearing adult to parent support in a system that there are some qualitative elements of good experiences. So we are huge believers at hands and voices the parent to parent support and deaf and hard of hearing to parent support, in order to be effective requires some training, oversight, peer to peer interaction. For me I really began to grow in my ability to provide unbiased parent to parent support by being able to have access to interaction with other parents who are providing parent to parent support. So at hands in voices we have the [side-by-side] program those are parents trained and essential elements of providing effective support. We have a deaf or hard of hearing component in the by your side program where the deaf/ art of hearing guides go through the same training in order to be able to support families unfortunately... I think in the old days honestly professionals new a couple parents or new a couple of deaf people. They would write down their number and say here you can talk to them. Sometimes that's a good experience and sometimes in your case for example not so much. I personally also had that experience in the early days of a little bit of hit and miss in terms of the deaf individuals I encountered. Overall it was really positive but I think it is important for us. This is when we talk about systemic influence and impact.

So the component appeared to parent support can kind of happen organically or naturally but what we want to do is create a system so that the integrity and the quality of that support is integrated and has standards attached to it. So I think deaf/ hard of hearing, if we are going to connect families who are initially going through the one, three, six EHDI system with deaf and hard of hearing adult and I will argue the same with other parents, there should be some element of trust and support that the parents and deaf and hard of hearing supports have some basic training. And also are emotionally in a space themselves to provide support. Listen, there have been times in my life as a parent, when I was personally going through, I do not think I would have been the best person to talk to another. At the time because it probably would have been no way for me to pull away from my own experience. So that feels a little bit about how you are describing. So trained... Ready and prepared guides, whether they are parents or deaf and hard of hearing, whether they are part of hands and voices or another organization, I would argue that there's some qualitative standards that should be in place so that the interaction is effective.

And let me tell you for whoever asked this question, if that was your experience, move yourself to other experiences where you will, and maybe you have already, where you will begin to also have the opportunities for some positive experiences so that over time your own understanding of the, or expansive this will be filtered not from one experience but through many experiences that yes I had a bad experience with this, but that I met 10 other deaf or hard of hearing adults who supported our choice. I'm telling you guys I have met wonderful deaf adults whose modality was the opposite of my daughters who encouraged our family who supported our choices, who did not try to convince me otherwise. But just kept, challenged me in a really authentic positive way to make sure that we were thinking about all the things that we needed to think about in terms of support.

So I think just the elements of standards, of quality of those supports we have to look at as a system.

WILLIAM EISERMAN: we are at the top of the hour and that was really a rich conversation back and forth with everybody. So thank you so much for all of the questions and for all of your responses and information, Janet. If we did not get to your question, Janet can be reached through the hands and voices.org website. So if there are I know several of you have been asking about specific other resources you would like to put your hands on. So I would encourage you to reach out to hands and voices with those questions. Several of you also asked questions about getting a copy of today's presentation. This has been recorded and will be on infant hearing.org in the next couple of days. So if you would like to access this information again or share it with others that's how you can do that.

Before you run off, if you wouldn't mind clicking in the middle of the screen there to give us some feedback, and to get a certificate of attendance, if you desire that. We would appreciate it very much if you would do that. Thank you to our captioner again and to all of you, and of course to Janet DesGeorges. Thank you.