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EHDI Annual Conference

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(Captions provided by a live Captioner.)

Captioner standing by.

>> Greetings. Welcome, everyone. It is time to get going, so let's start. Hopefully, everyone is ready for this workshop. The title is Train‑Go‑Sorry. My name is JoJo Lopez and I have a masters in sign language education. Any background I went to a Deaf school. My first language, primary language is sign language. I identify as Deaf and Hard of Hearing. And I work at the New Mexico School for The Deaf. I am a developmental special I'll pass it on.

>> KATHLEEN: Good evening. My name is Kathleen. It's easier to say Kat. I have a master's degree in social work. But what I do is work as a developmental specialist at New Mexico School for the Deaf under the early intervention program. Really, if you had a medical label for me, someone would say I was Deaf. But when I look at myself and I identify myself. I identify myself as Deaf and Hard of Hearing and hearing. The reason is when I have the devices on, I'm great. When they're off, I'm Deaf. My first language is spoken English. But from here on out, I will be using spoken English. It's easier for me to impress myself in my first language.

>> ROBIN:. Hi, I'm Robin Getz. I have two masters degrees. One in mental health counseling and the second in Deaf education. And I work at Colorado speech and resources as a coordinator. What I do is help coordinate Early Intervention Services for families with Deaf and Hard of Hearing children. From birth to three years old. and with the hearing differences. So diversity. And the diversity hearing. I was born deaf, I was raised aural in mainstream school. My primary language is spoken language. I can speak Spanish as well and sign. So, probably what I will be doing is, for the duration, I will be using the spoken language. There may be some SimCom‑ing going on at the same time but more than likely I will just do spoken language.

>> Can you hear me? Okay. So, before we begin, I just want to say one caveat, and that is the technology Deaf and Hard of Hearing. We're going to be using it interchangeably. So if you hear one or the other, just know it means the same thing.

So the history of deaf education began back in the 18th century where the philosophy was spoken language only. This approach picked up popularity and speed throughout the 19th century, especially around the first School for the Deaf that was aural began in Germany in 1778, and spread to other parts of Europe and eventually to the United States, where Alexander Graham Bell took his momentum further. For one, he had a deaf wife and he believed all Deaf or Hard of Hearing individuals you be integrated into the hearing society. Therefore, aural must be the way to go.

>> I would like to talk about the Milan conference back in 1880. That conference ran from September 6th through September 11 of 1880. What they were talking about was what approach do we take in education for Deaf and Hard of Hearing individuals. That was the main point of the entire conference. What was eventually decided on was that Deaf and Hard of Hearing folks need to be educated in spoken language, auralism. Sign language was not to be allowed. That was the consensus. There were some dissenting voices at the conference, but the overall decision was that sign Language was not to be allowed and auralism was the best approach.

>> Okay. So with the historical aspect of the 18th century, including the Milan conference that JoJo mentioned, over the centuries our Deaf and Hard of Hearing children have been exposed to various philosophies on how to best provide or teach language in the areas mentioned by my colleagues. With this, let's take a look at today's aspect. Where are we now? Let's take a look.

During this presentation, our perspective as Deaf and Hard of Hearing interventionists and some personal viewpoints may be shared throughout. Studies have shown early exposure to language is critical for Deaf and Hard of Hearing children with consistent, visual access to language can help prevent some language delays. But three of us belong strongly in empowering our families in their decision‑making process as this journey is often overwhelming and confusing. While seeking answers, parents traditionally follow recommendations made by medical professionals related to technology and communication.

We'll do a quick poll here. How many of you think that speech and sound is not necessary to become a successful reader, true or false? Raise your hand if it's true.

>> All right, so everybody thinks it's true. Okay. Next question.

>> One more question. And true was right, by the way, obviously. With hearing technology, you will never need an interpreter or captions, true or false? I see everybody signing false. See, we've got a great audience here. False. Robin.

>> Okay. So, now, we're going to be taking a look at the medical and sociocultural perspectives. Now, I want you to take a moment and look at the chart. You will see on the right side they look at the medical perspective on hearing differences. So you will see some of the technology like loss, failed, fix and impaired and disability. Okay. Now, on the left side, on the sociocultural perspective, you will see some more positive language where they're not using the words like loss and failed and fixed and things like that.

So keeping that in mind, historically, medical professionals do not have the training for aural extensive knowledge on best practices in supporting our Deaf and Hard of Hearing children's communication development. And, typically, after mingling with the medical professionals like the audiologists or even the ear, nose and throat doctors, appear often con‑‑ parents are often confused, feared, upset or they feel defeated due to the negative framing that they are hearing from those professionals, and they feel like my child cannot do anything before they even leave that office.

So there was a pediatric otolaryngologist named Dr. Bauer, and he was from Arkansas children's, and he said by removing the words like loss, failed, impairment, and so on, that allowed a family to have their children viewed as equal, healthy and whole. And parents need to hear and know that there are many successful Deaf and Hard of Hearing individuals all over the world from all walks of life who are doctors, lawyers, teachers, et cetera. And mingling and working with Deaf and Hard of Hearing professionals early on in their journey often helps alleviate these concerns and fears and helps families move forward with a more positive outlook.

>> So I'd like to take a moment to talk about language deprivation. How many of you are familiar with the term? Most here are familiar with it. You've heard the term before. Language deprivation just means no access or not complete access to receptive and compressive communication. And this is a Jill Morford quote of what language deprivation is. Yes, this is true. Language deprivation is not due to deafness.

We all know what language delays and language deprivation can do to a child. It has nothing to do with their ability to hear. Rather, it's just a lack of exposure to language that they can access. And the really critical ages for language acquisition, in order to expose them to language as early as possible is birth to five. And that's really the point of our topic. The point behind that is missed opportunities. Imagine a child with a hearing loss that is experiencing language deprivation, they are surrounded by missed opportunities and barriers.

So now it's time for a second poll. Here's our question:

What do you think, should we stop signing when the child starts compressing them using spoken language? True/false? Who thinks it's true? Anybody? Who thinks it's false. Good job. Obviously, that's false. No, keep on signing. Even if they start talking, expose them to as much language as we can.

Your child has full access to spoken language with hearing technology regardless of which option they choose in daycare, school, family activities and the community. Is that true or false? False? Okay. You got that one right, too. That is also false.

You guys are good. Wow. You guys are smart. A smart group here. Back to Kat.

>> I forget the mic. As you guys read this slide, the American Academy of Pediatrics, back in 2023, shared the children who are Deaf and Hard of Hearing are high risk of permanent deficits in language acquisition and downstream effects as poor academic performance, personal/social maladjustment and motional difficulty. It continues to share that identification of children born Deaf and Hard of Hearing through the newborn hearing screening as subsequent timely early prevention can prevent roar do you see many of these adverse consequences.

So I want to share with you, in my former job as a school social worker ‑‑ I have to back up even farther than that. So when I was a high school student, I actually had the opportunity to volunteer working at a pre‑school that focused on the unspoken language for Deaf and Hard of Hearing children. Later, I became a social worker in the school system of those little children who are anywhere from one through five years old, and now my students are my case load. I have had the privilege to observe how their language as a child to their teenage years was impacted because their life skills, their academic performance, their personal social skills, educational/vocational opportunity and, of course, daily routine, all of that was impacted, which I witnessed. Their receptive and compressive communication, understanding, empathy and conflict resolution was an area of need. That was the reason I was a social worker.

For instance, they could not differentiate between mad, frustrated, angry. Another example, they could not differentiate it ‑‑ happy, excited and thrilled. These children could have had the full language access and understood many of these areas at a young age if they had been provided with all the areas and tools for the communication. Unfortunately, those pre‑schoolers I once worked with will go to high school and now adults continue to pay the price.

I'll go ahead and voice this. This slide shares that reading and language delays are caused by language deprivation. It is not the hearing loss or sign language that causes these delays it has to do with back of exposure to the accessible language.

>> How many of you here ‑‑ how many of you hear that language and reading/writing delays are often taught by the child's hearing loss or hearing difference? I mean, it's a lot more common than we would like to admit or hear. So here's another question for you: What percentage of language deprivation cases are preventable?

Yeah, some of you said 100. Some of you said all. That's correct. All children are born ready for language, no matter what, whether they can hear or not. They are born ready to learn language. It is a biological and experience‑driven process. And children mention earlier appropriate access need to happen for language to develop in the first three years of life. Language is used for everything. And studies have shown that it is harder to close the gap after age three. These kids still continue to progress and make gains, but they never fully ‑‑

And here's a surprising piece of information that have been shared, and that is there are no other documented cases or population group worldwide of language deprivation, it is only among our Deaf and Hard of Hearing population. Is that surprising to any of you? So the Deaf and Hard of Hearing population is the only population worldwide that have documented cases of language deprivation. None of the other language groups, none of the other cultural groups have documented cases of language deprivation. They may have language delay, but it's not language deprivation. And it's because those are the population groups who have access to language, where the minority of our Deaf and Hard of Hearing children do not always have access to language. And this is a major public health issue.

So let's take a moment to read this from the ACLU, which is the American Civil Liberties Union.

So the ACLU made this statement back in January of 2024, and they state that the gold standard to providing access ‑‑ to language is by incorporating both spoken language and sign language from the get‑go.

>> Early intervention and communication opportunities ‑‑ my mouth is so dry it's not even funny. And I have been drinking water. That's not helping.

[Laughter]

So as you guys take a look at this slide, I'll give you a moment to read it.

The part that I truly like from this slide is it says, no one size fits all. This includes auditory devices. The ability to hear everything or most everything does not mean you can understand this perfectly. I see this a lot with a lot of the children I work with, the passports will say, oh, my child has a hard of hearing or cochlear implant, the audiologist says they're hearing at mild or normal hearing. Just because they're hearing at that level does not equate clarity or understanding. And, after time, I will explain that to parents.

So, historically, professionals have put an emphasis on language acquisition in the first few years of life with the parent. As early intervention Deaf and Hard of Hearing professionals, we recognize that providing a Deaf child with adequate access to language continues to remain challenging for our parents. This becomes a crucial role for us to share the resources and all of the tools available to support the parents' language goals with their child in a multi‑sensory manner.

As Gibbons ‑‑ and I don't know if I can pronounce this last name ‑‑ Skolaski ‑‑ I tried ‑‑ in 2019 shared, one tool in the toolkit is not enough for a Deaf and Hard of Hearing child to learn and keep up with their hearing peers. As Robin mentioned earlier, all babies are ready to learn or perceive the world in a multi‑sensory fashion. Social language really depends on multi‑sensory input. For Deaf and Hard of Hearing babies and children, language is best learned in a multi‑sensory way in order to get the best outcome. It provides the opportunity to make sense of their world by integrating information in all areas.

>> I'll give y'all a moment to read this.

So, as you can see from this slide and the one before, the comment from the ACLU, studies have shown that cognitive ability as well as language ability, it's so important for children to have access not to just one language but actually to multiple languages, the benefits down the line are huge as they are exposed to more than one language. So, in this case, it would be both sign and spoken.

The author of the study I'm referencing is Humphries, back in 2022. They state the benefits of a signed language ‑‑ exposing a child to signed language cannot be overstated. As long as they are exposed early enough to both spoken language and sign language, their cognitive abilities only benefit from it, exposing them to gestures, finger spelling, sign language, body language, all of that is exposing them to language, so it really doesn't make any sense to remove one from the equation. Why not give them the benefit of any language that they can access?

All right, I've got another poll for you.

Sign language isn't beneficial for all children, only the ones that are ‑‑ get this ‑‑ really deaf is that true or false? What do you think? You're absolutely right, the answer is false.

Next question: Schools for the Deaf provide spoken language support and speech therapy. Is that true or false? Yeah, you're absolutely right. Yes, this is true, most Deaf schools, they provide speech therapy, language support, they want a child to have full access to communication as well as sign language.

All right. Thank you so much. So there's many audiologists that don't believe in that ‑‑ excuse me ‑‑ that don't believe Deaf schools provide speech therapy and access to spoken languages. That's a common misconception that we would like to rectify here. Thank you, Kat, for reminding me.

So Deaf and Hard of Hearing children do not have consistent access to incidental language and the various daily scenarios around them like hearing children do. What do you think, true or false? You're absolutely right, true.

Robin.

>> Okay. So, let's take a minute and read this slide. It's about executive functioning skills.

Okay. So executive function is something that is very important to everyone, not just the Deaf and Hard of Hearing children. It is the ability to control and regulate one's thoughts, feelings, behaviors, flexibility, problem solving, planning and paying attention in order to complete a task or activity. This is all developmental and are building blocks for other development of important life skills. Exposure to trauma or adverse conditions can impact the development as can language deprivation.

So, this also applies to theory of mind as well, same thing. So a lot of our Deaf and Hard of Hearing children are labeled as being impulsive and having attention deficit and things like that, and it's because of that lack of full access to language.

>> We all know the speech, we use muscles in our mouths to produce sounds or words in an intelligible way. Language is the ability to pick and choose the right words or signs to say and understand their meaning, a way to compress one's self. Language, as we all know, is everywhere in our daily routine, within our educational setting, culture, families, and society.

>> Less than 10% of children. Wow. All children are ready to learn the minute they're born, they're ready to learn, every child. It's not just a few children. Every child. Gallaudet did research in 2012, and what they said was that 92% of Deaf and Hard of Hearing children in the United States do not have access to language. 98% of Deaf and Hard of Hearing children throughout the world do not have access to language. 92 in the United States, 98% worldwide. That is astonishing.

People disagree about early exposure to language. They think just speaking is it and that's what should be done. But there is language acquisition. There is showing a language. It's role modeling a language. If we're talking about bilingualism, it's being able to see that as they grow up. Knowing a language, knowing the structure, understanding the process of using the English language on their own, and, at the same time, using sign language. And that gives the child the opportunity for full understanding, full visual, aural, auditory, all the exposure that they need. And that is by having both languages given to them and them having access to it as they grow.

>> From this shied that you need, parents do not need to be fluent or strong in sign language to be able to use it with their babies. They can learn alongside with their baby, and both momma, dada and baby will pick up the language together. They need to stay on top of things and stay one step ahead. But research is showing parents who started with their babies by six months of age, they are expected to develop ASL vocabularies. Even if they begin learning after six months of age but before three years of age, they were still able to make gains. They may have had a small delay, but the point is they were still making that progress.

Boston University studies show that children with strong ASL skills from early on were likely to have English vocabularies comparable to hearing children. And the bottom line from all of this is that the parent‑child connection is developing and is strong and meaningful because they both have that communication access from the get‑go.

>> As you can see from this slide, if a Deaf child sees ASL all day every day, they will likely become fluent in it. If a Deaf child wears their implants or hearing aids all day every day, they are still at risk to acquire an incomplete first language. At risk, that is a powerful statement. But we as professionals need to remember, we as professionals should avoid assuring parents that a cochlear implant or an auditory device is a clear path to hearing and language. From the article in 2022 called Deaf Children Need Rich Language Input From The Start they shared that, regardless of the technology used, Deaf and Hard of Hearing children may have delays in spoken or signed communication which affects their daily lives. The authors don't share there are two critically important environments, the school and the family dinner table. If such environments do not afford impact and visual ‑‑ do not afford, impact visual language input for sign language, the child has reduced opportunity for incidental or contextual learning. Simply put, sign language simply supports spoken language, and this advantage goes both ways. Sign language and spoken sign language support ‑‑ I'm sorry ‑‑ promote the development of the other.

>> Deaf and Hard of Hearing individuals bilingual with ASL and spoken language have access to language. Role models, enriched communication, enriched culture, enriched access to the family, and they can support the family dynamics and support the family. The goal is to be able to provide a strong foundation for the cognitive understanding, the communication, the academics, the social skills, and the vocabulary that a child needs to succeed.

JCIH is who has given us this information. In my experience working with families with early intervention, I meet so many different families and often, I don't know, after the fifth, sixth home visit we see them, we often have conversations. We talk about how are you feeling? How do you think it's going? What have you learned along the way? One question that comes up instantly is, you know, where are the Deaf and Hard of Hearing individuals? Where are the role models and what are their experiences? The topic that comes up very often is I wish I had met this person the first time I learned about deafness, the first time my child was identified as having a hearing loss ‑‑ a hearing diversity. If I had known that, I would have had a better path to follow, known what questions to have asked, I would have known what to expect. But because of that, there was a lot of angst and upset and worry because I didn't know, because the parents believe and still believe that it is a huge impact, having a Deaf or Hard of Hearing individual, a successful individual that they can meet and say, okay, this is someone's life and it can happen and you can succeed. And in that area, it's so important with early interventionist specialists to make sure the Deaf Community and the Deaf individual is allowed the families to have exposure to that individual.

>> Let me just clarify that last paragraph that JoJo shared. He said, there is a critical area within early intervention for families to meet Deaf professionals shortly after the child is born. I just wanted to make sure we got that.

>> Okay. So, now, I'm going to be moving on to hearing devices and, also, intervention learning opportunities. And this is also working with Deaf and Hard of Hearing professionals can help support the families because we often have our own personal experiences with hearing devices, and how they work for us and in a variety of different settings.

As you can see from this picture, it says, hearing devices are not a cure for deafness, they are simply tools. As Kat mentioned earlier in the presentation, we do not just use one tool in the toolbox. This is just one tool. Hearing devices do not level the playing field for our Deaf and Hard of Hearing children, no matter the hearing levels. Everyone benefits differently.

With or without the devices, we are still deaf and hard of hearing. And a lot of us are not able to access spoken language completely, nor do we understand everything that is said to us at all times around us for a variety of different reasons. Additionally, listening fatigue is very real, and it can manifest itself in many different ways and, in children, that can be manifested through their behavior ‑‑ I'm sorry?

>> (Inaudible).

>> So ten minutes. Okay.

Incidental learning is the ability to overhear or follow conversation not directed to you throughout your daily routine. Our Deaf and Hard of Hearing children do not have consistent access to incidental language, and did you know that 80% of language is learned the first five years of life? Our Deaf and Hard of Hearing children miss out on a lot of that because those experiences happen through language that is not directed at them. So things like slang idioms, vocabulary, names or places, situations, objects and people. However, when there's a visual language in the mix, in addition to the spoken language, it will be much easier for our Deaf and Hard of Hearing child to be able to see what's happening, what's being said, and to participate in those conversations happening around them, and to pick up on other language‑learning opportunities.

>> If any of these are true, your child does not have full access. These can affect daily interaction, result in communication breakdown and incidental learning opportunities are limited or lost.

>> So this photo, this picture you're seeing, what do you see? It's a family, they're getting together, they're having dinner, the baby is there, everyone's included, the kids are all included, but there's one thing that we need to understand, this is called DTS ‑‑ dinner table syndrome. How many of you have heard of this technology,dinner table syndrome? It's when the family is all together and they get together and talk ‑‑ you know, when everybody is hearing, you talk about work, what's going on, and you have a Deaf child who's there who's trying to engage and understand what's going on but they're missing out on the conversation, they're missing out on what was said and they have to find different strategies to try and understand what was said, the conversations during dinner time when everyone was talking.

So here are strategies to include when you're talking about at the dinner table. Make sure the lighting is good. Make sure that the background noise ‑‑ there's no music, there's no other sounds going on, so the Deaf child can follow the conversation. Make sure they're included, make sure they're part of the conversation. Have an interchange with them, you know, with children and with adults. Incorporate gestures or hand movement or signs, whatever you can do, but incorporate movements and make it very visual. And don't say, oh, I'll tell you later, it's not important, I'll tell you later. No, no, no, don't say that. Repeat what you said, if it wasn't understood the first time, say it in a different way. It's also important to check to see if they're understanding before you just go on full.

Hearing people talking with their mouth full, forget it. We don't want to see that. We don't want your food on us. We don't want to see it. Take a drink, clear your mouth, then talk. When you are talking, don't cover your mouth when you're talking. No way anyone can understand, hi, how are you? You're still not going to see fit your hand's over your mouth. Again, just repeating, oh, I'll tell you later, it's not important, don't do that. Also, provide visual cues to the child or the adult, making sure they can see or understanding where the conversation is coming from or who is talking. Something else, how about a round table instead of a square table? When you're at a round table, everyone can see each other. All the strategies are important to fit for your family and to include everyone in the family in those conversations.

>> Accessible language is a human right. Deaf and Hard of Hearing children, regardless of hearing levels, the technology used or not deserve more not less. After all, Train‑Go‑Sorry are missed opportunities. Missed opportunities, different ways, you want to sign it or share it, can be avoided. Let's give our Deaf and Hard of Hearing children everything we've got. Accessible language is a human right, a human connection that we all crave and we need. What are you going to do about it? If you have any questions or comments for any of us at whatever time we have left, we are happy to take it.

>> We are welcome for any questions.

I have a comment. Yes, we'll copy sign for you. Go ahead.

>> There was a lot of great information that you shared with this, and I'm thinking about access and the language deprivation and what you're talking about this. You're talking about the 20%. But there's also the 75 or 85% of individuals who not only just during that age, but from three to five, being able to catch up with language and being able to get the language that is provided to them. Sometimes we talk amongst ourselves and say you have to look, I have to have eye contact, but, also, how do you do that when you have your hands full and you're saying what or something else, but it's difficult to pass that on and have spoken language and sign language at the same time when we're trying to provide information to children.

Two minutes left. Anybody else with a question or a comment?

>> As a hearing parent learning sign, how can we help our child with the incidental language acquisition and learning environments? Should we be explaining what's going on around? Just suggestions for how to provide experience for all the language going on around them.

>> I would just say ongoing repetition in the language you're using, whether sign or spoken, constant repetitions. Oh, mom is going to wash this pan. Oh, let's wash, wash, wash the pan. Or whatever. Whether sign or spoken, however you use it. So just the ongoing repetition throughout the day. You're going to get so tired of hearing yourself talk or sign.

>> Well, also, you can also say with your child what you see happening at that moment in time.

>> So I know you guys are all early interventionists in your own way, and so am I. Do you come across, in your practice, parents getting very confused, coming back for medical appointments? Because, when they're being amplified, the audiologists or clinics are telling them, well, now you only have to use this or that method, where we are trying to explain to them we're just going to throw it all to you and give you everything, but then they come back from their appointments and they're, like, well, the teacher is telling me this. So how are you guys kind of dealing with that on your end, necessarily? How are you having that?

>> So, while we are a parent choice program, we inform our parents, you know ‑‑ I mean, we share information about the different communication modalities and what current research is showing and that we will support the passport with whatever modality they choose to use for their child, but we make sure that our families know what the current research is showing.

>> I just want to add, we always refer back to the medical professionals. We definitely don't want any conflict, et cetera. However, as a Deaf and Hard of Hearing person, I can say your child appears to be tired, frustrated, angry. What do you see that he or she may want to take off, the auditory device or the cochlear implant, it's okay. And they're, like, but, but, but ‑‑ I'm, like, as a Deaf and Hard of Hearing person after a full day of work, my ears are off. We all need that auditory break. So it's up to the parent. I say it's your choice, but I definitely would not tell them to choose one or the other. They just need to make the decision that's best for the child.

>> Just going back to this. Just the same thing as was just told, you know, parents do their own research. Provide them with support. You know, bring them ‑‑ introduce them to other families with Deaf children. Being able to see it from different views and perspectives is very important.

>> ‑‑ parents follow their child's lead, follow their child's lead. A lot depends. The child knows best.

>> Thank you for letting us be here today.

[End of session]

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Captioner standing by.

>> Hi. Good afternoon. Are you okay with us starting, even though your partner is not here? Okay. Thanks.

Good afternoon. I'm Evelyn Shaw, one of the presenters for this session, Successful State Collaboration Between EHDI and IDEA Part C: Strategies, Resources and Upcoming Activities. I want to make sure that, in the first chair of every row, there should be a handout. If you haven't gotten one, please ask someone at the end of the row to pass it down to you. Thank you. We're going to be talking about that in a little bit. Okay. I can move this forward myself, can't I? Yes.

So, the agenda for today is that I will be introducing and reviewing, obviously, what we're going to be doing today, and that is an overview of the national Early Hearing Detection & Intervention, EHDI, outcomes committee, of which I'm one of the co‑chairs. We'll have an initial discussion that relates to, you know, some of the things that you already thinking about in terms of what are your challenges and what are some successful strategies, we will be doing that. We'll give you some examples of successful collaboration. We'll talk about another product that has to do with one of two products, that's one the EHDI outcomes committee is working observe which is a planning, agenda and collaboration meetings, and then we'll continue to have a large‑group discussion and think about next steps.

Okay. Well, our presenters are ‑‑ two of them will be on their way because they are leaving another presentation that we all were at, up and were presenting. That's Stacy Callender, the Mississippi State Department of Health, and Marsha fort, the North Carolina EHDI coordinator. To my far right is Judy jungle who is the Wyoming Part C coordinator. Myself, and I'm with the early childhood technical assistance center at fort Graham institute in North Carolina. Here comes Stacy. Wave or say hi or smile. And Sharon Walsh, center for IDEA, early childhood data systems or the DaSy Center. And Marsha should be here soon.

First, we want to know about you. Raise your hand as many times as you want, as it applies to you. Do you work with the EHDI program? Okay.

The Part C program? Some of you with both. Okay.

At the state level? Many of you.

Local level? Okay.

National level? Hey, I see a few smiling faces in there.

We should raise our hands, too. But that's okay.

Are you an administrator? Okay.

Or a provider? Or both? Okay. Same.

Family members? Good. Welcome.

And do you work with a family association or family‑based organization? Yes, quite a few of you.

Did we miss anybody? Students?

Anything else? I guess not. Welcome. We're so glad. We're going to have lots of perspectives here in the room as we really will appreciate as we talk about the work on this committee. Curiosity, how many of you are on the EHDI outcomes committee? A number of people. So you don't have to talk necessarily to me or Sharon or any of the others here, you can talk to some of those other members.

And welcome one of our members. Marsha. Glad you're here. And none of us got ice cream. We were too late from one session to the other, or cookies or anything. That's okay. We didn't really need it.

Let me tell you a little bit about the national Early Hearing Detection & Intervention or EHDI outcomes committee. That committee was formed in 2016, and it meets monthly and still does, except sometimes we take a little bit of time off in the summer. Initially, it was a partnership between the CDC, the National Center for Birth Defects and Developmental Disabilities and the Early Childhood TA Center at FPG Child Development Institute, that is an Office of Special Education program's funded technical assistance center. With the addition of DaSy Center in 2018. Members include many of those like you who are represented in this group, EHDI and state pars C coordinators, staff, CDC, NCC, HRSA, staff, OSEP, NCHAM, Hands and Voices, the FL3 center, ODDACE center. And then our own, of course, staff.

What was our initial work is this initially, the work seemed to have a very specific focus in terms of looking at outcome data that the EHDI program could collect and, mostly, what they could collect on the functional standards, and that would include collecting data from Part C or early intervention in the state. Part of it, the job of that committee, was to think about and identify those challenges in collecting and sharing that data and review and make recommendations about modifications, additions or other recommendations related to the functional standards in that sharing data work. What priorities, what they discovered, the committee members discovered, I wasn't on that committee. I have been on there since about 2018 and the winter, late winter of 2018. What was discovered is they had a lot of questions about what data could and couldn't be shared. How can states share that data between those programs without even parental concept? Is that even a possibility? We know that Part C data systems vary greatly from state to state. That includes the types of data being collected and how that data are stored, and that there's only a small amount of data that each state is required to share ‑‑ to report on a yearly basis.

So there was clearly a need for more exhaustion between all the agencies ‑‑ federal agencies involved in these two programs. And I've listed those. And a much greater need for an understanding of the other's programs, especially at the provider level.

So what have we been doing since 2016 till now? Well, we feel very lucky that we've had really invested partners ‑‑ partnerships between the agencies and also with those members of the committee. So what we have done is that we have developed supporting a way to understand how do you support understanding what those data elements that are collected that could be shared, and what is the caveats around that, especially those that relate to those functional standards.

We've identified challenges and some really successful strategies for that data sharing, and included in that are state successes between those two programs. We've provided focus presentations at national meetings, including the National EHDI conference around data sharing, Part C eligibility definitions especially as relates to diagnosed conditions and what States list in terms of children who are Deaf and Hard of Hearing and outcomes research on young children who are Deaf and Hard of Hearing.

We've provided recommendations to the CDC functional standards committee on some programmatic goals listed here under goal statement 4, and we've promoted and facilitated more collaboration between federal and state partners. We've also detailed strategies that support that data sharing. And I need my water.

So some of our products, and I'll show you a mockup of where you can find them, we've developed guidance for State EHDI and Part C to local agencies about the importance of data sharing, why it's needed, strategies for sharing that data. So there's an understanding down to the local level. Around data sharing. We've developed a data sharing agreement checklist and we, meaning the Committee, not me or us necessarily up here, although they are very important partners in developing that. We've developed a data sharing agreement template and collected and continue to collect data sharing agreements with the State's consent and provided a central location for posting those agreements, which is really at the infant hearing.org site.

So here is what it looks like open the ECTA or early childhood technical assistance center Web site. This is the page. I've offered specifics so that at the bottom of the page there is the link directly to this page and it's called early detection intervention program and early intervention. You will sea the data sharing partnerships improving systems, that is .pdf and also readable on the Web site, along with the data sharing agreement template and examples from EHDI and early intervention programs, again, readable, online and available .pdf for downloading, and then the data sharing agreement check lists for EHDI and early intervention programs. Same thing, readable online and also downloadable, and with NCHAM, that's where you will find the examples of the data sharing agreements.

Okay. So our current work is two different things. It's really working on what we call the partnership agenda discussion guide. You will hear a little bit more about that later on. It includes what we call the continuum tool, which helps you think about the steps going from a cooperative relationship between EHDI and Part C, Part C and EHDI and other important partners within the state to a partnership. We are having critical topics, critical, desirable topics, including having suggested agendas that are part of that. We have ‑‑ we are collecting anecdotes of successful collaborative work. We would love to hear from you during this session on states resolving obstacles and barriers. We have a Q&A section in that.

The other piece that we're working on is those examples of successful collaborations, ways that these examples can inspire others, other programs, and there are really solid examples of collaboration between the two programs and resources from successful states.

So let's ‑‑ am I still doing this or are you doing that?

>> I am.

>> I am so glad you're going to take that.

>> Your voice is going.

>> I know.

>> Thanks, Evelyn.

Good afternoon, everyone. I'm really glad to be here. Sharon Walsh from the DaSy Center. This is an opportunity for about ten minutes for you to talk about what collaborations you're involved in, the ideas you can share, any successes you've had, any challenges you've had, and we're focusing on the core relationship between the EHDI and the Part C programs. I want to emphasize something we have been hearing in sessions all week and fits in the title of this session which is that notion about, to be successful in collaborating, it's all about building relationships. And, so, I think you will see that and, hopefully, you will hear that from us a lot. We had somebody say in an earlier session, you know what I did? I just called them and I made friends, and we went out and had lunch and then we started planning what we were going to do. That feels so intuitive, right? But I think sometimes we get so caught up in the work we're doing and what we need that we don't stop to take that first important step. So that's my little soapbox for the moment.

Let's just open it up. We have a mic that will go around, so please wait for the mic. Any one of those questions, you can open it up, and let's just go for about ten minutes.

>> I wish I could report collaboration success. I would love to have those stories, I haven't given up yet, our state's EHDI program, it's phenomenal, above and beyond. They get it. Early intervention program is an Island unto itself. It refuses to look at, speak to or acknowledge any of us who are down here screaming. And I'd appreciate any help I can get. I'm tired of coming to this conference every year searching for answers that I can take back home and it gets me nowhere. Nowhere. So anybody has any help to offer, let us know. It starts with a K and ends in a Y.

>> Okay. So we started with a challenge, right? And right after my comment, I do hear how frustrated you are. I think I need somebody to give a good at least possible solution. A couple of people have raised their hands, because people don't want you to be in this position. Sounds like you have been in this position a really long time and there's no need for it. Somebody help me. I have four hands up with ideas.

>> It would be helpful if, when you ask a question, you could tell us what your role or job or position is, because I think that might make a difference in regards to how we might respond.

>> I am the new executive director for the commission for the Deaf and Hard of Hearing, and President of Kentucky chapter hand to voices. I am on the EHDI board, have been for several years. I'm involved in many, many things.

>> So, I will add to that. Anita has worked directly with Kentucky EHDI for years.

>> Hi. So I'm from the great state of North Dakota, and I am happy to say that we do have some pretty good collaboration, but we also are actively working on improving that and building it, and I think one of the things that has brought about better collaboration is the addition of that language acquisition piece into the EHDI grant. And, so, what EHDI did, they created an advisory committee, and we meet via Zoom just because we're a rural state and we're dealing with winter. But we get together once a month, and it's EHDI, it's Part C providers, it is the School for the Deaf, it's other stakeholders within the community, audiologists, and we're really looking at ‑‑ so this is interesting to me about data collection and privacy concerns related to EHDI and Part C, because I'm with Part C and, of course, we're constantly doing data.

So, I would be curious just to know how we're working on that including School for the Deaf because they provide some of those in‑home Part C services as well.

>> Thank you, Rebecca. A couple of quick tips or a new topic. We don't have a lot of time, unfortunately.

>> Hey, y'all. I'm Carol from Georgia, coordinator for the DeafBlind project. I'm an old interventionist. I don't know her name in the jean jacket. I was curious if you tried to infiltrate your state inter‑agency coordinating council? Anybody can just show up and make public comment, and if you gather a possie of people to go and make comments, that might be an inroad if you're not formally invited to play with Part C.

>> Great suggestion. Hey, I'm sorry. Also for ‑‑ I'm sure you guys just said her name, but the lady in the jean jacket. But the way we started working with our Part C Department was showing what we could provide to them. So, you know, we provide newborn hearing screening results to Part C Department and we have a seamless referral system so when we identify a child with hearing loss we can connect that family with Part C quickly. If you can show what you can provide to them, they're going to be a lot more likely to work with you.

>> Thanks, Brian. Another one?

>> This is Sara from New Hampshire, EHDI coordinator for the state. One of my jobs is to enhance the partnership with Part C. This is something for the woman in the jean jacket, as well. I have been really focusing on asking Part C what they want from us and creating materials for them, trying to build that partnership, and it's been pretty successful so far, so I'm going to them, asking them what do you need from me in the EHDI program? And that's been a helpful, successful strategy for us, so far.

>> That's a great strategy. First, ask what you can bring.

All right, let's get one more.

>> I'm Ashley Renslow from Colorado, early education cord near the. Four years ago, our do you want of human services commission for the Deaf and Hard of Hearing in partnership with our Part C EI Colorado applied for our HRSA grant and got it so they are co‑PIs for our grant in Colorado, we just got the next five years. It's been awesome to have them working together. Our EI team, our state team halls someone in the task forces overlooking brochures, sending some of their information to us. So I think we have, over the last four years, started a really strong partnership and looking forward to that continuing over the course of the next five‑yore grant as well.

>> Another great strategy. Thank you. Have we used up all our discussion initial time, I think? All right, we've got one more in the back. Here comes the mic.

>> Super quickly. So I'm a parent in Washington State, and I was involved in our early intervention program. As a parent, there's a parent leadership, and, so, I was part of that group for many years, and then they asked if any of us wanted to help out with our first‑year FRC training. So, as a passport, I was involved in that process. And then, you know, the relationships, you're working with people. Unfortunately, staff changes. So having to do that all over again.

>> Marsha, do we have time for one more?

>> One more.

>> My name is Natasha and I am with the Florida EHDI. I'm a parent consultant. So, we have been trying hard to get our enrollment rates up for our population with Part C, Florida School of the DeafBlind has done monthly collaboration projects meeting with Part C providers, but we still have not seen a level of enrollment that we want. So we are in the process ‑‑ we're fortunate in our state that the EHDI and Part C are both under the Department of Health. Our new Part C director ‑‑ well, she's not new, a couple of years ‑‑ is our former EHDI director, so she totally gets it. She's 100% on board with collaborating, so we are in the process, currently, of creating a training for our Part C staff because the issue we have is we are identifying these babies super early. We are referring them within a week of diagnosis to early steps. They are getting to early steps one month, two months of age, and their contact there is saying, oh, come back to us in a year, or, you know, evaluating, and your baby is doing fine, come back to us at a year. So that's been the frustration. There's turnover. So we're hoping to do, at the Part C, their staff training to, you know, present there but also have it filmed so that, when there is turnover, it will be part of their training, so these folks get it and understand these babies need to enroll as soon as we refer them.

>> One more.

>> I just want to add, in the State of North Dakota, Deaf and Hard of Hearing is one of the auto‑qualifying conditions for Part C services. So it's automatic. So I struggle to understand. I feel sorry for all of you.

>> I'll say ‑‑ my name is Stacy Callender. I have both served in my state previously as the Part C coordinator and the EHDI coordinator, and, so, I can tell you, every state sets their eligibility criteria. They have guidance on that. And, so, there are some states where eligibility is automatic for any degree or type of hearing loss. There are some states where only bilateral loss is counted. There are some states where it's only loss of certain decibel levels, right. It's not ideal in the sense of it would be easy to say every state has the exact same criteria or the same eligibility, but they don't. And, so, that is actually one of those things, though, that can be really helpful for sharing. And I would strongly encourage the state I.C.C. as a place to start. We're fortunate in our state it requires the EHDI director to make an annual presentation to the state I.C.C. to make recommendations for that. So sometimes it was me presenting to myself.

[Laughter]

>> That happens make collaboration really well, by the way.

>> It was awesome. We should do this! I agree!

[Laughter]

Yeah, we did lots of stuff like that. But I should say, in other states, there are ways and mechanisms and, certainly, all of us here are willing to share about that. But I will say, one of the reasons this group actually exists is ‑‑ I mean, in the start, it came with EHDI got some new requirements, you got functional data standards. You need to have this outcome. Part C, give us your data, and Part C said, no, that's not how it works, and we don't have that, what are you talking about? So all of this came out of that. So we really have been focusing on giving everybody those nuts and bolts tools so you can figure out how to do that. That's one of the things my work group is actually working on now. Evelyn presented earlier, we've got things around the formal data sharing agreement, but how do you even get to that because you've got to have a conversation with the people and figure out who the right people are in the room. And, so, that's one of the things that we're working on. So the goal of our work group right now, and it meets monthly, you know, we break out, we do work group meeting kind of during our meeting time, and some of us do work in between and some of us go, oh, yeah, I forgot but I'm doing it quickly while we're in the work group, and I do that too, because we're humans. Our goal in the work group is focusing on the guidance of how to have the collaborative meetings, right. And we know it's meetings, it's not a meeting, it's a whole series of ongoing conversations. And, so, what we did is we thought of ‑‑ we brain stormed a list of types of meetings or reasons we would have that and for each meeting we will provide guidance on, we'll give you what the purpose of the meeting is, what the pre‑meeting activities are, a sample agenda that you can adapt, a whole bunch of discussion questions that will help lead into interesting conversations, and then what do you do afterwards to not lose the momemtum that you gained at the meeting? Okay?

So that's part of what we're doing with this guidance document.

>> So to add a little bit. Even though the topic today is Part C and EHDI collaboration, these materials that are being developed can be used for any partnership, any key partnership that you need. We are trying as a work group to think of the key partners as best we can for the different topics related to Part C and EHDI. But this is something that can be adapted for any key partnership development that you need for your program.

>> Absolutely. Absolutely. And one of the things that we begin with ‑‑ give you a second there.

One of the things that we start with in the guidance document is we think about, first, how do we come to some understanding of where we are in our process of collaboration? And speaking of our great partners, we got this from Hands and Voices, so if you've worked from them, you might have seen something that looks slightly similar to this.

It's a continuation or a continuum around collaboration. So it starts oaf on the far side of co‑existence, right? For our developmentalists, this is the parallel play of programs, right ‑‑ I stay in my lane, you stay in your lane. We're not bumping each other off the road, it's not roller derby, but we do our own thing and we're not formally working together.

Then it moves along for networking. We started talking and staring, hey, we're doing the training, send this to your people. Okay. And then you send me some more information you've got. We're giving that back and forth, right? We're just communicating about some of our activities and sharing some ideas. Would be some joint training or something like that, right?

But then we move further into cooperation where the programs are engaged in more formal interactions, but it may be on one specific projects or for some time‑limited purpose, right. So we've got an activity, we're going to do one shared thing, we're putting something together, an we're going to create a shared script. That's great. That's wonderful, you know. That's moving us much further along.

Then we move kind of further along the continuum to collaboration. This is where you get more of that long‑term, ongoing, formal interactions, and you may even say, okay, these are our goals and our goals. Oh, look, we have shared goals, let's focus on those things and build long‑term work around that, and we continue to do that. And it moves all the way to true partnership where we work with each other, and we would never think about rolling out something new without telling our best friend here about the stuff we're doing. Not only are we sharing our goals, but also our resources, decision‑making, and all of that is ongoing. So this is a large continuum. You will notice we put odd numbers because some of you want to be on the line in between, so we left space for y'all, too.

>> And we'll also note that sometimes you may go forward on the continuum and then back up for different reasons. Turnover, I think, may already have been mentioned. So you may go back and forth. It's also interesting to you rate yourself where you think you are on the continuum and have the other parties at the table with you also rate and see if everybody's perception matches.

>> Yeah, that's like I was saying earlier, if you ever take one of those relationship quizzes and give it to your significant other and see how they rate it, you're, like, what? No! Like, all right, so ‑‑ so we wanted to let you know, that's part of it. And you think in your head, where are we? Where are we in my state, you know? And for some people, you are way down there at the one end or, I don't know, somewhat kind of falling off the chart. And then there are other of us who are further along. Most of us in the mushy middle, right. Somewhere in the middle place, we've done some stuff, but it may not be quite as formal or whatever. So I was saying, we brainstormed a list of topics. For each of the topics, it is what would be the purpose or the takeaway from the meeting we're trying to get, what's the desired outcome? Then what's the pre‑work that we need to do? What's the actual meeting itself that need to go on in the meeting, the sample agenda and the discussion we can have around that topic, and then what are the next steps to follow up. So, for some of it, it does look like it's in a sequence, but don't feel like you have to use it. Pick and choose wherever. And we're really hoping people can take and adapt it. If you look and go, oh, those questions don't work for me, that's okay, don't use those. Find other ones. Make it your own. It's just a tool to help you think through. If nothing else, it's a tool that says, hey, come out, we're supposed to do this, so let's try to have the meeting to do that. We'll be talking about all kinds of things like just getting a basic understanding of who we are, looking at referrals, the loss to knoll low up, the expand to screening or early onset identification. Looking at how to better the services, train professionals, work on data outcomes and, the holy grail, use the data to actually improve outcomes. So there's lots of ways we can do.

I understand you can't maybe jump into all this stuff at the beginning, but there are times ‑‑ and you will go back and forth on this as well ‑‑ there are times where you may have, to depending on if you widen the circle, go back to the first meeting, now we've widened the circle and included more parties. This is what it's going to look like even if you can see on there. It has big graphs on there, what have you. These are screen shots and you can see an idea of what it's going to be. So we have a second workgroup that's doing something to supplement and enhance that work.

>> So we've talked about this overall committee that works and we're always looking for new members from Part C and EHDI. We have data sharing templates, tech lists, examples of data sharing agreement. This good, important pre‑work up front. This other work group is working on collecting just a brief overview, we're calling them gems, and we've collected a couple listening to you in here, gems of collaboration. And we're creating a web page that will be searchable by state and topic. And it's evolving. We'll add new things all the time. It will be iterative. Right now, Judy will share some things we've already collected, not state‑specific, but they will be on the web page. So be thinking of the really great work you're doing and talk to us because we would like to profile your state collaborative activities. You will probably see the web page by summer, we're hoping. I'm going to turn it over to Judy and she'll share some of the great nuggets or gems we've discovered, already.

>> Okay, so we've compiled examples from four different states, and I'm excited to share some great things happening out there. Regarding training and technical assistance, we're seeing collaboration between EHDI, Part C and Hand and Voices to provide specialty training Part C providers. We also see that same collaboration to provide Training and Technical Assistance in Community of Practices parent sessions, conferences, and other efforts coordinated throughout the year. Part C systems partner with planning organizations to determine need for families. Assistance teams support EI providers to enroll in ASL classes and attend the EHDI conference in one state. I won't go through the examples as you have the slide, but you'll will see the themes to get groups together about what training is needed.

So next slide. So the next area we wanted to talk to is referral, screening and assessment. So you will see common themes here. A lot of collaboration through the data systems via notifications for referrals, and then EI referrals being received directly from a family advocacy program. This leads to 100% referral rate to Part C in one state through a parent‑driven referral process. We have parent organizations involved in the referrals. Local EHDI coordinators receiving automatic referrals, and then coordinating closely with the local Part C programs.

Regarding vehicle and assessment, in one state EHDI purchased hearing screening equipment and trained EI providers for home screenings through Part C infant‑ toddler program. Part C provide funding for training and technical assistance on the screening process and in turn EHDI tracks the training and equipment status statewide. EHDI provide training to EI providers on late onset hearing and data tracking. The data tracking is a huge piece of that. In rural areas, funding sources were sought to provide screening equipment to midwives, and then they refer to EI. And EHDI supports infant assessments through the use of a mobile bus and tele‑audiology in another rural state. A lot of exciting things happening there.

Data sharing. I think we all have probably herd about this over the years if you have been in EHDI or Part C for any length of time. So EHDI data sharing arrangements address data sharing, security, storage and destruction, through contracts, data sharing, parent consent. Data included in integrated system under certain circumstances. The tracking of newborns to ensure they are enrolled in EI by six months of age. Dates of IFEPs start states and EI outcomes are shared. And one state has an integrated child health information system that supports the sharing of EHDI and EI data.

One other example is child I.D. numbers are assigned from education to follow children who are Deaf and Hard of Hearing from their initial diagnosis through high school.

So family engagement. Part C, EHDI and Hands and Voices address training for parents of children who are Deaf and Hard of Hearing, also train Part C providers on family engagement strategies, and have developed a tablet of resources for providers.

Similarly, Part C programs partner with Hands and Voices for family support. The Hands and Voices program has parents sign a consent to share information with Part C, and once that child is enrolled, Hands and Voices continues their work with family engagement, while Part C provides EI services. So, really, all the components working together is very important to support family engagement for these families.

Service delivery and collaboration activities. So, we have a lot of examples of Part C and EHDI serving on each others' committees, and stakeholder meetings and other groups throughout the state, EHDI advisory groups and the infant hearing screening advisory committee. Collaboration for service clear includes EHDI, a network for educational services for children birth to alien 5 and Part C. Another unique example, Part C team collaborates with a speech language pathologist experienced in working with infants and toddlers with hearing loss to plan appropriate services. And then that person is part of a larger EHDI work group that collaborates with all the other partners involved.

Services are provided by an educational entity for all children with hearing loss in collaboration with Part C. In another state, services in early intervention provided by the School for the DeafBlind in coordination with the EHDI programs. We have three entities working together on that.

And I do want to take a minute to mention some challenges. It isn't always easy working through these dynamics. I don't think any of you will find these particularly brand‑new. I think we all know we have high turnover in our fields, and then navigating data privacy and integration can be a challenge. Across the country, we do hear about the lack of speech language pathologists in general especially those experienced working with very young children with hearing loss. Also different providers having different perspectives on assessments. The hesitation of families to get involved with government agencies, and then when you have multiple agencies or entities coming in, it can be overwhelming for the family. And then sometimes obtaining a release of information can be a challenge to share information back and forth.

My final slide are tips. It's worth reading through each one. Looking at the collaborations, the number of partnerships you have and could have to make things happen. This is a good one. Understanding that everyone wants to do the best for families. They are often limited by the data they can share freely across programs. So navigating through those challenges. Don't take a passive role in assuming collaborations and partnerships will develop. You may have to repeat the message several times. Also, don't make assumptions that others know what you do and why you don't do other things.

So I think ‑‑ is it Evelyn? Okay.

>> Thank you. Now we're just going to have a large group discussion. Anybody who has idea, questions, reactions on what you've heard? Surprises? Ah, we have one. Now's not the time to be quiet. It's late and they had ice cream and cookies and we did not get that.

>> I did not get either.

>> Then we're in the same place.

>> And silence makes me uncomfortable. So I am with the Part C system but at a local level, so I'm not a state employee. I'm director of a non‑profit who serves all infants and toddlers with disabilities in the State of Alaska. One thing that has frustrated me for decades is siloed everything. So siloed funding, siloed data, siloed conversations. And when I see this, I hope that, you know, getting to collaboration across different funding sources, different governmental departments, non‑profit organizations is really challenging, and turnover is, like, you're going to have to start this eight times, right. So ‑‑ and key, you have to keep massaging this. And, so, you know, I'm always hopeful. I'm a glass half full kind of gal, but it is challenging, and sometimes these state, local and federal‑level systems are really challenging because they are so siloed.

>> That's a really excellent point. And I think that's one of the reasons I think we thought the Committee was really ‑‑ was critical, to have our federal partners on board. And there's federal collaboration, even not just with our committee, but there is federal collaboration across agencies.

Yes.

>> I just wanted to say thank you from North Dakota and Tennessee. We didn't know there's a state inter‑agency coordinating council in our states, we didn't know that. Thank you, so we will be talking to them. And then just also, for me, I do long‑term follow up through newborn blood spot screening, and this has been a great conference, but I just want to say sending e‑mails to the people that you're making referrals to in Part C is so helpful. I've explained it a thousand times what I do and why I'm asking questions, and now I'm starting to get e‑mails back because, you know, the data sharing stuff is kind of limited. But I am getting some e‑mails back saying we have met with this family, you know, things are moving forward, whatever. So it's baby steps, but it is ‑‑ just keep talking.

>> It makes you feel hopeful that maybe there will be larger steps in the future. Thank you.

>> Thanks for all the great ideas. I'm an audiologist from Missouri, and we haven't been able to make friends for over twenty years. So we have EHDI is an education. I'm sorry, we're in health and Part C is in education. No trading of data whatsoever. Their excuse is FERPA. Is that insurmountable? Is there anybody that overcame FERPA without having to have a release signed by every family?

>> Let us just clarify previously, and we can all talk anytime in the hall or later with follow‑up, it's very possible to share data, but you have to follow the federal and state requirements around privacy. So I have HIPAA requirements in some states, but anybody in an education program has FERPA requirements. It doesn't mean they can't share, that's what all the data sharing agreements are about, you can always share with parent concept and you can always share with what's called the participating agency, but even without that in your situation, you can share, but you need an inter‑agency data sharing agreement under FERPA. So it's very possible. In the work the committee's done which hit me the most over the years is the EHDI people and the Part C people telling each other things the other one didn't know. Like sometimes, for instance, the EHDI person wanted and needed data on a certain things, and the Part C people don't have that data. Those data are located in individual child records at a local level. So, sometimes the data are not there. Sometimes the data are there, but the Part C person needs a little help understanding how FERPA can work, because they might be saying FERPA won't allow me and FERPA would allow. It's hard work. So I would just encourage you to keep those conversations going. And there's technical assistance available, too.

>> And interestingly, we just passed Lead K and that committee is forming what measurements they are going to do, so education is going to have that information. Right now, I don't know how we're going to get it.

>> But we do have some TA and documents and examples that are available. Plus, we have the webinar that was recorded, and I'm not sure we even included that in that list, but there is a webinar that was recorded last August, September, that had to do with data sharing privacy, FERPA. Definitely the documents. So that's listed and those slides are up. And you can contact us, too. Yeah. And I can give you my contact information. It's probably on the program, too.

>> A simple question, I promise. I'm curious if it's standard practice for EHDI programs to not be allowed to make referrals to Part C?

>> No. There have been a couple of places where states have said, we're not allowed to give that information because it would "violate HIPAA." And HIPAA says continuity of care, and federal regs for early intervention say, if you know of a kid, you need to refer to us and, as a matter of factually, EHDI is listed as a referral source in federal regs for Part C. So we've ‑‑ that is ‑‑ there are lots of lawyers who apparently have a lot of jobs to sit and haggle over law, but the fact is it's sitting broadly in the federal regs that say these two groups should work together. And, so, there are challenges and difficulties with the two different laws that haven't been updated or changed to really acknowledge that relationship fully, but there's tons ‑‑ tons and tons of agreements, and, as a matter of factually, most of the EHDI programs make direct referrals to early intervention that we know of.

>> Yeah, so it's definitely not standard that EHDI programs don't ‑‑ there are a couple of locations where the state agency that EHDI is housed in, their leadership says absolutely not. And the EHDI coordinators in those situations have battled for years to get the leadership at the state organization to understand that these federal regs do say we can.

>> Okay. And we're out of time, but I do want to leave you with this last question. Think about that, what can you do by next Tuesday? What you could do by next week? So, with that, I just want to thank everyone for being here. Your questions, your comments, we really appreciate that. And I just encourage you to look at the slides and to go to the resources that we have listed. So, thank you very much.

[End of session]