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MANDY JAY:

Good afternoon everyone, this is Mandy J doing and audio check for today's webinar which starts in two minutes. The Power of the Deafblind Technical Assistance Network: What's in it for You?

We will start in two units. You need to know this webinar is being recorded so if you are unable to participate for the entirety, you will be able to find it over the next few days on infanthearing.org

MANDY JAY:

Good afternoon or good morning, welcome to today's webinar The Power of the Deafblind Technical Assistance Network: What's in it for You? On behalf of the early hearing detection national resource center, or the EHDI you TRC at Utah State. Before we get started I have a few adjustable items to cover with you. You should know that the webinar is being recorded. It will be @infanthearing.org in the next couple of days so if you are unable to participate for the entirety of the webinar you will find the recording online. You can also use the recording to share with others who you think should have attended or couldn't attend and missed some great information.

If you would benefit from captioning today, at the bottom of your screen click show captions and that will activate your ability to see the captions. You will also notice the vertical bar between the PowerPoint slide and where you can see the video windows of the interpreters and presenters. You can resize these by moving the | to the left or right to meet your viewing needs. Thank you so much to the interpreters and captioner today, these are real people helping make this webinar accessible for all attendees today and we are grateful for them.

Before we get into the webinar, after the presentation today, we will open a Q&A box so we are not going to get to questions with throughout the webinar but you will have an option to type in questions at the end and we will relate them to the presenters and they will answer as many as we have time for. We will stop at the top of the hour.

Write your questions down if you have them and then we will get to them at the end of the webinar. Also at the end of the webinar we will post a link in the chat that will take you to a short evaluation of the webinar and it will produce a certificate of attendance for you. Don't forget to click on the link before you log off today.

With that I want to introduce the reason you are here, presenters for today. We will hear from four people. Emma Fricke, from the National Center on DeafBlindness. She is headed this with organizing everything and we will hear from three people from the state of Tennessee. Holli Allen is the program director for the Tennessee EHDI program. Lissa Elkins is the parent of a child with Stickler Syndrome.

And then, Danna Conn is the project coordinator for the Tennessee Deaf blind project at Vanderbilt University.

I will let them share a little more about themselves with you and handed over to Emma.

EMMA FRICKE:

My name is Emma Fricke and it is to be nelson if you are confused. We are thrilled to have you today to talk about the collaboration and opportunities between the debt by network and hands and voices, EHCI and all the rest of you here.

What we are hoping, is through the conversation today we want you to think about your

State program, EHCI program and what Lissa's story comes up for you today to maximize outcomes for families. During the story we hope you will jot down questions you might have or comments you might have about the approach that was taken around the collaboration and the processes that were in place for her son Leo. And primarily, we are hoping you will increase your understanding of how these collaborative partnerships between state organizations can create positive outcomes and engagement for families.

Also, an awareness of this network and resources that are available to support all of you. I lead the identification and referral network and I will pass it to Danna to introduce the other

Participants, presenters.

DANNA CONN:

It is exciting to share how these have made an impact. You will hear from one of our amazing parents Lissa Elkins, we pre-recorded her video since she has a lot of mom duties in picking up kids and taking them to school. So you will get to see that and we are so appreciative of her sharing her journey with Leo.

As was said my name is Danna Conn and I in the project for Nader for the Tennessee outlined product -- project and we will talk a little more about what the state deadline projects offer and I will have Holli introduce herself.

HOLLI ALLEN:

Thank you, my name is Holli Allen and I am the Tennessee early hearing detection and innovation... And I will talk about how we collaborate today. Thank you.

DANNA CONN:

What you see on the screen now, I will go through a set of pictures that Lissa shared with us about Leo's journey from birth. And then you will hear her reference back to them in her video. In the first picture on the left, is a picture of Leo a few days after birth. This picture is of Leo laying on a hospital caught sleeping on his side with many wires attached to him. On the right-hand side, is a picture of

Leo during a follow-up hearing test when he left the NICU. In the picture is sleeping in a woman's arms and they are sitting in a medical office.

On this slide on the left, is a picture of Leo at five months. He is sitting in a booster seat with new glasses and hearing aids. He has a bit of apprehension on his face, the world is new to him. It is like he was seeing and hearing for the first time.

In the middle is a picture of Leo only eight months of age. Already in auditory/verbal therapy. He is sitting at a table using a toy for listening and spoken language-based exercises. Isn't he the cutest, I just have to say that. On the right in the next photograph it shows Leo sitting on the floor at 16 months of age still plugging away in auditory verbal sessions.

In the next slide, on the left, in February 2020, Lissa found a conference being held in Nashville for parents of children with hearing loss. It was sponsored by the EHDI and CARE Project. Here you see the agenda, registration and notes. On the right, is a picture of Leo at age 2 years standing in the hallway at the Children's Hospital about to walk into a therapy session.

We will play the video and you will hear a little more about their story.

(Video plays)

LISSA ELKINS:

Hello everyone my name is Lissa and I live in Chattanooga with my husband, two stepdaughters and our three children. Four of the five kids are girls and our youngest, being our only boy is named Leo. Leo is 4 1/2 and we refer to him as our mighty lion. He has Stickler Syndrome, a progressive connective tissue disorder that causes DeafBlindness. There is a picture of Leo a few days after birth. In the picture he is laying on a hospital caught, sleeping on his side with many wires attached to him. They are hooked up to many different monitors.

On the red there are pictures his sisters drew of a lion with his name. Hence where the mighty lion name was born. He was born on February 1, 2019, he could not read on his own when laying on his back. He presented with a job that was malformed which would cause his tongue to fall into the back of his throat when laying on his back. He would choke. He presented with a cleft palate. Both things had to be surgically fixed in order for him to eat and breathe. Since we had no family history of these issues, a geneticist was assigned to see if it was a genetic cause or an isolated event. With the results of the EHDI newborn screening along with his newborn vision screening, the confirmed loss for both hearing and vision. The results of these screenings helped our geneticist narrow down what type of syndrome you could possibly have.

Blood tests were conducted to confirm that it was in fact, Stickler. Here's a picture of Leo during a

follow-up hearing test when we left the NICU. In the picture he is sleeping in a woman's arms and they are sitting in a medical office. Maybe Leo is connected to many buyers placed on his head and his ear that are hooked up to during detection machines. The woman in the picture is obviously not me. She is my best friend of over 35 years. She flew into town to see us after I shared just how terrified I was from receiving Leo's diagnosis.

I felt beyond helpless and ill-equipped to take care of my own son. No one was giving me a guidebook on how to help him and there was no manual or YouTube video that my husband falls back to very frequently. For what to do next. So what did I do? I just started researching nonstop.

The more I research on mind the more I read about that critical window of a child's early years. I learned that between the ages of birth to five, the brain undergoes the most rapid growth and development in a human lifetime. This is a period that a child is most responsive to intervention. I did not know this. Never had to know this.

Reading this statement letter firing me. I guess you could say the mama lion was awakening. The more I read, the more I learned and knew I had to take action to get Leo the support he needed early.

it is honestly the only thing in this situation that I felt I could control. This was out what in the world do I do moment. I wanted to take the time to share what I learned through my experience and what I deem to be the three important components for us to create a plan of action for support for Leo. It can be applied to any child with special needs.

First and foremost, hands down, was screening and assessments. This is where the early identification happens. As I mentioned earlier, not only did screening help our geneticist get the answers she needed, we also were able to figure out what Leo's immediate needs work. As importantly, it confirmed the fact that he needed your needs and high prescription glasses to see and hear us. Because of these early screenings, we were able to get these things for him by the time he was five months old. Pictured here is Leo at five months sitting in a booster seat with new glasses and his hearing aids. He has a bit of apprehension, it was like he was seeing and hearing at the very first time at five months old. You can't get support services or medical devices when you don't know what your child needs.

Screenings help identify these areas of concern. This begins with orders from your pediatrician or your child's specialist. If these medical providers aren't ordering tests, and I am looking at you parents and caregivers, need to be requesting them. In our case, the plus side of Leo having comorbid issues presenting at birth was that our doctors did order testing because they need to figure out what was going on. That is not always the case. Sometimes the only way these things can be brought to light is by parent feedback. For example, noticing that your child is not responding to sound the way there siblings are. Bring up your concerns to your doctor. Parents and caregivers you know your child better than anyone. I hear it all the time to me, and I always thought it was cliché but it is so, so very true. You have the right to have screening done if you have any feeling that there may be an issue.

The second component in creating, is creating an individualized plan of therapy and intervention. Thankfully for us the identification of Leos DeafBlindness from the screening test, showed that he

would be eligible for early intervention services provided by the state. In Tennessee it is known as TEIS. Like contacted them and representative came to the home to do their own screening and interviews and he was approved will stop we were assigned a case manager who helped coordinate the support services he needed.

Here's another picture at eight months of age already in auditory verbal therapy. He is using a toy for auditory and language-based exercises. The next photograph shows him sitting on the floor at 16 months of age, still plugging away in auditory verbal therapy sessions. In the picture he is popping bubbles during another verbal exercise. In addition to the AVT therapy, Leo received occupational, developmental and eventually, physical therapy. We notice later this was something needed.

All of the support services are out there and ready to be utilized. We would have never received it through TEIS beginning at such an early age if we had not had Leo properly screened. The third component in my opinion, it's really the most important. Finding supportive organizations.

Beyond therapy there are so many resources out there. The problem is in many cases, no one will hand you a list of them. I waited for that ended never happened. This is where I encourage you, parents and caregivers, to research what is out there. Ask your professionals. Professionals, compile a list of resources and support organizations to help your families. Google, Google, Google. It has been a treasure chest of resources all over the country. I found that national family Association for Deaf blind that way and I am actually now part of their national board. In February 2020 I found a conference by googling that was being held in Nashville for parents of children with hearing loss. Sponsored by the Tennessee EHDI and the CARE Project. I signed up. On the screen is a picture of my table, sitting at the conference with my registration, agenda and notes. I went alone. I had no idea what I was doing but I did it. There were exhibitors who had table set up with information and that is where I met Danna Conn from the Tennessee deadline project. They have been one of the biggest allies of support in Leo's journey. Even recently being involved in his transition from early intervention into the school system.

That is a perfect example of the organizations collaborating. You have to take initiative to find them. In addition, I have met parents nationally through joining the organizations. Parents going to the same things I am. That feeling of being alone that I mentioned earlier, I don't have that feeling anymore. I may not know anyone locally in my town with a Deaf blind child but they are out there and the connections have been invaluable. I would never have had them otherwise. In summary, it is these three things that I know have made a world of difference in early outcomes for Leo will stop one was the screening and early detection, two starting therapy and intervention early and three, seeking out support organizations. It all stems back to these things. Starting as early as possible.

Here is a picture of Leo at the ripe old age of two years. Standing in a hallway at the hospital about to walk into a therapy session. He is looking down at the design on the floor and above him is a sign for children's there be services. Seeing this picture reminds me of the countless hours I have spent in those therapy offices. I want to be clear and honest with all of you, everything I shared today is not a magical cure. This road has not been easy. There were many periods where I saw no improvement with Leo's ability to communicate, and eyesight that continue to get worse, we struggled with behavior

and major sensory issues disruptive to everyone in his life. We kept going. We kept returning to appointments and I kept getting help. It was the only thing I could control.

I remember clearly an appointment was Leo's ENT at Vanderbilt when he was three years old. The doctor began the appointment asking how things were going like he always does. And I started sobbing. It had been a very difficult few months and at the time, I felt we were not seeing any improvement like we should. After everything I had been doing, providing him, I was defeated, tired and scared. When I was sharing these concerns, the doctors stop me, he let out -- he knelt down in front of me and he said look at me in the eyes: Leo may never speak, I need you to know that I am seeing firsthand how you are providing him with every possible support available. And that is enough. I needed to hear that and I am sharing this in case there are parents, caregivers or professionals that need to hear it as well. If you are providing special needs child with the support resources available, you are doing enough. There will be days with big wins and days with no wins, but in the future you will see the results of this work. I want to leave you with a short video clip that gives you a glimpse of where you is today. He and I are on the floor practicing speech sounds. He is wearing glasses but not hearing aids as we were doing a bit of lipreading practice. I was able to capture this incredible moment. I heard three words I was waiting to hear for four years. Who knows if I would've heard this and so many other words had we not had the support services we got. Thank you so much.

(Video plays)

LISSA ELKINS:

I love mama!

SPEAKER:

I love mama! (Laughs)

SPEAKER:

I love mama!

(Applause)

(Laughs)

LISSA ELKINS:

You said it!

SPEAKER:

I love mama! (Laughs)

DANNA CONN:

Well, I think everyone here would have to say what an amazing journey they had. And especially, these are the words that everyone wants to hear. I am so appreciative to Lissa and her family for sharing their story with us. Their experiences and the honesty that she used in talking to parents and professionals in the room today.

I would love now to have Holli Allen come on and she will talk about the collaborations we have had between our EHDI and state Deaf blind project. And I will come back on and talk.

HOLLI ALLEN:

Thank you. We recognize that partnerships and collaborations are vital to the work that we do in supporting our children and families in Tennessee. At the Tennessee EHDI program we are fortunate to have built strong partnerships with organizations across the state and country including the depth one project. In Tennessee Danna represents the Deaf blind project on the advisory committee. This collaboration provides an opportunity to share knowledge and experiences with other partners and stakeholders. To strengthen the system of care and ensure that the children and families we are serving -- receives the appropriate care to ensure the best outcomes. In addition to our advisory committee, Danna serves in the learning community. We were lucky enough this past summer to have her present to the group on the services at the Tennessee that point project and we received great feedback. We were delighted to hear that many families served qualified for services. As was mentioned in the presentation, we host parent professional collaborative and family retreats in partnership with the CARE Project.

These conferences we bring together families and professionals and provide an opportunity for families to link with professionals and resources that could be beneficial to their family. Just like what Lissa and Leo accomplish at the CARE Project event. We are always happy to support our stakeholders and families by sharing information about resources and educational opportunities that could benefit the children and families we are serving. We recognize that the rich resources are an invaluable asset and are essential for the success of our activities and our programs.

I would like to share that in March of this year, at the national EHDI conference I had the pleasure of attending an instructional session led by DAnna and other representatives from the national Deaf blind project. The session focused on classroom and life experiences of children with complex need. And we heard from various professionals who discuss methods and strategies for assisting these children through different scenarios that they may face. And to say it was the highlight of the conference for me would be an understatement.

I recognize that I couldn't do the job that I do and we certainly wouldn't be able to serve the babies in Tennessee the way we do without partnerships with organizations like the DeafBlind project. Thank you.

DANNA CONN:

Thank you. We are so happy to be able to collaborate with our state DeafBlind, EHDI and the work they do. There are a variety of ways in which EHDI and state DeafBlind projects can collaborate.

These collaborations not only benefit both programs but also the families and babies we work with. As a result of serving on each program's advisory committees, trainings, Emily conferences and the EHDI learning community, babies have been identified as DeafBlind and referred to our program in the state. You also heard Lissa in the video emphasize the importance of newborn hearing screenings and assessment, follow-up, family support, individualized services and resources. By strengthening the infrastructure to coordinate services across the state, we are better equipped to improve language acquisition outcomes for children who are Deaf and hard of hearing. These programs help to support communication development and outcomes through the partnership with early intervention professionals and families. We will talk a little about what supports and resources can be offered.

Every state has a DeafBlind project. They are federal grant funded by the US Department of Education, office of special education programs. We are what's called a technical assistance and dissemination grant. All services are free to families, educators and other professionals of individuals from birth to 21. So what as was mentioned once we coordinated with her and met at the care conference, and we met Leo, he was under the age of three at that time and so as he transitioned into preschool, we were able to work with his team, provide training and support to be able to help them access the general education curriculum in his classroom. We will be able to go on with him up to age 21 as he progresses through the transition age. We provide consultations anywhere and everywhere that family professionals need us, whether it be at home, school or community. We provide resources, support and information based on the individualized needs that the child and family have. There are lots of great resources online through the national Center on DeafBlind and other agencies such as EHDI. There local handset voices so we can definitely connect with families.

We help teams look at appropriate individualized instructional strategies. Each is unique to the children we work with. We provide workshops, trainings, conferences and we can also help connect families to other families that have a child similar to theirs in the area or so many of the symptoms or conditions we work with maybe really rare or low incidence and we can help to find another family member for families to talk to.

We do provide the state child find on DeafBlindness and everyone conducts a Deaf blind senses to make sure we recognize the people birth to 21 in the state that have combined deafness and vision loss. There is a link at the bottom here to access the PowerPoint to again, connect with each state DeafBlind project.

EMMA FRICKE:

Let's I don't know if you're still here but you shared such

An incredible story and it was inspiring to see the joy on your face and hear the laughing when he says "I love mama!" For the first time. And how many hours you put in and how many Leo put in and all the support services that wrapped around you. It is really inspiring to think about. Thank you for sharing the experience with all of us.

This will not be as fun. I am so glad that you are all still here. We will back up just a little bit and talk about the uniqueness of DeafBlindness. This will be brief so I will talk most about DeafBlindness and a

short bit about data around DeafBlindness and we will have another opportunity in January to reconnect at a coffee chat where we will be lucky enough to have the data and evaluation manager with us. She will share more specifically and answer any questions you might have then. As I go through the next few slides, here is what I hope will happen. I hope you can sit and just consider what would happen if Lissa hadn't been able to find the services and support or if the services and support weren't available. And what if DAnna was in at the conference. If these are not happening at your state this is a great opportunity that we will give you resources about how to make that happen.

As was mentioned in the last slide, there is a link you can click on. There is the identification to the screening and assessment that was talked about. There is also the referral to state DeafBlind projects. That will connect to people that can help you with the pieces and questions you might have. And then, as was said early identification of hearing status as well as a vision status will bring about the best outcomes for kids long-term. The earlier the better, connections are key and no one can do it alone.

DeafBlindness is often thought of, we think of Helen Keller, someone who is totally Deaf and totally blind. In actuality it refers to any level of combined vision and hearing loss that significantly impacts the child's ability to get information from people, places and activities around them. These losses can cause developmental delays in the areas of language and communication, social emotional skills, cognition, adaptive self-help skills and motor skills. A very small percentage of children are profoundly Deaf and totally blind. Regardless of the levels of vision and hearing status, the earlier they are identified, the earlier they received services and supports that will maximize their access to the world.

The access will provide opportunities for them to learn and grow using all the residual vision and hearing they have. As Lissa said the road will not always be smooth, there will be ups and downs but like Leo, the sooner they are identified, the sooner the supports can be put in place. Identification is the first step. As was said the second is connecting to specialists including those who understand the unique needs of learners with DeafBlindness. Referrals to your state DeafBlind project will provide the opportunity for resources to be shared and support to be provided to the whole team. The percentage of children who are totally Deaf or totally blind is small. In addition to the federal special education child count, part C and part D the US Department of Education office of special education programs, also known as OSEP has authorized another child count that is specific to children who are DeafBlind. They requested it to begin back in 1986. Just as a quick difference, annually, there are less than 2000 children with DeafBlindness ages 3 to 21 who are reported on the special education child account with their primary disability being DeafBlindness. But there are over 10,000 on the DeafBlind child account. This discrepancy is thought to be largely due to the fact that 90% have more than one additional disability. Consequently, the majority are not identified as DeafBlind on the special education child count and the impact of their dual sensory loss might not be recognized or addressed.

In order for a child to be counted on the DeafBlind project must be referred to the project which is what was talked about a little bit. This graphic is three different concentric circles and it gives a perspective of the low incidence nature of the population.

The large blue circle demonstrates the United States population of all the children in the United States.

The yellow circle, represents the special education population in the United States. And then the red circle, which is so small it has to be magnified to be seen, shows that children with DeafBlindness. That is birth to 21 and this is from the 44th annual report to Congress on the national DeafBlind child count. I know you have heard me say this before but this really highlights the importance of partnership. For every family with a child with DeafBlindness, even though it is tiny on this graph, that red dot is everything to that family and it is their whole world. It is so important that we remember that and that we really work to make sure those resources are available to them.

This data is from the 2019 child count. It is old data. And hopefully, this will be able to be updated soon. What I love about this and what hopefully, we will be able to update you with shortly for more recent data, is the variance in the percentage of the entire... Let me think about how to phrase this correctly. I'm not the data manager, and Carly will be coming. Sometimes I get mixed up so I want to say correctly. Out of each state's full child count, this data is the percentage of those kids who are ages birth to two per state. You can see the red line is the average. That is 6.2% of each state child count average, is around 6.2%. But there are higher ones and lower ones. And what this highlights is the critical importance of reaching out across organizations and funding agencies within your state to figure out how to identify the children as early as possible and refer them to the project. Some of them are as high as 18% of the total child count and some are at zero. That is not the full of any agency in any way but it is about the fact that the more we can work together to figure out how to find these kids, the more we are able to report them on the child count and we are able to know about them and what they need and support those kids and families.

This is one more graph, table that shows that low incidence equals small numbers. As I said before, the numbers are small but it shows you how small. These numbers are not national numbers.... They are not state numbers they are national numbers. We are slowly making progress in identifying them but as you can see, nationally in 2019 there were 63 children under the age of one who were reported on the national child count. By the time they became six there were 523 nationally. That is a pretty large increase. We know if we work together early we can find them earlier.

That you've seen the numbers are so small. Even though it is a small population, it is so important to identify them early because their needs are so, so great. A few tips to take away: for identification and referral are that any child who is identified as Deaf/hard of hearing should be evaluated for a loss in vision. Often that occurs around six months of age. It can occur before that if there is like in Leo's case a genetic syndrome identified or other things that would point to a need for that. Evaluations should always be repeated regularly. I was just listening to a podcast Earworm and the first episode talks about not late onset hearing loss but late identified. It can be the same with vision. Thinking about repeating the evaluations as often as needed and also for kids who have very complex needs, where assessment might be tricky to think about how to work with those evaluators to think about how the information can come from many different people throughout the child's life to give information about how the child sees and hears. For a full picture of that.

Additionally, it requires partnership and collaboration, the better we do for the families and kids. Once a child is identified, that training can happen. So, both the training will be able to help the child learn how to use their residual vision and hearing but also they will train people to learn those skills that

support the child's unique learning needs in the areas of communication and language development, social emotional development, motor development and increase independence.

When you get this presentation, you will be able to click and explore these links. There are five links on this page of resources. The first one highlights the four families website on the national Center on DeafBlindness webpage. The second is also from the National Center on Deafblindness and talks about what services and organizations can be available to families. The one after that talks about causes of DeafBlindness and the one below is the etiology code list. What those are really are talking about the red flags to keep an eye out for. It talks about the common syndromes associated with DeafBlindness. The prenatal and post-natal complications that can arise that are associated with DeafBlindness and it is a great resource for you to take a quick look at and see what might be a red flag. We are thrilled that the last one was made with collaboration with professionals across United States and many families. It explores the foundations of early intervention with children who are DeafBlind and talks about how providers can best encourage their communication and concept development. Lessons include ways of expanding the child's world to more places and things and supporting the transition to preschool. And so, the module has 430 minute lessons that provide practical need to know information and strategies for working with infants and toddlers who are DeafBlind. A new one is being created right now that focuses on communication element specifically. And how to really support those targeted language outcomes. And how partners, partnerships can happen within the team to maximize the learning. All of the resources are free and you can always contact me if you have questions.

What we know about adult learning is that zoom is hard and there is so much happening and we are all in all of these sessions all the time. And away I am hoping you all can take some of this away is just to do this reflection activity before we open it up for questions.

So, I am hoping you can take a moment to jot down three things that you learned, two questions that you leave with, and one thing that you will share with a team member.

I want to thank my presenters, and all of you for being here. It really feels like an honor to be here. The EHDI conference is one of my favorites to be part of and all interactions I've had with so many of you at both hands and voices and at EHDI have helped me to grow so much in my understanding of early identification and referral. Even if I did come out a little awkward with the data part of my presentation. You have helped me learn so much and I'm grateful. I also want to thank the interpreters and the captioner and I will hand it to you Mandy to open for questions.

MANDY JAY:

Thank you to all the presenters we are grateful for you and all the great information you shared. We have opened the Q and a box if you have questions. We will take those now. One question is, is there a link for the early intervention module on the DeafBlindness that was mentioned. Is there a link to that?

EMMA FRICKE:

I can put this in the chat if that works for you. It is also going to be linked in the PowerPoint

presentation as well.

MANDY JAY:

While were waiting for questions to come in, I may have missed it and if I did I apologize, the links, the resources you shared what they show the state DeafBlind project? If a person is looking to locate their estate DeafBlind project they can click something and connect?

EMMA FRICKE:

Yes, do you want to talk about that at all?

DANNA CONN:

In the PowerPoint there is a hyperlink and you can click on it and it will take you to the National Center on Deafblindness DeafBlindness webpage and you will be able to locate your estate when you go there and it gives you the contact for the state. It'll give an email address along with the phone number for you to contact them. So definitely do that. If you have trouble, you can reach out to one of us and we will definitely get you to where you need to be.

MANDY JAY:

For clarification purposes, is every state called the DeafBlind project or do they have different names by state.

DANNA CONN:

Great question, they have different names. We are called the Tennessee DeafBlind project and in Georgia it is the sensory assistance project. So the name may be a little different.

MANDY JAY:

Thank you.

DANNA CONN:

That will be on the webpage and when you go it tells you the name of the project.

MANDY JAY:

We have a question asking the Jews use hands-on or tactile communication before the baby or toddler was able to speak early? This is probably a question for Lissa and I don't think she is on.

DANNA CONN:

That would be a question for Lissa.

EMMA FRICKE:

What I can say is typically touch is such a huge part of interacting with babies that are DeafBlind, any baby but even more important for babies who are DeafBlind. I imagine if they were connected with the TEIS and your project, I can imagine that it wasn't a part of what they were using. And another really cool thing that I think her story highlights is how just like hands and voices, that Technical Assistance Network we support families where they are with whatever communication works for them. So you can

hear that they were talking about auditory verbal therapy and that is what their family chose and other families choose other modes and we are just there to support whatever is best for the kids and family.

MANDY JAY:

We have a couple more questions right now. Does anyone have suggestions on how to formalize referrals between EHDI and DeafBlind project. I am a parent of a child with DeafBlindness, charge syndrome and work for the Florida EHDI program. I am aware of the DeafBlind project and I refer babies as I get them as newborns but it is fairly informal.

EMMA FRICKE:

I feel like you are a plant in the audience, that is our dream. To work together. All of us to figure out to make a more seamless system. I know it is something we have talked a lot about with Mandy and it's hard because every state is different and the funding source, with state DeafBlind projects, and EHDI will come from the same agency. I don't think it's a challenge we cannot overcome together and as we continue to take steps towards talking about it and brainstorming, the closer and closer we will get.

Also, we are planning to offer at the end of EHDI, a work group session where people who really want to dive into collaboration both in terms of identification but also the referral piece you mentioned, people who are passionate about it to come. So stay tuned, we would love it if you'd be interested in being a part of that. Do you have anything else to say about that?

DANNA CONN:

Know you did a great job.

MANDY JAY:

Are the modules useful for other service providers such as OT's, SLP's, special education teachers, etc.

DANNA CONN:

We love these modules and we always work closely with the SLPs and OT's in our state. It is appropriate for anyone working with our little ones for sure.

MANDY JAY:

The next question, is there a vision screening program similar to EHDI?

EMMA FRICKE:

That is another great question that we are working on. No there is not. And it makes it really complicated to try to figure out how to identify those babies as early as possible. There isn't, we wish there was.

MANDY JAY:

This is Mandy again, I feel like Emma fainted people in the audience today. To be ready for the EHDI workgroup coming up in March. Trying to solve some of these problems together.

The next question was where can we get access to the PowerPoint. We will post it with the recording. And it should be online. I think by next week with the Thanksgiving holidays I am not going to promise that. Usually it is only a couple of days. It will be with the recording of the presentation. You can share the PowerPoint and presentation with others.

EMMA FRICKE:

Do you mind trying to put the module in the chat? I am worried that if I go off to find it I will mess up all the screen sharing.

MANDY JAY:

Any other questions while we, look up the module to put in the chat. We won't close until we have that but we want to give an opportunity for any other questions.

This has been great information, thank you so much for sharing. And again, to give a plug for upcoming events, we have a couple of webinars coming up in January with the national DeafBlind technical resource Center so be looking for notices about those as well. We list them on infant hearing.org where you can see past webinars and upcoming ones as well.

Have another question: I used to work with the DeafBlind student and I noticed that their pace is very different from typical children. How they absorb information. It was a struggle to catch up because some teachers didn't understand the importance of pace. Do you have any comments about the pace of working with DeafBlind students or resources.

DANNA CONN:

Definitely, we know that processing time can be longer for our children to have dual sensory loss. There is another module, module one and it goes through a lot of the foundational teaching strategies, building relationships which are all huge parts of working with this population. I will also put that in the chat and you can look at it for additional information.

If you have more questions reach out to your DeafBlind project and they can help you specifically.

MANDY JAY:

We have a couple links in the chat. Emma referenced the earworm podcast and the link to that is in the chat as well as the modules, module one and two that were just posted.

OK, we want to thank you again so much for your time. We appreciate the great information. Thank you to the interpreters and the captioner. Again, please don't leave until you fill out the evaluation form and that will also get you a certificate of attendance. Thank you to everyone taking time from your day and we will talk soon. Thanks.

(Multiple speakers)

Thank you and goodbye.

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