>> Hello and welcome to Building connections and supporting learning with infants and toddlers who have complex needs, including Deaf-Blindness. I am Sarah and I am honored to introduce these people. My daughter was also born Deaf-Blind and this project and this program has been a blessing to my family. So, this is Donna Carpenter. Um -- Danna Conn, Robert Hill, Kristi and Emma. If you need anything, I will be the moderator for today.

>> Thank you. Hi, everybody. Thank you so much for taking your Sunday afternoon to come and hang out with all of us. We are going to try really hard to make it so worth your while, that you will want to just talk about Deaf-Blindness forever. So, today we will talk about building connections and supporting learning with infants and toddlers who have complex needs including Deaf-Blindness. We will just take a couple seconds to introduce ourselves. So, I am Emma Nelson. I work for the national center on Deaf-Blindness. Running mostly like the identification and referral initiative and focusing on early identification.

>> And my name is Kristi Probst. I am lot was national center on Deaf-Blindness. I am the initiative lead for interveners and qualified personnel.

>> Hi, everyone. My name is Robert Hill. I am with the South Carolina Deaf-Blind project and South Carolina Department of Education.

>> And I am Danna Conn, project coordinator for the Tennessee Deaf-Blind project housed at Vanderbilt University medical center and I am super excited to see so many faces in here and Tennessee fans. Well, Tennessee faces, not Tennessee fans. It's getting --

>> Hi, everyone. I am Donna Carpenter and I echo what she just said. I am so glad you are here. This is something you had to pay for to come here. We are so excited that you are part of here. We will make it fun, hands off and you will get lots of cool stuff. I am the coordinator for the Kentucky Deaf-Blind project. I used to be a teacher for the deaf hard of hearing many moons ago and we are really happy you are here.

>>> So I'll take you through the agentday. We will all say hi, then I will talk super brieflily about what Deaf-Blindness is. These folks will take you through evidence-based practices which I think is why you are all here. That will be the bulk of our time. Then we will have all discussions, ask all the questions. We will try to answer as much as we can and find out things if we don't know. And then we will leave you guys with some resources and training tools and then we will say goodbye.

So -- our objectives are here, I won't read them out loud. But what we really want to know is who you all are. Who has the mic? Danna has the mic. Donna has the mic. We will ask you all just to say who you are. Where you are from, what your role is, and then if you are willing to give just a short "why" like why did you sign up for this instructional session? What are you really hoping to get out of it? Because then we can try to target your hopes during the session.

>> Hi, everyone, my name is Lauren Freeney, I am a second-year, no, third-year audiology student at Washington University in St. Louis. Previously a teacher for the deaf and decided to switch over to audiology to learn more about classroom amplification and accoustics serving that need. I chose to come to EHDI serving on the student committee, helping out with a lot of events but joined EHDI to learn more about early intervention services and decided to come to this session to learn more about Deaf-Blindness. We don't get much instruction about that in our training. So, saw it as a great opportunity to learn.

>> Awesome.

>> Hello, everyone. I am Liberty Moore, also a student at Washington University in St. Louis. I am a second-year master's of deaf education student. And I am also on the student committee with Lauren. And, I am here because my practicum -- I am wanting to learn more about how to meet her needs.

>> Hi, I am Tracy Duncan from Tennessee and I am the statewide coordinator for the birth to 5 language and literacy program through the Tennessee schools for the deaf outreach and I am a lifelong learner. I don't know anything enough, so I am always learning.

>> Hi, I am Jodi Wooton, recently from Florida. We moved from Kaine. I have an 11-year-old deaf child and he has been recently diagnosed with low vision. So now he's still sensory and this is my first EHDI conference. I am here to learn about Deaf-Blindness and also about more how I can advocate for him and give him resources.

>> Awesome.

>> Hi, I am Nina. I am a teacher for the deaf and early intervention in North Carolina. And I am so excited to be here. I am specifically at this session because I have maybe 60% of my caseload now has complex needs. Including Deaf-Blindness and I want to learn as much as I can.

>> Awesome.

>> I am Karen from Vermont and I teach sign language to kid was special needs. All sorts of different needs. And I am also on the Board of Vermont hands and voices. This is my first time at the EHDI conference and I am excited to learn more and I work with Emma with kids in Vermont when she used to be there. Looking forward to learning more.

>> Hi. I am Penny. I am from Nevada Hands and Voices. I have a daughterrer who has charge syndrome and is Deaf-Blind. I am also a member of the Board of directors for the charge syndrome foundation and I work with hourly asson group. I would love to chat with any of you who have questions about that. I would like to learn how better to empower other parent guides in our guide program to not be afraid of our kids that need additional support.

>> Hi. My name is Letti. And I also work in Nevada hands and voices as a Deaf and Hard of Hearing guide program coordinator. I don't know much about Deaf-Blindness. You know, I have worked a lot with Deaf and Hard of Hearing folks. Sorry, just having a -- we are doing copy signing with interpreting. Thanks for your patience. But so I wanted to learn more about the Deaf-Blind community and, yep, that's why I am here. I guess I'll stand over here. I hope everybody can see me ok. Hi there. My name is Andy Altman. I am from Wisconsin. And I am involved with early intervention ASL specialists with an organization Wisconsin Sound Health. Sound as in healthy and strong. So, we are -- work with the state EHDI program and I have been in that position for two years but of course I grew up working with so many different people and diverse groups of folks. I have a lot of experience with Deaf-Blind children, as well, and so, I am here to learn more about how to provide better quality service for the Deaf-Blind children. Thank you very much.

>> Hi my name is Riley, a third year audiology student at the University of Tennessee. This is my first EHDI conference. I am really excited to be here. To echo with some other students we don't get this education on Deaf-Blindness. I am here to learn more and see how I can be a better clinician for these patients.

>> Hi, my name is Emily Johnson. I am also a third-year student at the University of Tennessee. I have been there for seven years now and I love it. I am mainly here to just add some more tools to my toolbox and, as a future clinician working with those with special needs. I want to learn more.

>> Hey, everyone. I am Ginger, a fourth year at the University of Tennessee. Completing my externship at Heiser Hearing in Louisville, Kentucky. I am here specifically at this talk to learn more about providing support for our patients who are Deaf-Blind, and their parents.

>> Hi, everyone. My name is Laurie, Director of the deaf education interdisciplinary graduate training program at Utah state University and, so, even though we don't focus -- I mean I just -- Deaf-Blindness is something I want to make sure that we are covering most comprehensively as we are able, in that program. So I am here to learn more. So thank you.

>> Hi, everyone. My name is Kathleen. And I am a developmental specialist for New Mexico school for the deaf and I am taking this workshop because I want to support a family who has a child who is Deaf-Blind, plus other complex issues.

>> Hello, everyone. My name is Joe lopez. I work for the NM -- New Mexico school for the deaf. And I am a specialist with them. Work with Deaf-Blind students, as well as complex needs. So I am here to learn more resources so I can be able to support families.

>> Hi, everyone. My name is S is hinia and this is my son, Maverick. We are here because he was born -- we are here because Maverick was born with a virus called CMV which causes progressive hearing and vision loss. He is deaf in both ears and has spacial blindness in his left eye and I just want to learn more about becoming a better mother and advocacy for my son.

>> Hi, there. The I am Darcia and I am an EHDI coordinator in the state of Minnesota and I am here because I am always trying to learn how we can identify kids who are at risk for Deaf-Blindness early.

>> Hi, everyone. My name is Sarah Beth. I am with the Hersa maternal and child health health bureau. I am here to understand how to best support the needs of all of the organizations and communities that are represented here.

>> Hi there. My name is Andrea and I am from Idaho. I, in a former life, was a pediatric and neonatal intensive care unit nurse. I taught high school and then two of my three kids were referred and diagnosed with a hearing loss. They are now, my oldest does not have that. They are 16 and 12. And, being a nurse I was relentless in trying to figure out the cause. I knew it was recessive at that point and found out fairly early than most that they were diagnosed with Usher type 2. When my daughter was about 18 months old. So in my grief, I went back to school and became a teacher of the blind and low vision and an orientational ability instructor so I have a huge case load that's doubled with the majority of my students having dual sensory loss. So just always looking for more information. I lover working with those kid -- I love working with those kids. It's a lot of fun.

>> Hi, I am Debbie, program manager for Oklahoma Department of Health's Department of audiology program. We have 10 clinics in rural Oklahoma. So, we are able to reach very vastly these kids out in our rural parts of our state. We just recently got a contract with the school for the blind in Oklahoma in Muskogee. We will be going in house to provide audiology services there and we work closely with our Oklahoma Deaf-Blind project early intervention. I am just here to make sure we are up to date in working with this population.

>> Hello, everyone. My name is Delphanie. With WOU. I am an audiology with the children's hospital of Philadelphia. Fairly new there.

I was lucky to have some learning from people who were Deaf-Blind. Always more to learn. Definitely want to see how I can better serve and support the Deaf-Blind children on my case load.

>> Hi, everyone. I am Iva, Perez. I live in New Orleans, Louisiana. I am an early interventionist teacher for the Deaf and Hard of Hearing birth to age 5. I am here today just to learn more about helping my families who have children with complex needs because there's not a lot of information out there. So I am just open to learning.

>> Hi, everyone. I am Misty, teacher of the deaf early interearningsist for southwest Louisiana. Also the mother of a deaf daughter who will be 12 next week. But I am here because a majority of my caseload has Usher syndrome types 1 and 2. I would love to learn more about the different resources I can take back to help my families there.

>> Hi, everybody. I am Peter, the fourth year audiology extern and trainee at the Kennedy institute in Baltimore, Maryland. We see a lot of complex cases including Deaf-Blindness. I just wanted to learn as much as I could about it.

>> Hi, I am Holly, the EHDI coordinator for Tennessee. And this is my first conference. So I am very excited to learn about how to support our families with complex needs.

>> Hello. My name is Betsy. Here is my sign name. I work out of Columbus, Ohio. For deaf Services Center. I am an early inner convention specialist for central Ohio. I am an audiologist by training. I have several children on my caseload that are Deaf-Blind, have complex needs, and this is a population that's very near and dear to my heart. I also volunteer as a support service provider for the central Ohio Deaf-Blind association. And I am just looking for any more creative ideas to try to, you know, help with language development with very young children who are congenitally born deaf and blind. Thank you.

>> Hi, everyone. I am Emily Wolski. I am a special language pathologist from Washington, D.C. And I work at an outpatient therapeutic clinic. We do a lot of early intervention contracting work with D.C. strong start. I provide speech therapy sessions or hearing services. I am a hearing services provider. Just looking forward to learning more about Deaf-Blindness and I happened to recently get three Deaf-Blind kids on my case load. So I want to learn everything.

>> Hi. My name is Ashley. I am also from the University of Tennessee. I am a second-year audiology student. This is also my first conference. Very excited. I am interested in learning more about Deaf-Blindness and complex needs because it's something I know absolutely nothing about.

>> Hello. I am Megan. I am also a second year at the University of Tennessee. And I am -- this is also my first conference. Super excited to be here. And, I want to learn more about Deaf-Blindness because I think a lot of audiology programs, unfortunately it's not really as focused on, in our stewedy. And that's really kind of an area that we don't know that much about. So that's why I am here.

>> Hi, I am Sarah and I had a daughter, Bella, and she was born with congenital CMV and Deaf-Blind with other complex issues. And I am glad to be here.

>> Hi, I am Megan and I work at the national center on Deaf-Blindness like my colleagues up there, Kristi and Emma.

>> Hi, I am Jill. I am a special language pathologist at the Kansas school for the deaf. I work with early intervention program. I am here because all of a sudden I have a whole lot of Deaf-Blind kids on my case load. I need some help quick.

>> Hi, I am Nicole. Colleague here with Jill from the Kansas school for the deaf. I am also a special language pathologist working with the early intervention program birth to 3. Sound Start. And also the language assessment program. So, I also have children who are Deaf-Blind with complex needs that I am seeing and want to do everything I can to make sure we are providing the best service. Thank you.

>> Hi, I am Thea. I'm part of the parent infant program. I am the coordinator for the learning center. I am also a parent of two deaf children. And I am here to learn more about medically complex deaf-plus children because we always have some in our program.

>> I am Lauralee, a parent support coordinator for those families with deaf children in Kansas, at Kansas school for the deaf and these are my fabulous co-workers.

>> I am also in a deaf mentor trainer and I work with the Deaf-Blind families and those are the families I am going to work with for the long term and I want to learn more about that.

>> Hello, I am also from Kansas school for the deaf. Willamina is my name. Tyla is my name. Thank you for the interpreter correction. I am an early intervention specialist. I have one kid but really several kids and this one child is deaf and blind. We have some Deaf-Blind children, but this child is particularly unique and so, we work with the visual interventionist specialists and so, we need to have more awareness about this child's special needs and I would love to learn more about how to collaborate with interventionists because that would be so helpful for the work we are doing.

>> I didn't miss anyone, did I?

>> Yeah.

>> Oh, Lynn, no, you gotta talk, Lynn.

>> Hi, I am Lynn and I direct the master's program in Def-Ed at Vanderbilt University and luckily a few years ago I had a grant that was on Deaf-Blindness and I got hooked. They can't get rid of me.

>> I am a consultant in the Deaf-Blind project for Tennessee.

>> Thank you, everyone. This is Donna speaking. For introducing yourselves. I know it take as long time but it helps us as the presenters. But it also, if there's someone in the audience you really click with, you can grab them before they leave and get more information.

>> Thank you guys also, I will say that again, too. Just reflecting on what all of you just said, and really thinking about where you are all coming from, I really think that our presentation addresses most of the things that you said. So that feels great. But also, if at any point you are like hey, wait, can you stop, can we go into this a little bit more? We have a lot of time together. Please don't hesitate to always just raise your hands, ask for clarification.

I will take just a minute to tell you a little bit about what the Deaf-Blind technical assistance network is. We are funding by the office of special education programs at the Department of Education. And, we are basically two different organizations. So we have the national center on Deaf-Blindness and then state and multi-state did he have-blind projects. And so, at the national center, a lot of what we do is really focused on creating products and training. The state Deafblind project folks that they can go out and help all of you and connect with all of you to really be able to learn about Deaf-Blindness. State Deafblind project can all tribe more but they provide resources, consultation, networking and training opportunities and they are fabulous and their work is free. So -- I am just going to say, they are amazing. And what they do every day is really great. So never hesitate to reach out.

The network serves birth to age 21. And we have four initiatives. One is transition, which focuses on transition to adult life. One is the interveners and qualified personnel initiative which is run by Kristi. Then, early identification and referral. And then Jana is not in the room anymore but we also have a family engagement initiative and that really focuses on providing families with a lot of resources that they can use, and also connections. That's all I got.

>> Ok, everyone. This is Kristi speaking. We are going to take one minute literally one minute to just do an activity where I am going to invite you -- don't do it yet -- I am going to invite you to close your eyes and what I want you to do is focus on what you are feeling. I want you to focus on your body. You may or may not know the largest organ on our body is our skin. So that's what we will do. We will focus on what we feel through our skin. So I will ask you if you feel comfortable to close your eyes and for one full minute we will sit here and then I will discuss with you. So let's start now.

>> Ok. Open your eyes. Come back.

What are some things that you felt?

>> I felt my pulse.

>> Yes. Your pulse. Your clothing on your body. Your chair.

>> I felt relaxed.

>> Yeah. Felt really relaxed.

>> Feel my breath in and out of my body.

>> Yes. Feeling your breath. Yeah, so you felt conscious of your legs being crossed, your hands on top of one another. Vulnerable? Ok. So inside you were kind of feeling that mental state of being vulnerable because your eyes were closed. Yes. Yes, a coolness on your legs.

>> Full.

>> Full? Full from lunch. Ok, she mentioned that where her skin was exposed, she felt vulnerable. But where her clothes were covering her body, she felt more safe. Ok.

>> -- the word vulnerable -- -- concern --

>> Yeah, so she's asking what's the best sign for vulnerable?

>> -- that description?

>> Yeah, ok, thank you for that question. Yes? Yes, shift in the air. Yeah. So, here's the reason we do this. Or I like to do this activity. Because our kids who are Deaf-Blind, they don't have full access to their distance senses, whether it be vision or hearing. So, what's the biggest organ they have access to that they are noticing all the time? Their skin. So all of those things that you are mentioning, they are feeling. And they are trying to take in all of this information from the largest organ on their body. And categorize it. And make sense of it. And you know, so, we like -- or I like to start off with this activity to just kind of make you think about that and keep that kind of -- keep that in the back of your mind as we are presenting and doing these activities and talking about the strategies that we are using. Because that is one of the most important things I think we tend to forget about. We tend to forget that the skin is always coming into contact with something. Whether it's our clothes, people, air moving, sunlight shining. All of those things. And that is going to impact how the child or individual interacts with you, how they are acting on their own. And just interacting with the world around them.

>> All right. So, we are going to move on. And I am just going to give you a very short overview of Deaf-Blindness. When I tell people I am in the field of Deaf-Blindness, they usually say to me what name? Helen Keller. Oh, like Helen Keller. And I say -- ehh -- not really. I mean yeah, some. But, there is a whole continuum that Deaf-Blindness can fall on. And so, when I tell people oh, if someone has low vision and has, you know, a mild hearing loss, they can be classified as Deaf-Blind. If someone has, you know, a cortical visual impairment or cerebral visual impairment where the visual impairment issue is in the brain and not in the eyes. And they are also deaf. They are Deaf-Blind. And that's when the light starts to sort of flicker on a little and then I say -- ok, yes, we do have some individuals who have no useable vision and you know are profoundly deaf, yes, those are the people you are thinking of. But, there's a whole continuum in there. So, the things that people often mistake are that oh, that kid just has a little bit of a hearing loss. Oh, they have just a little bit of a vision impairment. Um -- that still makes them Deaf-Blind. Because if you think about it, if you don't have full access to things that are coming at you visually, if you don't have full access to things that are coming to you auditorialy, you still are missing information. You don't have full access to your environment. A lot of times we tell people that Deaf-Blindness is a disability of access. We don't have full access to what's going on in the environment around us.

So every year, we, at the national Center, do an annual child count so we ask all of the state projects to look in their states and identify the kids that they have in their states, that are considered Deaf-Blind. I will tell you that we are certain that this is an underrepresentation. So if or when you go to the child count and you look at your state, Wisconsin is in the house? Yep, me, too. Go, Wisconsin. So, let's say you look at Wisconsin and you say oh, wow, there's only -- I don't know off the top of my head, but let's say 187 kids in Wisconsin who are identified as Deaf-Blind. And you go -- golly, that seems low. That's what we say, as well. We need parents, we need practitioners who know what to look for, to really say -- oh, this is a kid who should be identified as a dual sensory loss kid. This kid should be referred to the child count. That said, we do have many causes of Deaf-Blindness and the majority of those that are on our child count, 87% of those children have multiple and complex disabilities.

Yay, we get an activity. I love activities. So I am going to have.

>> Donna, can I say one thing real quick? If you want to know more about identification of kids with Deaf-Blindness, I will be at the poster session tomorrow and stand and talk to you all day about it. Why it's an undercount, what we think it will be and feel free to come by then and I will talk to you again.

>> This is Donna. Can I add on to what you were saying, Kristi, is that all right? If you go to your state Department of Education and look and see how many kids are listed as Deaf-Blind, here in Kentucky, well, across the river in Kentucky, there are nine students who have their primary eligibility listed as Deaf-Blind. And on our census, we have over 170 kids. And there's probably double that. So, I want you to think about that. Because then people don't know what they don't know. The people who are working with the children who have a dual sensory loss don't even know they are working with a child who has a deacon loss and they may not have the skills or early interventionists to work with them. So your state Deaf-Blind project, which is really nice, if you can contact them and make a referral, we are so happy to go out with the early interventionist and we are so happy to go to the school and work with them to start training and coaching all of the people who are working with our children. So, just keep that in the back of your mind, too. Do you want to say something?

>> Just to piggy back on that, in Tennessee we have 299 students identified. 17 primarily disability is Deaf-Blindness.

>> We will just keep piggy backing here. It's hard to stand there. In South Carolina, we have 15 under the Department of Education. But I have 163 on our child count. Two things that I would want parents and anyone advocating on this, not to take away from your poster session, but, two things to keep in mind. First of all, the child count census. All of us usually have a two-pronged verification process. You have to have a documented hearing loss and an adverse effect. And documented vision loss. Sorry. But it's usually a medical and then an adverse effect. So, a lot of times you will get IEP teams or IFSP teams who will say oh, they aren't Deaf-Blind because let's say they have Usher syndrome. There's no adverse effect in the vision. So they must be only deaf. Ok, in South Carolina, we would put that student on our Deaf-Blind census because we know, we can anticipate there will be a vision loss and we want to support parents in that process and in that journey. Can't say that's true in all states but in South Carolina, we do. And one more -- thank you, Tennessee and Kentucky would, too. The other thing that 99% -- no, I made that figure up. A majority of the time where our students land are multiple disabilities. I am seeing almost every head in the room go up and down. We are working aggressively in South Carolina. I know a lot of states are and there are efforts on the national level. I DEA very clearly says that students with Deaf-Blindness are not considered multiplely disabled. You flip over I DEA and there it is. Nobody's flipping the page. When you hear someone say we will do primary, secondary hearing loss, let's go back to IDEA. There are a lot of disabilities that are not allowed to be multiplely disabled. Deaf-Blindness is one of them. That's free. Ma'am, you had a question, still?

>> In Florida, I was working with a Deaf-Blind initiative to see for my son for what equal fies for for support. And for the -- what equal fies for for support. I think there's some confusion. Because the I can connect program, it has a different vision acuity listed and think that causes a lot of confusion because that number is so different than what may be listed as what they can provide as support. So maybe that could be -- because it was confusing to me. I was like oh, wait, he's identified as dual sensory, but yet he doesn't qualify for certain things that he actually does need to have access to things. Because it talks about vision acuity or peripheral and -- vision loss. He has a contrast of 50%. That is like, you know, you look at the wall and floor and your pants could look the same.

>> We only have three hours. So, I could go on and on about this, but what I will say, what makes it -- different organizations have different legislations with different formulas. Different states, students can be blind in one state and not in another state. I was just involved with an IEP meeting that had a teacher of the deaf and teacher of visually impaired at the meeting. Student has received services from both professionals for years and they wouldn't put the student as Deaf-Blind. They said we don't see a need. You have been provided deaf and vision services for seven years. You don't think they are Deaf-Blind? Clearly they have more than the deaf professional can provide because they have vision concerns. From state to state that formula changes within a state that, between agencies that formula can change. Department of Ed may have one formula you can qualify for but you might not qualify for bulk rehab services. I don't have all the answers, if I was to be very candid. It's very frustrating and we, I think that's what we need to do more and more as a network. And honestly, parents are the only ones that really have the strength. All of the professionals have tried for 40 years. But, we are seeing progress. Catch me afterwards and I'll tell you some other stuff.

>> This is why I just -- so many times when I was in Vermont, so many times when I was in New York, providing services directly to families, providers would say I am not sure that I am ready to talk to the families, because I don't think they are ready to hear the word Deaf-Blind. I don't think that they are ready to be on the census. I don't feel like it's time yet. What we hear time and time again. Sarah, maybe you can speak to this, is that families are saying -- ask us. Let us decide if we are ready or not ready. And then if you are talking about the census and why it's really important, as you can hear, there are so many different numbers out there and we cannot correctly advocate for these kids until we know the numbers. And so if the kids aren't identified, then we can't speak for as many as there are. And so it's really critical that we know how many there are. What kind of disabilities they have, and all of those pieces so that we can correctly advocate for what they need. Something else to say?

>> I just have one more thing to say. Sorry.

>> It's really important --

>> Well, and obviously, we are very passionate about what we do. Passionate about the families, students and individuals. So this is something that we could, you know, three hours is nothing for us. We could just stand and talk and talk. But I just wanted to say that we talk a lot about learner outcomes. And, where we want our students and our children and our clients to go. And when I did my dissertation, this speaks specifically to what I think Robert was saying, or maybe it was Donna. I don't know. But I looked at IEP's over many years for a number of students. And I looked at what's their primary disability category? And how did that impact their communication growth over time. And can I tell you, first of all, I called my dissertation chair who was a very close friend of mine in tears. Very often. Because, you don't want to read some of the things I had to read. It was horrible. But hardly any of the students had the label of Deaf-Blind. In fact, they went from multiple disabilities one year to other health impaired the next year and maybe if they were lucky, they got identified with Deaf-Blindness and then all of a sudden are back to multiple disabilities. And I had two students that actually, I looked at their entire educational career. One of them -- hardly any communication growth. Hardly any. The other one, once they hit middle school, completely leveled off. There was no communication growth after middle school.

So my point in saying that is -- a proper diagnosis is key. Proper identification is so important. And so, what Robert was saying about this kid has a TVI. They have a TOD. Why aren't they Deaf-Blind? It makes a difference. It make as huge difference. Ok.

>> I have a question.

>> All right.

>> Oh, sorry, just a comment. I work with just zero to 3 and I bring it out to every, the Deaf-Blind project for every visit. Talk it up, tell them they can get a home visit, flyers in the mail, different presentations. And I never had a family say no. It's just great to get them enrolled. My kitteds were in it when they were young with Usher. It's a great service.

>> I just want to say thank you because I just spoke with Lane from the Idaho Deaf-Blind project. She showed me the numbers. Are doing great work of increasing identification in your state. So thank you.

>> Hi, I have a question. When do you think parents like identify with either the term Deaf-Blind or the concept of like -- dual sensory loss or whatever, and that they could self-select into wanting to report? Like if we asked them are you ready to report? At what point do you think that they would know that somebody would have, you know, discussed that with them or something.

>> So I am walking over to a parent.

>> Yes. I am a parent and I do work with other families. I work with CMV families who have children and many of those are Deaf-Blind. And it seems like parents are ready to identify when we understand it. When we understand the importance of it. We don't like extra labels. My kid had like a dozen. So I don't like extra labels but when I understand what that label is for, and how it's going to help me, then I am all for it. Like let's jump on that. Let's get this so that I can get this, this and this. The but many of my families do not understand the label. They do not understand what's behind the label and they don't understand and a lot of the professionals don't either.

>> Go ahead. I'm sorry. Donna?

>> I was going to -- it doesn't have to be -- just provide the information to the parents ASAP. If you have not left the hospital, ok. That's -- I'm ready for it. Because as soon as you tell me what's going on to help me, I am all in and making phone calls or I am on the Internet. I don't want to wait. And then it gets the -- it gets both parents on the same track. Because if you start identifying later, it may be harder for one side of the parents to go wait, let's work on the first one. We aren't ready to work on the second one yet. Then that could cause some deterioration and support.

>> 100% agree and I cannot take away from -- sorry -- I don't want to take away from the comments that the parents just made. Because I think that's exactly spot on. I will say, and I think I am just trying to keep it real in here today -- time and time again, when I am meeting with early intervention teams and they keep telling me parents aren't ready for that, let me be candid. The early interventionist usually isn't comfortable breaking what they see as bad news for a second time. Or they are like I just told them they were deaf last week and now I got to tell them with Usher syndrome now that we have verification. I would suggest as a professional, sometimes you have to look in the mirror and say who is this most difficult for and find support on learning how to communicate that to parents because the parents need all the information and they need it as soon as possible.

>> This is Danna. I want to piggy back on what's said and then I know we have to move into the activity. And what Sarah said. In Tennessee, we also, we work really -- we are fortunate to be in the hospital and fortunate to get a lot of our referrals from medical providers and work closely with our early intervention providers and our school for the deaf outreach is wonderful for birth to 5 to refer. It's the terminology, too. Like Sarah was saying. Helping families understand the terminology. That's why oftentimes especially with really new little babies and new families, we often talk about combined vision and hearing loss. Dual sensory loss. So when I call them I often say hey, yeah, we got a referral for your child because they have both vision and hearing concerns. Which makes them Deaf-Blind. And I think really again like Sarah was saying, we have those conversations with our early intervention providers that are going into the home and medical providers to make it not so scary. And to not make it feel like it's just another thing to really show them the importance of that. So, Sarah, thank you for sharing that.

>> All right. This is Donna. Guess what. We will move a little bit now. You all can't get too comfortable where you are. This will be quite interesting because when we have done this activity with other groups we haven't had interpreter needs. So this will be a very interesting experience. First of all, I will give you instructions. If at any time doing this you are uncomfortable, you don't know what's going on or you want out, you can always raise your hand. I want to make sure that everyone knows that. There's always an out. Don't worry, we aren't getting pie, cream, or anything out to put on your face.

What we are going to do is we are going to go outside the door and line up. And my friends here are going to give you vision simulators and ear covers to put on. And we have three different activities in the room that you get to participate in. And we are hoping that we can come back and unpack that and talk a little bit about it. Because that's what will drive the rest of this presentation. Just that feeling that you will have.

So, if you can just leave your stuff where you are and we will go out the door and just make a big long line. Everyone get in line. And we will hand you your equipment.

>> Ok, guys. It's time to go phot next area. -- get you there safely. Once we get up here, we will sit in a circle --

>> Learning so much.

>> Could everyone please sit down. We will be right back.

>> Oops! Ready for reading, this is going to be fun. Where's the book? Has anyone seen the book? I don't know, kids. We have two books. Dinka Donkey and Angeli na at the fair. Which pictures do you like the best?

>> I can't see them.

>> Oh, they are really pretty. There's a lot of color.

>> Angelina at the Fair. Do you see what animal this is?

>> No.

>> I can't see the interpreters. I can't see the interpreter at all.

>> What do I do? It's -- the interpreter's blurry. -- understand them.

>> Try harder. Try harder.

>> Oh, ok I'll try harder. Ok. All --

>> Ok, you can sit close.

>> For a wonderful day --

>> Yeah.

>> Hey, stop, stop touching each other. Keep your hands --

>> Almost lunch. What are we going to do, class?

>> And last, when all the snow had melted -- soft and warm again -- fair arrived in town, Angelina's ballet classed performed -- in celebration of spring. Do you see there's a Maypole. Has anybody seen a Maypole before?

>> Is Angelina a girl or -- [multiple voices overlapping]

>> A great question. Is a mouse. Let's keep our hands to ourselves. Maybe if you flip a little closer. After the dance, Angelina was ready to go to the fair. But her parents stopped her. You forgot little cousin Henry -- he will be very disappointed. Angelina was furious. I don't want to take Henry -- [so much noise] Mary held out his hand just the same and Angelina had to --

>> Watch where your feet are. -- with a span of brightly colored balloons. See all the balloons.

>> What's a balloon?

>> It's a big rubber round -- [so many people speaking at once] oh, I'm so sorry we will have to learn more about Angelina next but we have to go to our next station. We are going to get up and --

>> Hurry up. Try harder.

>> I'm going it take you down the hall.

>> Ok. -- just a second. We will be right back. Watch out, everybody. Be careful. -- chairs and people. We will have you take a seat.

>> Ok. Sit down for storytime, please.

>> It's your favorite book. Lots of colorful pictures. You like pictures, don't you? Everybody likes pictures. What's your favorite picture?

>> Oh, guys I'm so sorry -- I had to go put --

>> That's awesome.

>> I will read you a story -- excuse me. Hands to yourself.

>> We aren't good at scheduling.

>> We don't lay down on the floor. So sit up, please. Martha blah blah. Can you see? Maybe you need to scoot up a little closer. Martha was a great communicator. Sad, happy, mad. See all her faces? A sad face, her happy face, her mad face.

>> One, two, three --

>> But when she ate Apple soup, the letters went up her brain instead of down her stomach. Have you ever had soup go up to your brain? Martha spoke words. Isn't it time for my dinner! Martha loved letters. She loved words. [Overlapping voices] -- can a dog be sitting on a chair?

>> Hey! Timmy stop.

>> Sorry teacher. My mom gets mad at me, too.

>> Timmy -- shhh. Of course Martha couldn't help but notice how much her family enjoyed having a -- how special they felt she was. There was someone else who loved letters as much as Martha. Alf Abbott was a man at grainy soup company. He made all the A's in the alphabet soup. Unfortunately the new owner had other ideas. She was going to -- why do we need all the letters in this is soup not --

>> I'll show knew a little bit.

>> Does your granny look like that?

>> Is the snake over here? It got out of its cage. Do you see the snake?

>> Is class over yet?

>> I think it's about time.

>> Ok. But she was really -- fewer letters -- granny -- the 26th -- oh, whatever it is. One of them was out. Within a week cartons of the new soup went to the supermarkets. No one will ever notice the difference, -- see what letters are in the soup? It looks like some of you are not paying attention.

>> This is an announcement.

>> Several days later --

>> We are all done, please. Can you return to your seats? You can take off your eye masks and ears and Robert will come around with a bag to collect them.

And then, because this was so much, you guys can have five -- no? That's what -- Danna said. No? No break. Ok. Later. Later. Later. Donna says you get a break in a minute. Thank you all for being so game. [Applause]

>> Ok. Everyone, this is Donna. If you can come back and get into your chairs. Some common themes throughout today is, of course, access. Touch. And why those are both at the top of the list that we should be thinking about. So, we did an activity where you had to do three different tasks. I want you to tell me how you felt.

>> Be honest.

>> I was so tempted to act like an actual child and like -- run around or like take all the toys or like lay on the ground like with the storytime. Because she's like can you see the pictures? And I'm like -- and she said oh, just move a little closer. So I obviously couldn't still see them so I was so -- I mean I didn't want to -- embarrass myself but it was tempting to take all the toys.

>> Mm-hmm.

>> I found listening fatigue is very real. It took a lot of effort to pay attention.

>> I just felt left out. Like I didn't really do anything. I just sat there. Until the book activity. And so I tried to just do nothing to see if anybody bothered to interact with me. And it was very lonely.

>> I want you to think of the words that people -- I'm sorry -- this is Donna. I want you to think of the words that you are listening to. Lonely. Left out.

>> Definitely didn't have any of my own autonomy, being grabbed, and I guess coming in as a teacher, you do introduce yourself so that was kind of hard. But even, I took it as like a break, I'm just going to check out for a while during storytime. But I even had the context of what a donkey is, kids who haven't touched or had concrete experiences --

>> I felt just disgusted. Because when I asked what things were, I was completely ignored. Things just kept happening. Messages were made, messages were given and I completely missed them and frankly my feeling is disgusted.

>> And I want to say thank you for some individuals that this was a little bit more for than others. And there were some auditory things happening that I know you did not have access to. A lot of us were running around hitting the walls, banging, being loud and obnoxious, some would say I am natural that the but I was trying to go over the top. There were comments like "try harder" things like "where's the make it" to inTim gate or catch you off guard. So those of you who didn't have access to that, there was a lot more going on that you may not be aware of.

>> It made me sad, because my son is deaf and cannot see out of like the sides of his eyes. So, it made me wonder what it's going to be like for him in situations like that in school. And it made me feel like I was him for just a minute.

>> For me, it kind of made me feel as if I were a student in that situation and not being in the correct or appropriate school placement with teachers with compassionate care and training to teach Deaf-Blind students and the impact it could have.

>> I felt very, very anxious and like I wanted to just retreat. Where I could just be safe.

>> This is Donna. Another word I just heard was "safe."

>> I felt frustrated. And fatigued. Because I was constantly straining my neck to be able to see out of one eye. So -- it was exhausting and the other Iowas just blurry. So -- -- the other eye was just blurry. I took out my Cochlear implacket. It was a huge challenge this is Megan. I felt very frustrated because it kind of brought me back to school. Like I'm not Deaf-Blind, but I do have implants and just situations where I have been in an environment that was not accessible to me. So it kind of brought me back to those days.

>> Sort of different phrase, but similar sentiment as some others. I very much felt acted upon and I wasn't given many opportunities to act on my own volition. And I got -- well at first I got thirsty just sitting at a seat and I had enough vision with the goggles that I just walked over to my bag and drank some water. Nobody cared that I stood up and walked around so let me keep doing it and I started kind of walking around and feeling things and seeing what it was like and whether for illustrative purposes or just exercise purposes, nobody cared that I was wandering around for a solid five to seven minutes and if you think about appropriate staffing in classrooms or other situations, somebody could very much wander off on their own and see what that was like. I also felt so I am hearing and so with the headphones on I had some access to sound and during the activity at the table, I felt like I was battling for which thing I had more access to. The teacher would be signing and then looking at me so I feel like I caught enough but the teacher would turn around and I would say oh, wait, come back. I am only seeing one hand signing. At some points the teacher would be talking and not signing. I thought no, I want both at the same time. So -- sort of having a, I guess partial loss in the two different ones made me feel like I was picking which one to depend on in different times and which one to lean into in different situations.

>> I am just trying to process what I experienced, just so that I have the right words to describe my perspective. Think it's different. I work with children and we know their labels and we think about how to support them. But when you are actually in that space, you can feel frustrated. I felt a little bit lost. I wasn't quite sure what was next. I was doubtful of what was going to occur and wow, those activitys were really interesting trying to figure out what was on the table and in the story activity, I felt totally lost. I had to turn my head to be able to see out of my glasses the right way. That was hugely impactful for me. It was emotional. I started to tear up inside my glasses. Because it really just touched me. Now I really have a sense of what they have gone through and how frustrating it is and I know that I want to support them more and do the best I can. So I am a little bit shaky from that experience. But it was really emotional for me. It's nice it see that perspective. Thank you so much for that activity. I really appreciate it.

>> These are such powerful comments and I would challenge you to keep in mind, you were in simulation for less than 30 minutes in a roomful of people you will probably never see again. Imagine being in a room of your peers that if you have a bad day or mess up, they are going to know about it the next day. And at the end of this, you know you are going to go home and have access at home. A lot of our kids don't have access at school or at home.

>> Yeah, a lot of the same feelings. I felt particularly -- I felt very frustrated at storytime and I sort of zoned out because I couldn't hear any of the words and at the -- when I sat by myself I was totally bored and didn't know what was going on. After it seemed like I had been forgotten, it looked like they were having fun at the table so I just went over there similar to your experience. I thought I'll just go do that. By contrast, even though it was that horrible pattern thing and I couldn't understand why we were doing what we were doing, the teacher was three feet away signing and it was like oh, I know what's going on. By contrast that awful thing was like so much better and she called me by my name and if I signed something she responded back and it was like light years better than having no clue, even though it was not a lovely activity.

>> Absolutely felt the way you guys are describing and just isolated. One thing that sticks out to me is that typically, I love touch. Like that's my love language. I love it. But I did not like being touched because I had no idea why you were touching me and it was like walk by and, I guess -- it really made sense, about the skin, it made so much sense to me because I was so aware of the touches, but then like somebody would touch me and I'm like ok, that means something. Then nobody was there. That was very interesting to me.

>> Others? In the back? While she's walking back there, this is Kristi. One thing that I have seen so often it just makes me cringe inside besides all of the things you are talking about that I didn't do but am like oh, I kind of wish I would have done that is teachers going oh, how are you? What are you doing? To a 17-year-old student. Right? Like -- that's another thing that I kind of wish I would have done, because as adults, you know, you kind of cringe at that and pull back.

>> The one thing I was thinking is -- services and wraparound services from like the moment baby's born through adulthood and through transition. And if that's just one point in time that we all shared, that's all I could think about is like the whole system in caring for the kid through adolescence young adulthood and into adulthood.

>> This is Donna. And it's Donna, I forgot to give you my sign name. Another thing to remember is -- kind of what we were sharing is that a lot of times we look at that paperwork of what all of those labels are for the student and we think we can figure it out. Really, we have to work as a team and we have to be like the best detectives. As my friend David brown would say -- the best detectives in the world. Because, it's your observation to figure out what are those sensory channels the student is using, the child is using, and how can I best use touch with them. How can I give them that information so they are accessible. So, I know this is an uncomfortable thing that we do a lot of times and I don't want it to be mean. I want it to be empowering to you guys. I want you to take that feeling, that gutteral feeling you just had and I want you to think about it every time you are working with a child. Because, it empowers you and empowers families. For everyone to understand that child, that they are more than just that document.

>> Another question?

>> Just one more thing to add. My vision was much more limited than it would have been with just the goggles. But as we are talking about how we felt and what we noticed, I think it's important to really internalize that we have the language to put words to what we are feeling. And, many of our kids don't have that. So when we are seeing behaviors and how they are processing, what we are sitting here talking about and processing ourselves -- it may or may not be able to do that. They don't have a label for this.

>> I wanted to piggy back on that. I was so tempted to be crazy, because I was really bored and that's what a regular kid who didn't -- we all have self-control in here and even those of us wandering around, it was a conscious decision to be like I'm going to wander around and see what they say. But most of us, if we were -- however, if we were in school, we wouldn't have -- we wouldn't just stand there and wait for the teacher to come. We would be grabbing all the balls throwing them, grabbing them from each other's hands because we were bored and then we would have been labeled a behavior kid. Oh, he's a behavior kid.

>> And I just want to piggy back on both of those in saying that just want to reinforce what was said. We all have our experiences. Whatever they be. Hearing and sighted. Sighted. Hearing. You know. Whatever it is. We have those experiences. When we are talking about kids, especially those who are born and have limited vision and hearing, they don't have those experiences. So while we can make meaning out of things, we canopies together, oh, I think I heard -- and I see this animal, so that's probably a cat. Our kids who have limited vision and hearing don't have those experiences, can't make those connections. It's something that we really have to work on. So -- we can break. We will give everyone a break. I don't know how long of a break do you want, Kristi?

>> Well let's do four minutes then it will be 2:30.

>> All right. Everyone go take a break. Stretch. For a few minutes.

>> Ms. Donna, you are next.

>> Ok. If everyone can come up and get in their z we will get into those evidence-based practices. That's what you all are here for. You want to hear, you want to know.

>> Ok. Welcome, everyone, back. We are glad to have you here. We are going to jump into the meat of everything. And we will talk about evidence-based practices. And so what we will talk about in this presentation, we will talk about building trusting relationships and that might sound really simple. But there are some little things that we can do especially with our little ones to build those trusting relationships. Child-guided approaches, active learning, and shared experiences. Appropriate hand use and respectful touch. There's that word again, "touch." Identifying appropriate communication modalities. And then -- predictable routines and cues. We will run through all of these.

Building trusting relationships. Probably one of my favorite things to talk about. A lot of times, and I really apologize, because I usually have lots of baby dolls at my house, because I have four granddaughters. But I just moved from my house to a smaller house and I gave them all away. So I wouldn't have to take the 50 baby dolls that were at my house. So, today, I am using this dragon and we are going to pretend that this is a baby. Ok? This is a baby. So -- when you are working with a child, especially a little one, my friend, Suzanne, always holds the baby close to her body so that the child can see and touch and feel what's going on. It's also giving that child that feeling of being safe. That was a word that we heard before. Safe. Having them there. Instead of holding them out in the air, leaving them on the floor with nothing around them, or not touching them. Ok? And if we look at our slide up here, some of the things that we have on the slide are -- you are going to want to touch in a neutral area. So, with a baby, a lot of times you are carrying them. But if you are working with a young child or even an older child, remember when you are going to use touch with them, you are going to want to try to go on their shoulder. My interpreters are reminding me that they are not my props. But like even touching, you are going to touch in a neutral area. Or behind their hands right here. If you are going to go into hand under hand. That's the way you are going to do it. Also, you probably already know when working with children, you want them to know who's there. I want you to think about everything we talk about today will tie back to how you felt during that time when we were under blindfold. When someone comes up to you and I come up to Robert, I don't want to go -- hey Robert! Or hey Robert, guess who it is. Have you heard that one, too? Where people would say hey guess who it is. Do you know my voice? Yeah. That's disrespectful. That's not valuing the student. So you want to come up and maybe give them a little pat over here and go -- hey! And I wait for him to look at me. It's Donna. Or if I know he doesn't have the vision -- it's Donna. Or maybe I need an identifier. Look. It's Donna. He knows that that means it's Ms. Donna. So I am giving him all the information he knows to know it's me. That I have come to him. And even before we start an activity or any expectations are done, we want to make sure that he knows it's me and that he's engaged with me also. Ok?

>> Let me interject on this. If you are a team in a school room, and you have an identifier, that can be many different things. I don't know if you saw Donna had something on her wrist. Deaf-Blind kids, I have literally been in a room where all the adult also different color wrist bands. Some of you got that real quick. Ok? Sometimes name badges will have a sticker stuck on it. But if they all have the same fuzzy sticker, it's not an identifier. You just have the same fuzzy sticker for the Deaf-Blind kid in the room. It has to be purposeful. Sometimes you can't be touching the child. Especially if you are a baby. There's a great video I wish we would have thought of having it. I think it's out of Texas. Sometimes you have that baby on the bed but when you are walking around the bed you can be moving your hand around the bed so the child always knows that you are in the room. And I can share that video with you afterwards. But -- be purposeful on thinking about what touch looks like. It may not be necessarily a physical touch but making your presence aware in their environment.

>> This is Kristi and I just want to add one more thing. Some people think oh, well I have long hair. So I'll just use my hair as that. Well, I forgot to tell the interpreters that my name sign, that was given to me, is K.P. Because I had long hair at the time. Do I have long hair now? Not going to help. If I have taught that child or individual that I am Kristi by having them touch my long hair and it's suddenly gone, for whatever reason, they don't know me. So that's something to think about. And if you use stickers, think about you better have a boatload of those stickers. Because those things come off. So -- you know, you really have to be purposeful and thoughtful about the things that you use.

>> And this is Donna. The other thing I was going to say, too, is -- everyone on your teamworking with that child needs to know how to approach the child, how to gain their attention. How to know when you have a child who is engaged. And also how to let the child know you are leaving, also. How many times have we just been working with a child and I need to bring back my -- working with a child and all of a sudden I'm like oh, gotta go. I walk away and leave them without any information that we are done doing what we were doing and that I am leaving. Remember we talked about touch communication. Just simple things like I'm here. I'm leaving. And then come back. I'm back. To let them know. Starting very young is really important. Because we are respecting the child's mode of communication and the way they take information in.

So on the slide up here, I'll go back one. We also say join the child in what they are doing. I always like to talk about, and it will be hard to show, but -- if Danna's a child and I am going to put her here and she will be sitting in the chair, and she may be in a wheelchair, and here's her tray right there. I am going to go over to her, I will let her know, hey Danna, it's Ms. Donna. Ok? And then maybe she's sitting here. How do I participate in what Danna is doing? So Danna has her tray there. What I like to do a lot of times is I will sit across from the student. And I will -- if you can't see me, I'll just tell you -- my knees are touching her knees. Right now. She knows that I am here. I am with her. I want to engage with her. I want to communicate with her. And then, sometimes what I have done is, you know, I just come up here and go -- I hit on the board. See if Danna will copy me. Danna copies. We are starting to build a trusting relationship. I am here. I'm following the child. Always look up VanDyke for follow the child. I will follow what she's doing and I will build on what she knows. All her experiences. And we will come up with new activities. But you can see how my legs are touching hers. If I can't sit across from her like this, I may sit to the side. My legs are still touching her. My hand is on her right here to let her know I'm here. Ok? And those are just simple things. If you are with a baby or an infant, and you are sitting on the floor, your legs could be in between your legs. So that they could feel that you are there. And they always have access to communication because I'm there. If I am sitting next to Danna like this, she knows she can reach over and grab my hand if she wants me to participate or communicate, whatever it is, I am here. I am accessible for her. And shoe's predictable for the child, too. If you are doing it and then you teach everyone else on that team hey this is the way we do this. And then the child can really understand there's my communication partner. I know I can trust them and build on this. And then -- wow. It just really takes off after that.

>> Also, if you are starting sound localization on the side is better than in the front. So if they are starting to be able to hear sound or starting to communicate, it's good to start on the side, also.

>> Question?

>> So I was just thinking for those who know, it's important to start young, of course. For example, my aunt had Usher is syndrome and we would sit knee to knee but she didn't like T she wanted to be further away to communicate T does depend on the level. Some kids are more sensitive to touch so you have to be open to finding solutions. If you work with them young definitely give them options but as an adult or if you are working with an adult, it might be very different. My aunt didn't like me to knee. She wanted more distance between us. Just an example.

>> This is Donna. I agree with you. As they get older, I think you have to find out what works for them. And the reason I say to start young is, we had our friend Emma Riley who has Usher. She's in her 30s and she spoke at our Deaf-Blind Summit and one of the things she said was, I wish we had started touch a lot sooner. Because right now, she's at the point where she prefers protactile communication. But I do think it's respectful. We should always find out what's comfortable and what's not comfortable. But I think definitely with babies and very young children, just letting them know you are there is a huge way to start a trusting relationship. Thank you for your comment.

>> Two things to consider, too, that I just heard here. Donna said, quoted Van Tyke and talked about following the child. What that means is all the way through. So like when Danna was rerepeating a double tap, great. In some situations I have seen where the teacher might -- using this example, say the teacher taps three or four and the child only taps twice, I have seen adults in the room correct the child. That does not build a trusting relationship. They will stop. Because they are scared. The other thing -- echoing this comment about the touch, also keep in mind in building relationships that kids don't have the same level of relationship with all adults in their life. So, Donna may be very comfortable being knee it knee with Danna. But if I come in, I try to mimic that, she may not be comfortable with that. It frustrates kids and sometimes me when I am observing when they say oh, this is what the student likes. No, this is what the child like was that individual. They may feel differently about a new individual. That comes into play even at home like at family reunions, Thanksgiving, Christmas, sometimes children behave differently around the weird uncle. Ok? So, anyway just something to consider.

>> They want a definition for protactile. I am not the best person to give that definition. If someone else would want to give that definition. Kristi?

>> She's the pro.

>> Don't quote me. I'm not the pro.

>> I can explain what it is. It's more like ASL. It's a signed language, hand overhand. It's how you communicate with Deaf-Blind folks. So, protactile is different than haptics. It's quite different. Haptics is more surrounding information. Just -- a specific system of communication. Protactile is a Deaf-Blind language to communicate through hand-over-hand sign language.

>> And one thing, this is Kristi. One thing I would like to point out that I think is really important about protactile, it's a language that was developed and is being taught and you should only learn from individuals who are Deaf-Blind. It is their language. And I think that's really important. It's very empowering and, I mean -- I want to learn protactile, but I am not the person to ever teach any of you. And that's why I love that she explained it because she knows it better than I do. Not that she's Deaf-Blind, but she could explain it much better than I could explain it.

>> Ok. Good?

>> Question.

>> My name is Danna. Protactile includes very specific feedback so that it's a two-way process so that the Deaf-Blind person says yeah I got the message. I'm following you.

>> Question on recommendations for perhaps increased frequency for home visits for infants that are Deaf-Blind, if that's a recommendation, so that providers can gain that relationship of trust? And the other question I have is about how to overcome tactile defensiveness in infants who have had prolonged hospitalizations.

>> Who wants to tackle those?

>> I'll start and then you come in. This is what we talk about. Tactile defensiveness I can talk about. And if you can repeat the question about EI, that would be great. So, a lot of times like you are saying, kids have prolonged hospitalizations, they are in situations a lot where people are moving their bodies all the time, not -- they have no idea what's going on. It hurts, is that what -- yeah. It hurts. They are just, you know, they are just touched all the time. Manipulated. So then they come home to a place that they don't know necessarily. At all. And are continued to be touched by early intervention providers. They get in the car, they go to the doctor again. So it's a constant state of that you aren't in your thinking brain. You are in your feeling brain and your feeling brain is telling you you aren't safe. So in my experience the way to overcome tactile defensiveness is to really start on this building trusting relationships just to say hey I'm here, I have no agenda, I am your provider but I will just sit beside you or lay beside you with your mom or with your sibling and we will just like -- have a non-talking conversation with our bodies, basically. And that's something that Barbara Miles, another Deaf-Blind wonderful person always used to talk about, because we come in so much with an agenda. And it is so hard, as you know, as -- as people who are providers, it's like what is our lesson, what are we going to do today, can I show that I have done it? Can I check off the box? Yeah. Just work, work, work, get done. And then what Barbara always said was -- sometimes the best thing you can do is just to do nothing except to show that you are there and then if you do that over and over again and coach the family to do that and have the family coach their medical providers about it, then slowly, over time, I have seen it and it's true, that maybe kids who are like up like this and everybody says it's like spastic, others -- they will relax. They will come to you. They will. But you have to give them -- I mean basically you have to give them the autonomy to decide if you are safe.

>> Emma, you did great. You didn't need me to do that.

>> My favorite thing to talk about.

>> Also along with that, we have to remember sometimes that we need to turn off our voices. If we are with a child who has hearing, even mild hearing loss, or profound. To make sure that sometimes it's just about the touch. And we are always -- you know, we are always talking. We do this when we go into homes and with early interventionists. If we are working on vision or if we are working on being able to be more receptive to touch, we need to take down some of the other sensory issues. So by turning off our voices and moving at a slow space, because we are all in a hurry, trying to accomplish what we are doing. As a parent you are trying to get things done. Just be in the moment and be quiet. Allow them to have that moment. That overstimulus happens so often with our kids.

>> And there's a video in the open hands open access learning modules which we -- I have -- I'm keeping a run running list of thing we can send you later. A mom is talking about the science of the brain. One of the things she's talking about is moving from your feeling brain up to your thinking brain and that you cannot learn if you are acting in stress. It's the same with all of us. Right? Like if you -- any time you are stressed you aren't really taking all the information in. And so if you really want kids to learn, you have to make them feel safe first.

>> I probably shouldn't say anything now because that was perfect. But I was planning on piggy backing on what Danna said. Because you have to sometimes turn that voice off. You have to do that in that moment but I would encourage us not to let the moment define the child. Think about it this way for us who are sighted and hearing. You are in a new town and you turn down the radio, because you can't process what's happening around. To me, that's the best analogy of what we are talking about. Most of the time I can handle both. But in that moment for whatever fatigue, frustration, new environment, whatever. I have to change how I take in information. That should not define who I am.

>> I just wanted to say to you like, because Maverick does have sensory issues, that sometimes he can tolerate things until he gets overstimulated and then I have to watch his facial expressions and body movement in order to understand that he does not enjoy it. So, you know, I could -- I may be able to do something now, but five minutes from now when he's overstimulated you can't do that type of thing. And I think a lot of people misunderstand that.

>> I think we will move on, unless you want to say something.

That's why families are so critical, that's what Emma is saying, to get that feedback. Because we can't read that. So there's building trusting relationships. This beautiful practice guide we will pull up. And it worked! Isn't this pretty. So -- everyone, this is a resource for you all. It's for you to have, for you to understand, to read through and to share with others. Building trusting relationships. Look how pretty this is. It has a little -- it doughs all the way down to the essential components. Look that the welcoming environment. Remember, we are the ones creating that environment that makes our children feel safe. Again, it goes back to you being the detective and figuring out what's working, what's not working, and just like you said, understanding what are those things that I am seeing in the child that I need to address now? Before it gets to a point where we can't move on from what we are doing. So, creating that environment. This is a really pretty resource guide. It's free. It's online. It's on the national center for Deaf-Blindness and I am sure that our friends Kristi and Emma will send that link to you so you can have that.

>> Yeah, it's linked in the PowerPoint. And then also, this is -- this is probably one of the things I am most proud of us for making. It was created by interviewing so many people. Family members, providers, experts in the field. And then taking all that content and distilling it down and sending it back to them and saying what did we forget? What isn't said quite correctly? How can we switch it again? You guys carry -- I have heard that maybe you guys carry these and hand them out. Is that true? Ok. These are linked in the PowerPoint.

>> There was a question. Can they get e-mailed to you? Is that what you are asking? Yes?

>> I believe these are linked in the PowerPoint and the PowerPoint should be in our session. No? They might have put the wrong one. We will get it to you. Maybe we will pass around a piece of paper and people can put their e-mails on it? If you are comfortable. Ok. Great. Great. We will do it.

>> Am I doing this? I can't remember.

>> Yes, you are. And then Robert's next.

>> Oh, I'm still talking. I'm sorry, you guys. I don't know why I am the one that's talking so much. Because these are the people that know so much more. So, child guided approaches, active learning, and shared experiences. What's active learning? Does anyone know what active learning is? Have you used it? Do you see it? Do you go to the site? So Danna says it's active learning, space,.org. It's probably one of our most favorite places to go. There's so many ideas on here. Because remember we talked about engaging and building that trusting relationship? Because we want children to engage with us and move into active learning. That they are participating. They are making decisions. They are playing with their environment and learning about their environment. So, up here it says incidental learning is difficult or nonexistent. So I think -- was it Emma that talked about remember that our children with vision and hearing loss, even if it's mild and mild, or if it's anywhere -- remember, there are two continuums. Hearing and vision. It's any combination on there. It doesn't matter what it is. Incidental learning, things that are happening beyond my Fingertips, is really hard. Hearing people walk by. Hearing your friends talk. Knowing what the teacher is saying. Knowing who came in the door. All of those things that we need that vision and hearing it take that information in. And also to take that information in and you build those concepts. Concept development, that are put in these little files in your brain that build on. Someone mentioned before about a donkey. You all know what that is. When you heard the word, this picture pops up in your head of what a donkey is. So you know just making sure that we take that into consideration when we are talking to our kids. Because a lot of times we have to bring the environment to the children we are working with. And we can't assume that they know what we know.

Follow the child's lead and interest. Of course. We would love to do that. We are make insuring we want to connect with the children. We want to build the trusting relationship and, to do that, we gotta find what they like and what they don't like.

>> There's a great video on youtube which we can also send to you but if you look at it, it's called Zoe in the little room. She's laying on her back, having this very cool, fun experience by herself in the space with these thoughtfully presented items. She's like waving her arms and then she finds the bell and then she's so curious about it. And so we will send that link but that's a good example.

>> This is Donna again. Danna just reached over and she said make sure that I put into your brains the word -- the name -- David Brown. Ok? So make sure you Google David Brown. Active learning. He's an incredible presenter. He's leader in our field. And, he has some great videos that are out there. Some trainings. You can contact your Deaf-Blind projects, too. They may have access to his training.

>> Oh, we also have an active learning practice guide, as well. It's not linked here, but, we will send the whole, just the whole website that links to all of them.

>> And also, talking about active learning, we will move into hand overhand here, or hand under hand in just a second. But for administrators in the room, we did something creative in South Carolina. I wish we would have thought of it years ago. But active learning, I always thought of it as like Donna said interacting with the environment, keeping it contained and letting it grow out from there. All of a sudden we are learning it's preliteracy skills. You can't learn to read a book if you don't know how to interact with your environment. This is a pray reading activity. And there's money there.

So --

>> Danna wanted me to suggest that you Google Nelson. I thought she said willy Nelson. Both are appropriate. You know. Both could be very informative.

For years in the field, I think some of you experienced it our simulation today. I had the opportunity to take some of you by the arm, by the wrist, and move you and had you do something. I never heard one of you say that you enjoyed that. It's threatening. It's defensive on your part all of a sudden. And you really were not engaged in that activity. And what it looks like, what we used to do and we did it in the field, we taught people how to do it.

>> We have all done it. All of us.

>> If I needed someone who was to do this, if I wanted a student to, for whatever reason, to pick up that bottle of water, I would take their hand and like here it is, Danna. Here's the water. You need it. Ok? She's not active in that at all. In anyway. She may not even know what it is. Ok? The hand-under-hand approach, you will realize why it's called hand under hand. Just come along the wrist and move it up there and guide their hand and let them discover. They may not find it at first. They may not pick it up. They may just touch it. But they are exploring. They are in control. You have given them total autonomy to decide what they are going to learn and what pace they will learn.

>> And Robert one of the things about, going back to the tactile defensiveness, is that if you have a kid who has had hand under hand for many years, they may not want to come with your hand. And so, for a long time it may be that you are just doing what Danna and Donna were doing where they were just sitting close to each other. Or, just having their shoulders touch or slowly they might be exploring a ball together and the person's hand like sometimes touches the kid's hand. Slowly you build that trust and slowly you can introduce hand under hand. The other thing is that your brain isn't thinking when it's being pulled. The only way for your brain to learn, really, is to let that child be the one that's guiding you.

>> You can go.

>> I'll give it right back. I promise. It is my slide. But go back to what you said earlier, though, about fight, flight or fight. It's that same thing. Because if you aren't in control, your defense systems are up and you aren't learning at all.

>> You don't have to use this just with kids who are Deaf-Blind. I use my kids. On everybody. It's great.

>> Just an added thing to what Robert was saying. You know, if you have to, you can start up here, even, with the child and bring your hand underneath. If I am going and they aren't following me, I can almost kind of hold gently, very gently, and just bring them over and even if they never touch it, we are still building a trusting relationship. Still working in tandem. Working together and eventually probably, she will reach over and maybe touch it for the first time and bring it back. Ok?

>> One other thing I know oftentimes people are like well with these little baby hands it's so hard to do hand under hand sometimes. So you can even just touch hire elbow and provide support there. It's the same. You are just providing that support, that nurturing relationship right there. And also, with their little hands you can sometimes just take their thumb and put your little thumb there and then guide them also. Because that's sometimes easier if they have little hands and you have big hands so just again making those connections and I know we always talk about for some reason we always want to do -- I know it's too close there.

>> Can you show the thumb thing again for a baby?

>> Yes. So just -- just going under the hand again and -- yeah, it was echoing right there, too. Going under the hand and locking your how many with their little thumb and just guiding them. It's another great way to do it. Then thinking of all preschools want to do shaving cream. Always. Always shaving cream and paint. Some of our kids when we are talking about not liking certain things, I wouldn't call it tactile defensiveness, it's just not liking it or not exposed to it. Not having experience with it. So how do we help with that? Again, you can do the same technique, hand under hand and guide them into it. Your fingers touch, maybe a little finger touches and they decide if they want to do it some more. That's another great way to give them experiences, new experiences for them to have the interaction.

>> It tells you when they are paying attention. If they take their hand off, they aren't communicating with you.

>> They can remove their hand at any time. They are in control. That gees back to that safety feature we talked about. They know. And you can learn from them. Because that safety sometimes some kids will move very quickly. Some very slow. You can start collecting data. If you want to say it that way. And who they react differently with. Who have they made trusting relationships with? Some they won't pull back with but others they will.

>> I have a question about that with the hand under hand. So you mentioned the thumb technique. If the child is not wanting to touch maybe paint or something like that, can I still use the thumb method? And maybe touch the paint together? Doing it at the same time, maybe hands side by side instead of under?

>> The important part of this is to remember is that you don't pull their hand forward or back. You guide. You are just listening to the child. And if they want to go along with you and they are good with it and they touch it and pull back, you allow them to touch and tule back. It sounds like exactly what you are saying. Yeah. Just making sure that you are experiencing it together. That's what you can really think about. You are experiencing the materials, the items, together. And just following their lead.

>> And we have a video that might -- and then if you have more questions.

>> Yeah, I have a second question. If a child, you know, we are talking about the thumb technique. Maybe kids have a missing limb or limb difference or they have maybe a shortened pinkie or shortened thumb or something like that. Can you alternate and maybe use a different part of their body, say, if they have a thumb, you know, issue, then they can use their pinkie or another finger? How would that work?

>> Holding the thumb is just one example of many, many ways you can do hand under hand technique. We were just saying for some children, it's sometimes hard to get under or so, sometimes that's just another way of doing it is using your thumb. But anyway that you are guiding under the hand or under the arm, you are exactly right. That's what you want it to be. Doing something with the child. Yes. Great question.

>> Ok. Sorry. Just one more thing and then we need to get.

>> Thanks so much.

>> We need to get cranking because we aren't going to make it. The other thing, so sorry -- the other thing I want to point out is that there are sometimes when an individual feels more comfortable using a different part of their body than the hands to explore. We all have had students who had rather, they have chosen to use their feet. Or maybe their elbows. You know. So, that just made me think of it when you were asking about, you know, if they don't have a thumb. So sometimes, ok, if you don't like feet -- sorry, but sometimes you might have to do foot under foot. Or, you know, something like that. Because it might be the foot that feels more comfortable for them to explore something. Especially if it's something that they aren't used to or or has a tactile aversion. Ok. Let's go.

>> Did you notice at first her hand was on the adult's hand but all of a sudden she felt empowered so she touched the whisk herself. There was a progression there.

>> I am not sure that we have time.

>> Think we can go through that.

>> Ok, good.

>> The next is looking at identifying appropriate communication modalities. This is extremely individualized to the student or child you are working with. And from early on, we will follow the child's lead again. We have already said that. We are going to listen to what their body tells us to how they are communicating. And everyone communicates. So even when people say they don't, we know our kids communicate. It could be through eye gaze. It could be through just the breath and their body just following that. You know you, yourself, when you get really excited, your breath, you start to breathe faster. When you are comfortable your breathing typically slows down. Just like the mom back there was talking about that. Following the student's cues. Facial expressions. You can tell so much. A grimace, a smile. Looking for those, as Donna said, when you walk into a classroom and you go over to a student and you squeeze their hand and say hey, you know, it's Donna. I'm here to see you. Waiting for them to look at you, to turn their head. For their breathing to change. All of those things are great indicators that they are with you. They are communicating. And again, we were talking about earlier, we all moved so fast. We talk fast. We -- in a classroom, everything is going really fast. So we have to slow down. We have to wait. And we have to watch for those cues. I know our, one of our little ones that has CVI, we were recently in his home and we had set up an active learning space on the couch. So we had put -- he was laying on the couch and we had put shiny items that he liked on the couch and we were shaking the couch to see if we could get him to notice the items sitting there. And it took a good 60 seconds for him to know what we were doing, recognize it, and then turn and look at it. So we have to remember to look for those communication cues.

So again, meet your child or student where they are. Objects. Are they using objects to communicate? Sign language? Different devices? Vocalizations. And you know this is a good time, too. When you are with families or working with families in the home or in a preschool classroom, it's really important maybe to get a communication dictionary. Ask the family how does your child communicate at home? How do you know they are hungry? How do you know they like something? And being able so that everybody in that child's life is on the same page. And that you are using the same language. Whatever that may be. And our receptive and expressive. We can all say we know our kids' receptive language typically is way, way up here. It's just getting the expressive out and finding the best way knowing that child and family and talking to be able to figure out what they are thinking and feeling. And again we talked about watching for those subtle communication cues.

Routine. I can't say enough about routine. And it could be because myself, I have to have a routine. And our kids have to have a routine. As Robert was saying earlier about active learning, at aves the very beginning to literacy. It's that very preportion to that. So like today, there were certain things everyone in this room had to do. That you had to get up, you had to wait 10 minutes before you know look on your phone, you then had to get your coffee. You then had to get in the car, drive here. But, you knew. It's what you do every day. Having that routine. To get you going. That predictability. It's the same exact thing for our kids. It helps to bring order to their world. It helps them to know a beginning, middle and end. What else is that? Literacy. Beginning, middle and end you look for in a book. Building those concepts. creates predictability. That goes become it our trusting relationships. They need to know what's happening to them. When we did that exercise in here, you had no idea what was about to happen to you. And that made you nervous. Anxious. You may have -- you -- some of you said I'm not even going to stay at this activity. I'm just going to leave. That's what our kids do. It's important that they know how to do that. And building it into the day. And we aren't saying that everything all day long will be predictable and routine. But as much of that as we can will help our students. As Emma was talking about, that fight or flight or where we learn. We learn when we are in a comfortable safe, secure environment. That what's this helps to create. I think, this is not the video, it's the next slide.

>> But now we will show a video -- sorry --

>> I was just going to share -- I have a tween. So whenever you get out of the daily routine you are now going on a vacation. So what I do is I talk to my son and I say ok, we are going to be going on a trip. This is what will happen. And I keep on telling this story over and over. It's kind of redundant but I kind of just ask him, what are we doing the first day? What are we going to do? We will get on a plane. When we get off the plane, what are we trying to do? Just trying to build it so he has a story and an idea of what will happen. When we get there, it could be very overwhelming for him.

>> I have a real quick question. I have a few children on my caseload that, you know, I was -- I have been working with a baby and he's probably 2. He's starting to sit up but how do you get to the point where you want them to explore their environment to crawl, to walk? You know -- showing you know that there's a big world out there to explore.

>> I can --

>> Yeah, so a little bit more about the child. Do they have vision concerns? Hearing concerns? What is that like?

>> He has a Cochlear implant. There is sound awareness. He has certain sounds that he likes but he's totally blind.

>> There are some really really interesting work by Soma Fryberg, is that right? Selma I think? We will send it out. About developmental milestones related to gross motor for kids who are blind. Which is really, really interesting. Because things like sitting up are not delayed but things like cruising, crawling, walking are, because you aren't visually motivated. And so you have to think about other ways to motivate the kid to want to move. And so whether that's that you are touching or making some vibration like a little bit farther away and they start to get curious and maybe roll or reach out further. What else.

>> Also, if you have a certified teacher of the visually impaired that works with your little ones, I would highly recommend teaming up with them to be able to look at the next steps and also your OT's are another. And PT's. Every state is different in what services they have for your younger kids. But definitely I would -- those would be a great place to start, too.

>> It's not going. It may be --

>> Hold on.

I'll scroll down to see if it's linked or if we messed up. Oh, yeah. There we go. Sorry about that.

>> Bedtime. How do you decide what's most important in a routine? First, ask the child's family how they do this routine at home. -- mother developed a bedtime routine that included his favorite vanilla scented ball. She tells him it's bedtime and starts the -- system. Go to bed and -- we tell him when time change -- whatnot -- -- we have a little system -- the same -- he knows what's happening.

>> His mother squeaks the ball and waits for him to reach for it. Go night night? Night night.

>> Christopher is expected to take an active part in this routine. His mother moves at a slow pace that allows him to respond by moving his hand to get the ball. Christopher's bedtime. One, pull up the covers. Two, squeak the ball. Three, wait for him to reach for it. Four, say good night or kiss him good night. His bedtime routine grew. They added more accessible communication. One of the keys to a good routine. How do you decide where to start when building a routine? -- physical routine that happens several times a day. At a child's preference -- add a child's preference such as the scented ball. Building communication based on what's most accessible to the child. Christopher has -- myopia, CVI and a moderate to severe hearing loss.

>> And these are all from the Washington Sensory Disabilities Project. We will send that link to you. Because they have so many videos that are really exceptional and really demonstrate a lot of the skills we are talking about. Hold on.

Ok.

>> We had a little activity, but we will move on. This is another one of my favorite areas, is preparing the learning environment. So, and this is, you know, from the day a little one comes home. We are making the environment accessible to the child. And it's so important and again, we are looking at, we will include those things. Routines, prees directlyability. The sensory level. So the sound, the light, all of those things are so important to our kids and they are important for us. I mean, you know, being in here all day long, we get fatigued just with these kind of lights. Yes? Thank you.

are they on now? Huh-uh.

>> Now they are.

>> Oh, for heaven's sake. How about now?

>> Yeah. We are just going to leave it like that. It's not change -- oh, there. Ok. Good. Talking about the environment. Again, it's so important. And this is another area where you really need to know the child. So, talk to the parents. Watch the child. Know what their vision and hearing concerns are and make it adapt sod they can best utilize what vision and hearing they have in other areas. Go back, sorry. This one we just showed some ideas. We knew that this is in a preschool classroom where you can see there's a backpack hanging and above his name, his name's Leo and there's a white square with red around it. That was the best way to target for him to be able it see oh, I see the red tape. That's my backpack. That's where it goes every day. So when he walks into the classroom, he knows exactly where to go, because they have had a routine. To put his backpack up there and then you see in the bottom picture, they have put an area of red tape on the table based on his vision needs to know that that's the target. So when I come and put my backpack up, this is my spot. This is where I sit. These are where the items I will be using that day are. And you can do this in the home, too. We do this all the time when we go into homes. You can set up your home environment the same way. So that the child has access to visually to what's going on where they need to be. You can put it on their highchair, you can put red tape to outline it. If they have a clear tray, which you see right through, it's so hard particular able to see on those trays. You can put Black contact paper on there and put the items on there. Again, to make it more accessible for them. So there's lots of things that you can do and again, you are a teacher of the visually impaired can really help you with that. Your Deaf-Blind projects can help you with that and your deaf and hearing educators can help you with those other areas, too.

One of my co-workers who we have already talked about. Suzanne, she came up with this. So, when working with families or in preschool classrooms, it's called clasp. It was just a simple way to get everyone thinking of how can I help to arrange the environment so that the child has the most access? And the first is to think about -- color. Contrast. And creating defined spaces. And that is what you saw earlier with us usinging the tape. That helps to create a space. When we came and did circle time over here, and it was chaotic, and the child doesn't know where to go or how to best find, because of their vision, how to best find their space, you can put on the carpet and you can use painters' tape, because schools really don't like it when you are putting tape down on their floors. You can take contact, I mean, painter's tape and put a red square. This is my spot. You can use, we have used hula hoops to help a child know where they can sit and giving them defined spaces. We know with our kids with Chard syndrome. How many of you have had a student with Chard syndrome? They love to get really, really tight into small spaces. Giving them defined spaces where they can feel comfortable, some may want to lay on their back and prop their leg. In a box. You can set a box in there. So, laundry basket. We have used laundry baskets to create defined spaces where our students can feel comfortable and where their body can feel safe and then they can learn. It's so important to remember those things.

Lighting is huge for our kids. And so important. If you are in, you know, a room and working with a student or even again, with families at home, if a child is facing the window, then it cuts down their light -- their vision over 50%. To be able to see. So you often want to make sure that the windows that if a child's in a play room playing and they are playing with toys, that their back is to the window. So they have that natural light coming through. So knowing the child. That's so important.

An amount of averages. Auditory and visual. Figure ground issues. We were just talking about the glass tray on their table. It's hard for them to be able, if you were to put something on their chair to reach, because there's so much going on underneath there. So, creating those -- setting those environments up again our kids to be successful to be able to learn. Positioning materials and the child is also so huge. Making sure, you know, if a child is in a wheelchair and sitting back and our expectation is for them to see something down here, we need to make sure we are either propping the materials up to where they can see them, or that we are moving the child into a comfortable position. If you are working with a child with complex needs, often time their trunk is weak and making sure, before they can use their vision and their hearing, talked about this before, their body has to feel safe. So, make sure that they are in a supported position where their body is safe and then they can reach for the items or obtain the object that you are looking for. They can use their vision. They can use their hearing. So again, your PT's and OT's are going to be great friends of helping you make sure that you are getting your kids into those right positions.

And then size. Everyone thinks if you are working with someone that has a visual impairment that big is best. How many of you in here wear glasses or contacts in is big the best thing for you to be able to see? If I make something bigger, does that make it better for you to see? Often times it doesn't. So, understanding what the child's visual needs are. Some of our kids only have this much vision. So a big bus, they can't see the whole bus. They can only see parts of the bus. So remembering that, too, of what is it that they are able to access in their visual field.

>> And then environmental supports. Based on consultations with the family and other professionals. We were just talking about that. It's a team, you know. Working with a team. Making sure always to include the family and the family's needs and following what the family knows. Because they know more about their child than anyone else in the room. And those were, yeah, sorry --

>> That was an accident.

>> Ok. And lighting, as we said, sometimes for our kids, making sure like for a child again we were talking with CVI, cortical visual impairment earlier. You may take the object and shine a flashlight on the object. Of course we never shine a flashlight into the child's eyes. Always on the objects. And again talking about background noise, minimized, and if we are working, if a child is working we want to make sure that we drop down some of the background noise so that they are able to use their vision better. Or just one voice instead of having so many voices. Because we all know we go into a home visit with our families and often, in Tennessee, so we typically go in with early interventionists when we first meet a family. There are three adults in the room and we are all talking. And so, it's really important that there just be one voice to help with those environmental concerns. Color and texture and contrast are huge. And then space allowed for making sure that we set the room up to have any special equipment that is needed and thinking about other staff. So that's what we were talking about there.

>> -- so we will -- this is -- I'm going to watch this video on -- I reached out to one of our families and I was like hey, we want to video about a routine that you do and she -- this is all the parent. I didn't give her any guidance and she did it so beautifully. This is actually what they are doing at home. So --

>> We are going to take a bubble bath. Ready?

--

>> Hi, ducky.

>> --

>> Are you ready for your bath? Here's some water.

>> Hair brush? You do? Would you like to hold it? -- little bit more. That's a big stretch, isn't it. What a good job! What a good job! Would you like -- with that?

>> I love that video. And you can see very different, you saw the bedtime routine, how the parent had done that one. And then this one -- mom had carried this -- started with the first, they started doing that in the classroom. She wanted to carry it into the home and the routine that they did at home. There is so much going on in this video. So many things. They are working on communication, literacy, numeracy, predictability. Bonding. There's just so much going on. Were there any key highlights that you guys thought about this video that you noticeed in do you think he had done this routine before? Did he know it? Absolutely. So, I just think it's just a great way to show how important it is. And, then they can build on it from here. Add in some other things. But he knew exactly. When she started -- she said it's time to brush your hair. He looked right at her. And you could tell he was anticipating that they were going to start the hair brushing. And she did it with him. She gave him the items beforehand so that he could touch and explore them. And you can also expand this then to do an object calendar. There is so much you can do with this. And he knew it. He was communicating with her. That, yes, I know what will happen yet and him talking back to her was just so perfect.

We will show another video now about things that we don't always -- we think we know what the child needs and what the child's communicating and that's not always the case. So, as Donna had said, we do have to sometimes be detectives and look a little deeper and watch the child to see what they are telling us. So we will get Cathy talk a little bit about that in this video.

>> You want to know where to invest a thousand dollars right no you? Well forget about stocks, real estate or crypto currency. There's a little known trend --

>> So it did bring back the whole idea about internal and external factors. I got a phone call from a teen that I had worked with about an hour and a half away from home. I went down there and they were struggling. It was a small team. It was a rural community. And one of the things they talked about was every day, when there was snack, this child seemed fine. He was snacking. He likes to eat. However, toward the end of snack, he would start screaming and becoming upset and they could not figure out what the problem was. So, I watched it. And one of the things I noticed is all the other students got up from the table and went to go play. This was a preschool situation. And he, interestingly enough, was the last one to eat. Because he loves to eat, so if there's food on that plate, he's staying. One of the things I noticed was on the other end of the table there was an aide who was squirting disinfectant on to the table because, after snack, we wipe the table off. And we get rid of the germs. And very shortly after she did that, that's when his behavior started to escalate. And so, they all thought it had to do with the other kids being gone. I said have you tried it out by saying to the kids no, we all wait until John's done? They said no. I said so here's another thought. Do you remember about his early life history? That he was in the hospital for a longer period of time after his birth, he went back in for many procedures that were done, and therefore, what do you think possibly that the smell of the disinfectant might do? And so, they said well, it might smell like a hospital. And I said -- bingo. You know? That would be my first guess. But I'm not sure. So, you can try out whether or not all the kids stay there and you know but then you start spraying. Because you can't change two variables. You can only change one. Or don't do that until he's left the table. And within about three days I got a phone call back saying they have not had another problem at the snack time.

>> I love that video. So I love smell, because it goes into our hippocampus which is our memory. I teach childbirth classes. We use a lot of smells to help moms relax before going into labor. I use it with kids who are blind or low vision. We have done object calendars, but also did smells so the same scent on a cotton ball for bedtime like lavender. I think citrus dad chose for doing something kind of peppy. That was really fun. If you think back in your memory some smell will trigger an old boyfriend or your grandma's house. It's pretty amazing. Pretty cool.

>> Absolutely. Ok.

>> Ok. So, we have just thrown so much, so, so, so so much. First, know that we are all here. You can reach out to us anytime. Clearly we all love to talk about this. So if you have any questions, never hesitate. And, there are a few different resources that we have linked to in this PowerPoint. All of which I am not going to go through one by one, but all of which are fantastic. A few things I want to highlight for you are that there is a module out right now from the National Center on Deaf-Blindness. Four lessons. Each lesson has about a few 10-minute videos in it and it is on our website. It is free. It is awesome. And, it's for certified educators. And then, what's about to come out that doesn't exist anywhere else and we are so excited about it is an early childhood module. So there isn't much out there about teaching babies who are Deaf-Blindness. This is really exciting. It's been done with a ton of support through both state projects and families. Which then, before we start a discussion, I just want to say that, without families, we would -- we are where we are and we exist where we are because of how much families have advocated for us and how critical it is for all, you know, all of this to be funded families are advocating and just, the cycle for example, we -- families advocated a lot and then another million dollars was given to state Deaf-Blind projects in the National center to support interveners because families showed up. So when we talk about why it's so, so, so important to identify kids is so that those families can get help and the families connect with other families. Wait. What? I'm so sorry. You just used a word that I don't know if everyone knows. Do you all know the word intervener? I see some nod, some shaking heads. Ok. An intervener, the easiest way for me to explain that to you, is that an intervener is a para-educator trained in Deaf-Blindness. I can give you lots of information about that. But I won't.

>> All right. So, all that to say that -- I mean we are all here for the kids and we are all here for the families and we know that's why you all are here. So thank you so, so, so much for giving us your attention for this long. Now it's on you. So we want you guy to take two minutes. We will set our timer and I want you to think about what you learned and all you would like to ask or have a discussion about. Just in the next 15 minutes. She will set a timer. You guys get two minutes. You can stand and stretch while you are thinking and then we will have a conversation.

>> All right. So, now it's just open. Do any of you have any questions? Any comments? Any thoughts you would like to share?

>> Any a-ha moments? Yeah?

>> My request from NCDV would be some recommendations for increased frequency especially for early intervention, because children require that trusting relationship and it's very difficult for us, for me, as a parent guide, to advocate for other families to have that increased frequency.

>> Thank you for saying that again. Because that was your first comment before. Thank you.

>> I think we just -- did we burn everybody out? Can I just make a suggestion? A lot of what we do at NCVB is based on what you just did. Recommendations. We take that into consideration. We work with state projects. But the other thing we do is we do literature reviews. So, we look through the literature and we say what does the literature tell us? And I know a lot of the literature, because we have to. It's what we do. And I would tell you that I don't know of any letter tour that's out there. So my suggestion, families, practitioners, students -- is to hook yourself up with a doc student with students who may be looking for a project to do. And work with them and their Professors and have some literature published. The other thing I would suggest is families, you can -- you can e-mail us because I have communication with Exceptional Parent magazine who are looking for things written to publish in their e-magazine. I know that sounds like oh, here let me just put it become on you. But what I know are procedures and I know that they are going to say that's a great recommendation. But why would we do that is if so -- you know, yes, I want to do that. But --

>> I have a system question. How many kids do you think are not reported to the registry because the Deaf-Blind is not their primary disability category? Or -- is that like a barrier I guess? I just heard you talking about primary disability category and that being not reported as Deaf-Blind as often as it should. So I was wondering if all of the kids are still getting -- obviously not all of them are getting reported to the registry, but --

>> So you are wondering the child count. The difference right now, so there's like 11,500 and something kids reported to state Deaf-Blind project child counts. So when that's compiled, the total is around 11,000. We know that's an undercount. I would say it's at least double. But when you look, I believe, and I don't know the last number, but in 2019, the number of kids with IEP's that had Deaf-Blindness as their primary disability was, I think, less than 2,000. I think it was like 1300 or something. But if you come by my table tomorrow, or if you want, I can send it to you, because I actually have a slayed that has that exact number so, I can give that to you as well.

>> Yes.

>> How do kids actually get on your child count?

>> Oh, my gosh! I am so happy you asked. Robert do you want to take that?

>> That was not a plant. We promise. Interpreter. Ok. Let me get up here. The best way to go is in your state probably type -- well no, actually go to NCDB and go to the website. There's a map of all the states. Click on there and get the current contact information for your state Deafblind project. Most of them have their form on their state website. But if they don't for some reason, you will have their contact information.

>> Yeah. Apparently that's not the full answer. There's more.

>> This is Donna. I just want to add on there, anybody can make a referral. It doesn't have to be a of pro recall. You don't have to have all the documentation. If you even suspect that the child has vision and hearing loss, you make the referral and it comes to us on the project and it's up to us to contact family, get documents, and then decide yes, they are going on the census or maybe we refer them to another group. But you don't have to do that. You shouldn't think oh, I can't do that, I'll have to wait. Someone else may do it, it's not up to me. Always go ahead and refer.

>> Yeah. And to find your state project, I mean you can Google it or if you know it. You can also go to national DB.org and up at the top, there's contact your state Deafblind project and then you can find any project here. So let's, for example, let's choose Tennessee.

>> We are redoing our website, so don't judge.

>> And you can either just call that number right there or you can go to their project website and learn information about -- you said don't go there, I'm sorry.

>> No, no, it has all the correct information. We are adding to it.

>> Got it.

>> So, yes. Exactly.

>> You can e-mail, you don't have to fill out a whole form. If you just want to reach out and learn if this person possibly this child qualifies, just e-mail and then we can help you do the forms if you need.

>> So sort of the flip side of that when you are talking about what's the primary did diagnosis on the IEP. I am on a lot of teams, but I was sort of defer to the special educator as it primary diagnosis. Is it, I think all because I've worked for Deaf-Blind have other disabilities, they do have multiple disabilities, is it better to have multiple disabilities or better to have Deaf-Blind? If I can -- because I know it's low incidence and they are usually open to my saying of oh, I heard this, but what would I tell them? What's best?

>> This is Kristi and I would say I think you might have even just said it the other day -- if you can't get in the door, you can't teach them. So, if they don't have visual or auditory access or if that is impacted, you are not quote unquote getting in the door.

>> That. Time and time again, students with a long list of areas that we gotta make sure we are doing services for, an example that keeps coming back, student was opposition defiant. The teacher, team were all upset, the kid's throwing the chair. I mean he's a handful. So they wanted that as the primary. The reason we found out over time, the dehave yore was such, is he had no communication system. And if deafness was listed first, we would have caught all of that. So from my experience if you focus on where we are getting into the information to the brain, which is always hearing and vision, not to take away that the skin is the biggest organ, but this is where information comes. Those have to be the two that we address first. Special ed's a buffet. Once you get the ticket, you can have all the services your child needs that meet your child's needs. So, I apples will say deaf and vision get done first and if they have the dual sensory loss, it's Deaf-Blind.

>> For sure. I was trying to find it but I can't but we will include it, there's a recently published administrator guide that talks about why the primary diagnosis should be Deaf-Blindness on the IEP which is a great thing to share with administrators. And what we will do next is we will write one that is a guide for families to be able to use to take to advocate to administrators about why it should be. So we have one coming out and we will include that in our long list.

>> And let me jump on this. This may be on the top 10 fights that the parents have to do in school districts I don't want to glass over this. This is big. You will get administrators who have not been trained so they don't know. You will get school psychologists who are maybe old school and I have had it said a thousand times it's just easier to do this. We will do primary one and secondary the other. It's just easier. No. We have to do it the right way. for a thousand reasons. It's the best way they ensure students getting the proper service. We could have three times what we know about. We expect between two and three times in each state is what's actually out there. That drives it. We can get more money from the feds, we can get more money down to the school districts, we can get more money so students in the classroom when we know what students are there. It's really important to properly identify the students.

>> This is Kristi and while they are taking the mic back -- I think we have two questions. But I just want to point out, I kind of want to go back to what you said about deferring to the special ed teacher. I want to recognize that often special educators are not trained in Deaf-Blindness. Neither are teachers of the deaf. Ok. They may have some. But I went through a T.O.D. program. I was not taught about deaf. I went through a teacher of the visually impaired program. We had about half a second of Deaf-Blindness. Then special educators generally speaking get oh, kids can be Deaf-Blind. Watch out for it. And that's it. that's where they are super important to talk about what are the real needs of this child? The other thing I was going to say is we recently did some work with a great organization and they, just to throw it out for you educators, they said what we found was that children who have a suspected dual sensory impact, did not achieve as well as students who had a diagnosed or identified dual sensory impact. So again, that's why it's important to say we have deafness or some kind of impact to the hearing system. Low vision, blindness, whatever, this kid is Deaf-Blind. I think that's super interesting. Let me clarify that.

Suspected do not do as well as identified.

Question?

>> You probably noticed have you paired up or tried have an MOU with the baby's count zero to 3 year project? We have to submit all the kids on my caseload for blind VI.

>> I'm sure you guys have that.

>> Yes. And so what is really exciting is that Linda from the baby's count and the HP count and our count are the three counts that are looking at vision and we have not communicated together for, you know, since 1984 or '5. It's been a long time. So now we just had a meeting with them to say a lot of the same people who are completing the Deaf-Blind annual child count updates are the ones who are completing the babies' count. So how can we really work together? So there's work in that direction. It's coming. And we are out of time. We have one more question?

>> Well, you can --

>> I had a question, but it's quite a lengthy one. I would just like to pose a question for the families in the room or hard of hearing individuals themselves. We are actually working on a research project, working with adults with autism. And, really primarily want to make sure that their first experience in audiology office is a positive experience. What are some of the things that audiologists can do on the forefront to make you or your child feel more comfortable? In our curriculum being we don't talk about Deaf-Blind and we don't have much education on individuals with cognitive impairments in general. I would love to know more, whoever wants to speak.

>> And that's a great question, because ASD and Deaf-Blindness are both sensory continuum disabilities. Very similar. A lot of the same techniques can be used for kids with blindness or autism. That was great.

>> This group gave a lot of good examples that you communicate with the individual that's there for the service. Like, if it's the child, then you meet the child, the child's needs and you engage with them so that they understand what's going on. Not the parents. Parts will follow. I think. After that.

>> And with that previewing, just like telling, like you were talking about, talking about the parents talking to the child before they come in or the adult to come in, what's going to happen. What the expectations are.

>> Did your clinicians offer mini exposures or provide pictures or supplemental material before visiting the clinic?

>> I was going to suggest that videos, introductions of offices, it is accessible for my daughter. When when we go to the dentist, we watch a video of their office and their staff. That's really helpful. And also, making visits not high stakes. That there are opportunities to come back and if the exam isn't completed, we don't show frustration. We just say we will see you next week. Or whatever that time is.

>> I think oftentimes, too, as a student, you are very nervous and so you are trying to work quickly through an appointment. So, I know how difficult that can be especially if you visit a University clinic. I know we try to rush through things and I apologize for that but --

>> I would say the implant audiologist was very engaging with my son. The first audiologist, which was at a University, was just, just like trying to get through the appointment. And it was just frustrating for the parent, as well. Because now you had a child that wasn't engaged. Parents who were frustrated because the child wasn't engaged and it just made the whole experience awful. But when we got to the implant audiologist, it used to be children's hospital in Oakland. It changed to UCSF Benihof and they were just used to working with kids and they just -- everything that you saw in the room, they were implementing all of those.

>> You might try to connect with child life specialists through a hospital. Because they will have tons of ideas to help with making a more child friendly environment or steal ideas from them. We have also made kits like for going to the eye doctor for kids to check out, play things for -- might be something for audiology. Tons of great books out there.

>> This is Kristi. I would just say that one of my research lines is -- sensory impairment with autism. And so I can, you know, I am happy to provide you with names of people you can look up and, you know, I am happy to talk with you.

>> We are out of time. But, I don't want to cut you off. If you guys want to go, by all means, get up and go. And then I think we could just continue the conversation. But before you leave, I want to say there's a graphic on another PowerPoint that we often do that has a huge circle for all the babies born in the United States and has a littler one for all the babies who are born who are in special education and it has this pinprick dot for kids who are Deaf-Blind. So often what we hear in teacher prep programs and all of these different things and in schools is well, Deaf-Blindness, we have one kid. We don't have time to train. We don't have time do all of those things. It's a small number to us, but to the family it's the entire world. It's on us to do better. Thank you to both interpreters for putting up with us and all of our surprises. We really appreciate that. And your patience with us. Thank you all so much for being here and, just for all that you have done and all that you continue to do for families and kids.

>> Just briefly, we have a deaf mentor parent advisor program and we start with little ones upon their referral. And we do all of those activities. We partner with audiologists speech therapists and TVI's and we take that into the home so it becomes meaningful interactive exchange between the parent and the child and some of those activities can be prepared for. So by the time they are going to a more formal evaluation, it's not outside their experience and they are a lot calmer.

>> That's great. Thank you. And then I think we had another question? Right in front of you, Danna.

>> For those of you who have collaborated with educational audiologists on the educational team, what has that experience been like and what are things that educational audiologists could do more to contribute to a future diagnosis of Deaf-Blindness?

>> You can refer also.

>> They can refer. And, do you have anything --

>> Yes, definitely they can refer. And, unfortunately there's not as many educational audiologists out there as I wish there were.

>> I think also just to in terms of audiology in general, when you -- and I don't actually know all the details about this, but you might actually, Danna, but, trying to figure out how to lump and Penny you might know, too, lump different things together so that when the kid comes into the hospital they are doing more than one thing at once, you know, they are doing it all. So if there's a time when the child will be sedated let's also do the ABR and other things so it's less impact on the child and the family.

>> But -- we are out of time.

>> Thank you guys so much.

>> Thank you guys so much.

[Applause]