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EHDI Annual Conference 2024

March 17, 2024

6:00 am PST – 11:45 PST

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(Captions provided by a live Captioner.)

DSHPSHWA Meeting

(Captioner on standby)

>> Good morning. As you're eating your breakfast make sure that you come here. If you did bring a gift the table is here. If you didn't, don't worry about it. It is totally fine. And if you brought a gift put your name in the bag for your buddy and in the bag for your own gift.

Also, while you're eating your breakfast, if you are new and haven't taken your photo go to the hallway to take your photo. If you didn't like your photo, that is completely fine.

>> Good morning, everyone. Welcome. We'll be getting started shortly. If you just come in, please make sure that you register in the back table. We're not doing the bill roll call today. Also, if you brought your gift don't forget your gift table as well. If you need a photo in the director, it will be out in the hallway.

Good morning, everyone. I know you heard it a few times if you have been here for a while. We're not doing the long roll call today. If you go back to Linda and Elizabeth. They will get you checked into the meeting. If you brought a gift don't forget to see Liz on this side. Once again, if you are new and haven't taken a photo for the directory that we share across the nation. I don't know how many of you are using the directory? You should be. If you haven't taken your photo go to the hallway. If you don't like your photo from previously, feel free to take another. We will get started shortly.

>> Good morning, everybody. Welcome to Denver.

This is our annual general membership meeting for the directors Of Speech and Hearing Programs in State Health and Welfare Agencies. I am Marcia Fort. I am past president. One of two past presidents. Linda waving in the back. Linda is our other co ‑ past president. I'm going to do the introduction of our aboard members and then we're going to do something that normally happens at the end of the meeting at the beginning. Not yet. We're doing this in just a minute. So she can do that.

Um, well, I guess I should. Can I have a ‑‑ we are going to call our annual meeting of the DSHPSHWA Organization to order at whatever time it is now. 8:15, 16, A.M. for our note takers. All right.

I'm going to do a board member introductions real quick. Oops. So, um, as I said I'm Marcia Fort. Linda Hazard, I've lost her again. She's in the back. Our co-past president's Bradley Hartman Bakken as served as president this year. Unfortunately due to family events he is unable to be here with us in Denver this year. We wanted to recognize that he has done some great work for us this year. President Elect who will run this meeting in just a minute is Tammy. Our Secretary Treasurer is Tammy O’Hollearn. We can wave her. Due to health reasons she cannot be here in Denver. She is listening via Teams call this morning. So she is with us in spirit and listening in to all of us as we talk.

Our Vice President for membership is Daphne Miller‑Stewart. She is in the back waving. She is from Virginia. Our Vice President of achieves is Ginger Mullin from Illinois. She is up here in the front taking notes for us.

Our Vice President for communications and outreach is Elizabeth Seeliger. I don't know where she is. Elizabeth? She is in the ‑‑ stepped out for just a moment. Our members at large are Liz Schardine from Kansas. She is back at the gift bag table waving. Our other member at large is Heather. And then we have non‑voting members that serve on the joint committee on infant hearing. That is Patricia Burk and Kirsten Coverstone who is sitting right here. Those are our board members. Now what happens in the conclusion of this meeting is going to happen now. So we are going to hand over the gavel for DSHPSHWA to our incoming President Tammy O’Hollearn.

I'm supposed to do one more thing. And we're going to start our gift exchange. So hopefully you've brought a gift and put your name in. So we're going to do a couple of them. So we're not doing 25 at a time.

Have you got names Patricia or are you taking the microphone. We're going to draw names. You can go back to the gift table. Select a gift. Not your own unless you want what you bought and brought. There should be contact information inside the gift for who brought the gift so that you can reach out to that person. So Patricia or Liz.

>> LIZ SCHARDINE: Okay. The first one is Shannon from Utah. Massachusetts. Elizabeth from Wisconsin. Ginger from Illinois. Mary Elin from Alabama. West Virginia. Nebraska, Angel. Ryan from Texas. Let's do one more. Marie from Guam. Okay.

>> Tammy O’Hollearn: . We have a different setup. I need to run two different computers from this meeting. While I like to multitask, doing these things are not my favorite thing to multitask. Another thing I wanted to introduce our interpreters. We got Randy and Christina. They are interpreters today. We ask throughout the meeting if you have a question or comment that you wait for the microphone. If you can state your name and state that you're from. That will be most helpful.

Good morning. It is really exciting to see familiar faces. While it is stressful getting to the conference and getting everything ready and trying to manage the schedule and do everything that we need to do back home with the travel requirements, it is so nice to then catch up with all my friends, parents, providers, you know our federal partners. A lot of different people. What's very exciting to me is that so many of you have helped me on my journey. I am the director for the intervention program in the State Of Iowa. I guess that makes sense. Iowa. I've been here for 18 years. I am going to be facilitating this meeting today in Bradley's absence. He did a lot of great work today. It is unfortunate that he cannot be here. I ask for grace as we work through challenges and technology.

A couple of things, I'm really excited to welcome all of you to the DSHPSHWA community. You will find some of your closest friends, probably that you will pick up the phone and not hesitate. Sometimes we text, e‑mail, Zoom and do all kinds of things to stay connected and really ask each other questions and bounce ideas off. Sometimes we laugh, sometimes we cry. Sometimes we express our frustrations and those kinds of things. This really is a community. It is, we're here on your behalf and we really want to make sure that we provide you with the support that you need. We do mention the EHDI coordinators. That is fun and enjoyable. You will hear about the various committees that we serve on to try to represent the DSHPSHWA's best interest across the nation. You will hear a little bit about that. Mostly we lift each other up and stuff. We know that everybody has a big balancing act every day within their states. There is a lot of people that you answer to both within your state and federally. We just want to make sure that we are here to support you. We will have an activity to talk about later on and talk about activities that you would like to see or some support that you would like to see coming from our board. So we're excited to be able to do that today as well.

A couple of other things. For those of you that are new to the DSHPSHWA community it started in 1950. It began to encourage the development of more efficient programs for diagnosis treatment and caring for children that are Deaf and Hard of Hearing. Today DSHPSHWA services as a nonprofit for organizations and speech and state and welfare agencies and service as a collective voice for U.S. and territory for our federal partners and other organizations. Marcia already talked a little bit about the state gift exchange. We're going to have two more opportunities later on. That tradition started a number of years ago and it is an opportunity to get to know one another and learn from each other and facilitate additional communication from other states that you don't know much about. Please enjoy that time. You should find who the gift is from in there and hopefully it is an opportunity for you to say hello to each other. Especially if you don't know each other already.

So we're going to, like I said have two short breaks. This morning we're actually going to hear from our federal partners. We asked them to join us for a short time to talk about the different efforts they're making at the national level or federal level to collaborate with other partners throughout the EHDI system of care. So we are going to get started.

Um, one quick thing. I will run through the agenda real quick. Like I said we're going to have our federal partners talk about their collaborations and then we'll start our business meeting. We're going to do a quick break for the state gift exchange and for people to stand up, move around a little bit. We're going to talk about the summary of our board activities from our strategic plan from 23 ‑24. We're going to take another quick break to do the gift exchange then. At that time as well we will then do planning for ‑‑ I'm sorry. We're going to do planning first and then the break for 24 ‑25 and have an opportunity to hear from all of you and the things that you would like to see. And then we are lucky. Michelle John, who has had nightmare travel experience is, she got in at like 4:00 A.M. and she is here with us today to speak to us. We're really happy that she was able to make it. She's going on no sleep, and she has had quite, she has quite a story to tell about this. Let's just say that. She's going to do a presentation on assuming competency. Okay. First up is Bethany Mlodoch with the American Academy of Pediatrics.

>> BETHANY MLODOCH: My name is Beth with the American Academy of Pediatrics. I want to say thank you for welcoming us here today. I apologize I have a few of my notes run down because never great coming from memory. I thought I would share a few updates and working with our parents at Hands and Voices and the NCRT team. I will quickly note that we have an upcoming EHDI coordinator Webinar coming up on the 22 that we worked with our NRCE team. Is that better? Sorry. Is that better?

I just wanted to highlight really quick about the work that we just did with the NTRC team and collaborating with MCHB with this Webinar that we have coming up and we had filled a survey back in the fall of 2023 about what we really wanted to see, what our state coordinators were looking for as a TA and support. We found emerging themes and we're very excited to host this Webinar and we apologize for the timing. I'm sure you're all going to try to rest by the 22, but we are going to be recording and housing on our website and you can always register and submit some questions and we are happy to answer those via the Webinar or afterwards. We just really appreciate working with our partners as we have ‑‑ I'm sorry. Is that okay? Um, yeah. I'm sorry. My slides for today are no longer opening, but I just wanted to quickly put that plug that if you see my name coming through your inbox or say hi within the next few days I would love to know who you are. Or if you know your state AAP EHDI Chapter Champion I'm happy to make that connection and work with you both. I will pass it on over to the CDC.

>> Tammy O’Hollearn: All right. Erica.

>> Good morning, everyone. We're going to do this together. You asked about collaboration. This is a show of our collaboration. I hope we get some smiles from you today and look forward to seeing you around. I'm going to let Sarah Beth McClellan start us off.

>> SARAH BETH MCCLELLAN: It is wonderful to see you all in Denver. I'm going to give my team a shout out. Sarah Beth McClellan. I'm going to, our branch chief is Chavy Brown and Dr. Achila Heggs. We're here to listen and support you. I want to thank the DSHPSHWA board and all of you for making remarks. The roles that you serve and individuals that you represent is an important ingredients to report.

Here we are Erica. You are next.

>> ERICKA ODOM: Well, let me first introduce myself. I'm Ericka Odom. I am the CDC EHDI Team Lead. I have a host of people who will be here supporting the CDC EHDI program this week. You will see our project officers. You will see parts of our team present. You will see Caitlin, Corey Lipton and Maria Sanchez and states that are supported by the CDC funding. No one is in the room right now and all traveling on their way here and hopefully safely doing here today.

The next thing on our agenda. Just to talk about how CDC and we collaborate. We are in regular communication with one another. On the team level Sarah Beth McClellan and I are involved in biweekly meetings and communicating about what it is that is going on in our programs. We really try to collaborate and ensure that our activities are aligning and not overlapping. That we stay in our lane. CDC, we're focusing on date and they focus on the partnerships. Our end goal may be the same in that we want to see all babies screened and those that need follow up they are getting services. For us that is about the data points at CDC. Beyond the team lead level, the branch chiefs meet on a monthly or so basis. My branch team that is Caitlin Rice meet together and above them and beyond them the directors meet. Jeff meets with my director. Above that the Center Directors meet. My center director is Karen and Michael Warren is the Center Director. We're sharing what is going on from the bottom up in the programs and specific state issues. We talk about funding. We talk about policies that are in play and at place that may be the little P policies within the state or federal programs that might be hindering your ability to collaborate well.

I wanted to share that with you. We are working very hard to make sure that we are working together. You know how like in your programs the working together ebbs and flows over time. This is a period where we are working really well together. I'm always excited to see my HERSA colleagues and talk to them and create a vision together to see the EHDI programs moving forward.

I will turn it back over to you Sarah Beth McClellan for the next example.

>> SARAH BETH MCCLELLAN: I want to say we do more than just talk. Yeah. I think that a really concrete example of that, and I'm going to share this. Big shout out to Maria Sanchez and the Hersa staff. Another example is a joint CDC model. I feel like it does represent where our collective goals, our legislation, how it aligns and differentiates what we do, but we're all here for the same reasons and same outcomes. A plug for Maria's poster is Monday afternoon to again see exactly where we're trying to align work in "specific example of that.

The other thing that I wanted to make note. When MCHB, when we were drafting the NOFO we reached out to our colleagues for comments and suggestions. They provided examples and are thinking through those kinds of things with us. I just want you to be aware that we are in lock step with them as we work through what this means as we implement and roll things out. We're here to support every state when we think about the outcomes and upcoming NOFO. The other example is the recent competitive supplements that generated interest from states and outcomes for deaf and hard of hearing children. The CDC providing technical assistance and evaluation and thinking about measurement. I know that you had a lot of conversations with states and us and individual states too. We could not be more thankful for them and all the work they do there.

>> ERICKA ODOM: Another great example for I missed it on the sheet. Thank you Sarah Beth McClellan. In addition to the work we provided on the competitive supplements. I'm excited that we were able to provide support on the evaluation piece. What you all do with the funds and being able to implement and explore this language area is really important for us to be able to think about what comes next? What did you learn? How can we support you at getting at the next incremental steps. We heard you. The next steps are hard. I get it. Thinking about what you're able to learn and the supplement funding that they were able to give helps us all explore of what the future of EHDI could be. I appreciate your work on that, and I appreciate those of you who are choosing to do the optional evaluation. It is really going to help us all. We don't take it lightly that it is one more extra thing, but it does help us all learn. And so on the next example is our work within collaboration with OSA, HERSA CDC have all started collaborating for frequently. You know that in November, December they started with Webinars and focusing on part C and trying to get at what we could share in terms of EHDI collaborations. And so we are actively working together to bridge some of those gaps. We know that working with part C is not always easy in getting some of that data. On a high‑level we are working with our federal partners at OSEP to really try and make that line of connection easier. And so we're exciting to be able to help you all on that. Sarah.

>> SARAH BETH MCCLELLAN: Much more to come on that. I think in closing we're here to support you as well. It is a back-and-forth relationship. We want to make sure that the needs you are discussing we want to make sure that we are responsive to those and conduits for you all at the federal level. We're excited at the next chapter and cycle to kick off Denver and the conversation this morning. Thank you, Tammy.

>> Tammy O’Hollearn: Next up, Lisa Kovacs.

>> LISA KOVACS: Good morning, everyone. I'm Lisa Kovacs. I'm the Direct of Programs for Hands and Voices head quarter and management team. I wanted to thank you all for what you do. Personally the impact of the EHDI system on myself as a family and the year 2000 my home state of Indiana passed my son Anthony was born that year. I truly believe that the work that you all do in the EHDI system had a huge impact on my family. Anthony today is 24 years old. He is graduating in December with his master's degree in theological studies and moving on to pursue a PhD in theological studies. I want to say thank you personally. I believe that without newborn hearing screening and everything that the EHDI system does his outcomes would have been different. Professionally I want to thank you again. As a parent in the year of 2009, new year of 2004 I funded the at the time in Indiana Julie. Some of you may remember Julie from years ago. Again, having that support from her for me as a parent to start a nonprofit organization and get involved in systems change in my state has really contributed from the support that I received from the EHDI program at the time. In 2009 we had a new coordinator Gayla. She was the first to come to us in the Indiana chapter and say let's implement family to family support. In 2009, I actually worked in our EHDI program. I was the first point of contact for all EHDI families. Though I talk to about 250 families a year who were just learning about their child's identification as Deaf and Hard of Hearing. I did that for several years before I got involved With Hands & Voices headquarters. She would say come on and I would sit beside her and funding opportunities and learned to write grants. They had a huge impact on me as well. Again, thank you so much for the work that you all do at EHDI coordinators. As far as collaboration we are collaborating with other federal partners. It has been an experience. I want to thank MCHB for your vision for including family engagement, family leadership, and family support in the National Technical Assistance for EHDI programs. We have partnered with the AAP for a very long time. I've been the parent representative; I've been blessed to be the parent representative and sharing the perspective with them and doing lots of work together through the AAP. With the CDC I know we've been working; Janet has been serving with the data for many years. The work that we did the FEDI. We were able to partnership with coordinators to come up with family support for data points for the annual CDC data. I know it has been a great experience to be able to collaborate with CDC. With NTRC prior to the FL 3 Hands and Voices worked too closely with MGM and had been blessed to be supported by MGM for several years. That relationship has just grown. We have worked this project period on several learning communities. Engaging EHDI coordinators and EHDI programs in the work that we are doing. Those projects were the FEDI data project. The outcome of that was to help family-based organizations come up with data points to collect on the enrollment of family-to-family support and Deaf and Hard of Hearing adult to family support. And we also worked on then a follow up to that was the impact of family support and engagement that IFSE learning community. And that learning community focused on coming up with family learning outcomes of receiving family support. All of this is on both the NTRC and FL 3 websites. We wanted to move the needle forward if we're really talking about every family getting enrolled in family-to-family support we need to measure the outcomes of families enrolling in family support. We as a learning community we came together with six other EHDI programs and their family partners and we established question bank of questions that family-based organizations and EHDI programs can use in following up with families who received family to family support to begin to get a measurement of the impact that that makes.

And then finally I'll talk about our collaboration with DSHPSHWA. That has come a long way. I remember in 2017 all of a sudden the FL 3 hit the EHDI world and there was a lot of like what exactly is the FL 3 center doing and what kind of TA can they provide? And so I think about kind of a continuum partnership. We were trying to find our way in 2017. In 2024 there is a beautiful partnership happening with DSHPSHWA that has a lot of EHDI coordinators and EHDI coordinators themselves. FL 3 we have 25 advisory board and meets a couple of times a year. You can imagine a ton gets accomplished in those meetings. What we have done in several years for the FL 3, we have core management team meetings weekly on Wednesdays. When the FL 3 is ready to roll out a new product or we're thinking about a new training we will think, who is the primary audience of that? And who from our advisory committee would we want to meet to advise us before we do one. Those that are serving on our advisory committee are invited to give us advice. Like real advice before we actually roll it out. So that has been really productive, and we really appreciated their input.

When I mention or technical assistance at the FL 3 center our primary audience is our family‑based organizations, but of course you all as EHDI coordinators are also who we want to support. Our, what we develop at the FL 3 Center is only as good as it works for you in the EHDI, and it worked for family‑based organization where you're located. Our technical assistance model I'm one of those. If you are not connected with your FL 3 technical assistance advisor I advise you to do so. We do quarterly inbox. How are things going? Here are the newest resources. Here is some support for you. Would you like to connect? We hope you will take that as an invitation. On average we have 85 technical assistance encounters a quarterly. That is 25 a month in the EHDI system. I hope you add to that account. I will close with some really exciting news. The FL 3 center is getting to rollout through our supplement funding that we received, we're getting to rollout a new resource for EHDI programs and family‑based organizations called Off to a Great Start. It is on our web. We're doing a soft rollout and ready for EHDI. This interactive webpage is for you and your family‑based organizations. It is taking the many FL 3 resources around environment into early intervention and language acquisition for children that are hard of hearing and package them in the resource. I hope you jump to the website and check it out. If you go to the block that says New Family Journey you can go to a great start off there. It has a cute bookshelf. Each toy has an important resource for families just getting started. It is fabulous. We also have created several promotional materials. Badges. Kind of like the EHDI pals that you used. We created promotional badges and resources for families that you can plug into your EHDI websites. I know easy is a strong word because you have to go through a lot of hoops to get approvals to get to your website. We have it ready for you once you get approval and for family‑based organizations. We got the code that you can also be able to put it on the website and providing that to you as well as postcards that you can disseminate and social media ready deliverables for you. If you want to promote off to a great start in your state or territory social media we created it for you. You don't have to create it yourself. Anyway, we invite you to something we did with the supplement. I just wanted to share it with all of you. We will be presenting on several sessions here at the EHDI meeting. I just wanted you to know, what our work we do is to support you and your family‑based organizations.

If you have ideas or there is something that you need, please don't hesitate to reach out to us. And again, I just want to say on behalf of the FL 3 Center thank you for the tireless work that you do to support families. Thank you.

>> Tammy O’Hollearn: . All right. Without further ado Karl White with the Technical Resource Center.

>> KARL WHITE: Thanks, Tammy. It is so good to be here with all of you. I'm reminded with the hash tag logo that several of you came out years ago. EHDI together. Everybody here doing it together. You can see that we have a couple of things going on. I always hate to follow Liza because it reminds me of one of my favorite cartoons where Charlie Brown and Linus are looking at the sky. What do you see? It kind of looks Michael Angelo's ceiling. Lucy says yeah. What do you see. Lucy says, "Over there. It is Leonardo ‑‑ there. How is that. Mona‑Lisa and sixteen chapel. Charlie, what do you see. I was going to say a horse and a piggy. I changed my mind. What is really exciting about this conference to me is all the wonderful things that are going on. Certainly some of the things that Liza talked about are some of those wonderful things.

I think if you take a look back at the last four years there has been some ups and downs haven't there? Certainly COVID created some challenges for us, but there is lots of other issues with EHDI programs and organizations that we have to deal with on a routine basis. That makes some of the goals that we have a little difficult to accomplish, but ‑‑ I'm sorry. You'll probably hear about some of this later in the day. We have a couple of staff members that were in a very serious calls last night. Those calls are updates there is not going to be long‑term damage it looks like. I apologize for the phone continuing to ring.

So this conference in my opinion is one of the most exciting things we do as the NTRC. It is because we don't really do it. It is all of you do it. As a logo says, everybody here doing it together. There were over 225 abstracts submitted for this conference. There are 19 instructional sessions this year. It is more than we ever had. The plenary sessions I think you're going to love. We even added a fourth quasi plenary session Tuesday afternoon, which will be a great panel talking about recent advances and gene therapy. There is so many great sessions here that I hope you'll take advantage of those. You always do. I mean one of the things as we plan these conferences and meet with the conference coordinators at the hotels they always say, you may have 1100 people registered but only 600 will show up to sessions. Not with this group. No. You better squeeze all the chairs in you can. We will be a little crowded in some of the sessions, but that is a great problem to have. And we look forward to all the great things that come out of this conference. Some of those things end up appearing in the Journal of Early Hearing Detection and intervention that is published for open-source journals and those that download and submit publications. There is another issue of that in May. You all know about the Webinars. Sometimes we worry that we may be over doing those, and people get tired of them. We continue to have for most of the Webinars 2 or 300 people sign up and watch them. We think we're doing good. You all know the various other resources we have. One of the things that we launched recently is a podcast called Ear Worm. Dialogues and Hearing Health you can't stop thinking about. If you are a podcast listener we encourage you to go and download that. We released one yesterday that is a great podcast from a parent talking about her quest to make a virus better known and better accommodated condition. We look forward to being with you throughout the conference. Stop me and ask questions if you have them. There is so much going on the and hope you take advantage of it as much as you can. Thank you.

>> Tammy O’Hollearn: I just want to say ‑‑ oh, no. We cannot have it restart. Before we get to the business meeting I want to take a minute to say thank you for the federal partners and technical assistance centers for sharing your work on collaboration today. I know that you do a lot. I think it is helpful for our membership to hear the many different ways you are working together to be able to support programs across the states and territories. Thank you so much again for taking your time to come. All right. We will get started.

First up is the approval of the minutes from 2023 Annual Meeting. Which seems too far away now, right. You did receive a copy or should of received a copy of the draft meeting minutes earlier this month in March from Marcia. My first is, does anyone have any corrections or comments they want to make or clarifications they want to make for the minutes? It went from the DSHPSHWA e‑mail and not Marcia directly. Sorry.

Okay. If there are no questions or edits. Is there a motion to approve the meeting minutes from 2023?

>> For the interpreter we're going to bring the mic to you. Say your name and state.

>> Mari Elin approves the minutes. I make a motion. Thank you. Correct. Too early.

>> Tammy O’Hollearn: Can I get a second?

>> I second that.

>> Tammy O’Hollearn: Thank you, Bryan. All in favor say I or raise your hand. Okay. Oppose. Same thing. All right. Motion carried.

Next up is the treasure's report. I'm going to pull it up real quick. Give me one second here. I don't think so. I'm going to give you an opportunity to review it again. Then if you have any questions we do have Tara like we said available for questions if anybody has any. So here is the Treasure's Report for 23 ‑24.

Are there any questions? Okay. Is there a motion to approve the Treasure's Report for 23 ‑24? Don't be shy.

>> Minnesota. Motion to approve the treasurer's report.

>> This is Patricia Burk. I second the motion.

>> Tammy O’Hollearn: All in favor say aye or raise your hand, please. Any oppose. Same thing. Okay. Motion carried. All right. Let me get this down. I'm sorry. It is a little bit of a balancing act up here. Oops.

Okay. Let me move on to open Board Positions.

So we're excited today to be able to present the nominees for the election this year. For Co‑President Elect we have Daphne Miller‑Stewart and Stephanie McVicar.

Vice President of achieves is Ginger Mullin.

Vice President of communication And Outreach is Elizabeth Seeliger. Member‑ at‑large Liza Then. Are there any more nominations from the floor? Okay.

>> Her name is Liza.

>> Tammy O’Hollearn: I'm sorry. So sorry. Her name is Liza.

>> I thought there was going to be a showdown. Let's see who is going to do it.

>> Tammy O’Hollearn: If there are no nominations from the floor is there a motion to approve the officers by acclimation.

>> This is Marcia from North Carolina. I make a motion that we elect the slate of officers as presented by acclimation.

>> Tammy O’Hollearn: Okay. Do we have a second?

>> This is Linda Hazard from Vermont. I will second that motion.

>> Tammy O’Hollearn: Okay. All in favor say Aye or raise your hand. Oppose do the same. Okay. Motion carried. Welcome. We're excited to have you on board.

One thing I want to mention real quick just for current board members and newly appointed board members if you can meet outside of this room, we want to get a picture too at the end of the meeting. All right.

Next we're going to talk about Committee Updates. You're going to hear from the different people that served from our board on the various DSHPSHWA Committee Updates. First up we have the Audiology Quality Consortium.

>> Um, so this is Marcia Fort from North Carolina. We share responsibility for two committees. So this is the Audiology Quality Consortium. That group we attend meetings of that group. They collaborate on the development of quality measures for audiologist for use in the centers for Medicare and Medicaid and other health care payers. We talk about the various quality measures that audiologist may be required to report in order to participate in Medicaid, Medicare or some various other payment plans or audiology. We are unable to report out any information unless it is in a public comment period. We are under strict confidentiality as various quality measures and coding things go through approval processes and get ready for public comment. We're in a silent period. We don't have any actively comment today. We will share that as it comes available.

>> Tammy O’Hollearn: Let's, um ‑‑ oops. Sorry.

We're missing some slides. Oh, no. Here we go. We also Bradley Bakken served on the Deaf and Hard of Hearing Association. I'm going to leave their mission and types of things that they have up here. We don't have a specific report for them. I wanted to make sure that we acknowledge that this is also a committee that we serve on. Bradley Bakken did that during his time. I'm going to give you an opportunity to review the slide real quick.

Okay. Let's move on to the Health Care Economics Committee.

>> MARCIA FORT: This is Marcia from North Carolina again. I repeat this is the Health Care Economics Committee. The difference between this one and the other one is that this committee deals with coding for payment. CPT codes and any kind of coding that audiologist need to use to bill for services. The same rule applies here. We are only allowed to share out to our organizations when items are out for public comment. We don't have anything currently out for current comment, so we'll be back to you.

>> Tammy O’Hollearn: Very secretive stuff. You can see why we need representation on there so we can have a voice and provide input. So thank you to Marcia and Linda for serving on those committees. Last but not least the Joint Committee on Infant Hearing.

>> Okay. I'm going to go off script for a moment and no one on the aboard is surprised. I think we need to give a big round of applause. Bradley Bakken was not able to make it. Tammy just jumped in. Give her a round of applause. You deserve that. I want to clarify another comment. When I thought there would be a showdown. Someone on the floor would say we want to be in a position at DSHPSHWA. I want to say that when you look at DSHPSHWA, I know sometimes we're maybe meeting once a year or getting e‑mails, but if you really want to get connected in this field, being on the DSHPSHWA board is one of the easiest ways to get connected. If I'm honest. What you see is what you get. I believe truth to the nth degree. I don't think a week or day goes by that I'm texting somebody or calling someone or messaging on Facebook someone or asking for support. The truth is, even in my new role, I was EHDI and a new role with Allied Health. If you have a speech we have a Head of Audiology in our state. Everyone is welcome to partake with EHDI. What this is today is hopefully the connection. When you are actually getting your bag, unless you got your gift make sure that you reach out to the person on the card. Those relationships are some of the things that sustain it or helps us with the grants or trying to figure out what is in logic model? What am I supposed to do? We hope next year you are fighting to get on the board. It is really something that helps the voice of EHDI.

Also, the other thing we can't all be the best. You need to know who does what. Are you on team you need the DSHPSHWA directory. You can see the faces. I remember her from the conference. I need to know about CMV. I need to talk to I can say you can find our information. Many of you have. I know some of you have not.

On the to the JC report. DSHPSHWA is the co‑chair, we're the chair technically. It is just two of us. In true collaboration and kind of in DSHPSHWA spirit we actually decided to co‑chair a few years ago. Last night we had a long day. Eight-hour meeting. As I laid in bed I thought isn't it crazy? When I joined I was in the room, and somebody was talking about EHDI. For those that are new we talked about JC. It is kind of the EHDI bible. Yes, we're not going to meet everything that it says or practice and aspirational. We're trying to move the needle and continue the vision. It is something that we go back to frequently. We want to have a voice. I remember the first time I walked in the room in JCIH. There was not a voice. Every audiologist reports to every EHDI program. Well, actually they don't. Yes, they do. No. I'm representing DSHPSHWA. I'm representing EHDI and DSHPSHWA just did a project on it. Actually had had the numbers on my computer. It was data. Here is the data from all the states right here. So it has been that way as we walked in. Coming back last night I was lying in bed. There is so many times. It does help we're chair. What does DSHPSHWA think about that? Or what does the EHDI coordinators think about that? When we're making best practice, 19 or 71. It was a one-page statement. No one asked EHDI coordinators what they wanted. There weren't any EHDI coordinators. Does that make sense? Because of DSHPSHWA that now gives each of you a voice on the national level to create practices that move forward. We hope you reach out to us if you have comments. We want to know what you are struggling with. You can reach out to the board. We're constantly talking. If you don't know JCIH. There are two organizations with two representatives each. These are the highlights from the last year. We have met quarterly. We heard your voice. We were all kind of annoyed that had has taken a long time for the statements to come out. There is like a nighttime reading when you are looking at the statement. It is hard when it takes a long time for a document to come out. It is one of the things that you see the need and meet the need. That is where DSHPSHWA fits in with chairing the DSHPSHWA. Our states need information faster. We have implemented quarterly meetings and in the bylaws that they will meet frequently and components. There are boring things that I did not put on the slides for us because there is infrastructure pieces that slow down. I hope that as DSHPSHWA we can expedite that as component. There has been concerns, for instance many of you have got called by risk factors. We broke it down to smaller topic statements. We have systematic documents. One is the journal with publication and the other is preparing to do the same thing.

We actually are trying to figure out what we can do to help serve you all in your states?

The other thing that DSHPSHWA has done this year is build a new role. Voice Town has actually been managing the funding for JCIH and as of this year cannot do that with the constraints with legislation and rules. DSHPSHWA stepped in and is going to be the treasurer for it. Thank you for being on the call. Now she's doing two budgets. We as DSHPSHWA will say we will continue to be in JCIH and will be the voices. We will make sure that DSHPSHWA stays relevant. We are so grateful on the next slide. Susan Wiley is a development pediatrician. We will be transitioning her into that role as the Vice Chair and into Chair next year.

Our statement had come out in 2019. We had a lot of questions. And so in many 2022 we did come up with a FAQ document. If you have doctors calling and asking you questions, probably those questions are on this list. We continued to receive questions. We don't want that one individual or that one state or one doctor whoever asked to get the answer of the we want everybody to have the answer. We have now launched the 2024 update of frequently asked questions. You can see they are in the free topics there. If you are not familiar with the statement feel free to check out the last in the website and the link from the presentation of 2022 conference. What else you want to say.

>> PATRICIA BURK: You are the voice for us.

>> KIRSTEN COVERSTONE: Anything else?

>> PATRICIA BURK: No.

>> KIRSTEN COVERSTONE: Now I have to bring you the mic. It is my job today. It is on my list.

>> Hi, Ginger from Illinois. Can you further define so we're on the same page. What it means systematic review of documents and what potentially the timeline is when those are available for us. I know it is crystal balling but,

>> KIRSTEN COVERSTONE: Oh, man. I'm thinking what do I think of systematic review? It makes my head spin. When we look at the field all together, we don't necessarily have enough research on various topics. One is CMV. We don't have research that is evidence‑based to lead the direction in the country. What is available and access it. In the 2019 statement, one of the comments was that we recommended that there is more research done in various areas. Two, that the research is reviewed. What the systematic review they have been reviewing, when I say hundreds that is an understatement. They pulled thousands of information and to make sure there is best practice.

>> PATRICIA BURK: They grade each of them. So the articles ‑‑ he's the expert in systematic reviews. They grade each of those and that information is out there to help drive change. The first one, the late identified one is out for a journal. As soon as we have an answer to is that we will share it also. Then the risk factor, this one I'm not sure.

>> KIRSTEN COVERSTONE: The draft is done and reviewed by the committee. Our hope was doing smaller and multiple at a time we can have more information coming out. A quick example is recently when you look at the JCI statement is six months for a recommendation. What? There is a nine-month recommendation? Why is that? We've been sharing and providing for evidence in the field for providers to have. Does that answer your question, ginger? This is proprietary information. It is not in the minutes. We have been working with the JCIH. We have risk factors on five groups. If you are working for NICU stay. With us and Susan we will do the planning and the future of JCIH. What does the field need? What do you want to see from the JCIH. Also we're going to look at the 2019 statement. Instead of in gigantic hole we will jump it down. Thanks for putting us on the spot, Ginger. We love you. That's what you do when you have friends. You learn and grow. Thank you for legit us serve and support DSHPSHWA in JCIH. It has been the highlight of both our careers. We appreciate it.

>> Tammy O’Hollearn: Big round of applause actually for all of the folks that are representing our committees for DSHPSHWA. They have done a lot of work in the last several years. Let's move on to ‑‑ we're going to take a quick break and do the state gift exchange again. We will read off some names.

>> Okay. Funny. Oklahoma. Patricia Burk. Jennifer from Oklahoma. I'm going to dig deeper here. Bryan Shakespeare. Annette from Alaska. Linda. Christine from North Dakota. Tamika from Maryland. Liza Then and Gayle from Rhode Island. Marcia. Tammy. Would you like to go get your gift?

>> Tammy O’Hollearn: I'll wait.

>> Virginia. Depali. Stephanie from Utah. I'll do one more and we will leave the rest for the next one. And Debbie from Oklahoma.

>> Tammy O’Hollearn: All right. Moving right along. We're going to go through the 2023 ‑2024 Strategic Plan. The work that we've done and areas that we feel like we've met and that way we can give you a little bit of an update. Hopefully everybody can see this. The first activity, we broke this down by ‑‑ okay. Let’s go ahead and take a five‑minute restroom break. We will see you back here at 9:35.

[BREAK]

>> Tammy O’Hollearn: Okay. Let's get started. We have to get out of this room on time. We can't go over today.

The first area on the Strategic Plan covers membership and infrastructure building. One of the things that we felt like we needed to do a better job in is making sure that we're contacting states and territories that are not participating in DSHPSHWA and not current members. We want to make sure that we represent everyone's interest. So after the last meeting last year we had someone reach out. I can try. Marcia is asking me to make it bigger. Let's see. Is that better? Okay.

We made an effort to reach out to the new EHDI coordinators and talk about DSHPSHWA and what it is and how you can benefit from participating. That was met. Another thing that we did was partnered with a National Center For Hearing Assessment liaison. We encouraged them to keep us informed about DSHPSHWA activities as well as, you know, membership and those kinds of things. Again, that was another area that we met. The next area of Strategic Planning and Outreach. For last year one of the things was to create and maintain the DSHPSHWA website. We didn't meet it, but we were able to secure, we do have a website and we have a domain paid for, but it is in the process of building built. We did not meet that. Communication with membership through electronic media. That is an area that we want to do better. We talked about ways to do that in the coming year. I would say we should have probably put partially met. It was met but an area that we definitely want to improve upon. Providing data and partners. We have quarterly partner meetings. Like that we meet with HERSA and CDC lead staff to talk about mutual areas. We do that. Then also we do that through various ad hoc meetings that we might be invited to as well as through e‑mail.

Plan membership and EHDI meeting. That has been met. We've got this meeting that we have and host every year and then this year we have our Tuesday afternoon sessions for 7:00 and 8:00 that we hope to see all of you at. The next strategic area is public policy. Again, this surrounds those committees that you heard about earlier. So obviously we met all those. We have people that attend those meetings on a regular basis. Provide input and feedback and those kinds of things. Those we've met and talked about that already. I'm not going to spend a lot of time on that area. And then strategic relationships. We feel like there is important conversations that need to be had. Both federally as well as in the state speech and hearing programs. And so we've made an effort to do that. We have our monthly DSHPSHWA Board Meetings and then again our national partner meetings that we meet with. That also includes AAP and the FL 3 as well.

Last but not least is investigate opportunities to connect with AAP and family leadership or the FL 3 and organizations that impact federal, state, and hearing programs. Everybody this morning talked about the federal partners talked about the two‑way communication. We want to maintain that and keep that open. Especially as we go to a start of a new federal grant cycle. We know that we will be diabetic this again next year with CDC.

Does anyone have any questions? Okay. I'm going to ‑‑ yep.

>> MARCIA FORT: This is Marcia. For any of you that are new to DSHPSHWA, many of us in our jobs with State Health Departments or state agencies are not always able to speak up or provide feedback or ask questions freely, as freely as we might want and might feel a little, I guess I can stand up. Might feel a little hesitant to ask questions. DSHPSHWA is your avenue to get those questions moved forward. We can do that on your behalf in a way that has no effect on your employment. If that makes sense. So that's one of the real key reasons that this group is so important to EHDI programs and other even non‑EHDI speak and hearing programs and states. It is that we can be the voice. When sometimes we as individuals cannot do that. I just wanted to make sure, even people that have been around for years the reminder. This is the avenue. If you are hesitant to ask a question or whatever feel free to contact anybody at the DSHPSHWA board and we will move your voice forward without identifying anybody. We just move the voice of our membership forward.

>> Tammy O’Hollearn: Thank you, Marcia. So we had a board meeting yesterday. Executive Board Meeting. We started a Strategic Plan. I'm going to share that with you and kind of go through it. We added another area because we feel like in the coming year we need to do a needs assessment. We're going to do that. Then we're going to take a few minutes after that and I think there is going to be index cards. Is that what we're using? I'm not sure. So gather ideas from all of you. You're going to have an opportunity at your table to brainstorm. If there is something that we did not include on here and like to see in the strategic plan please do so that that we can get it added at our next board meeting. Talk about what it is and add it to our strategic plan. Then we can get that sent out to all our membership.

First I'm going to go through our draft for everyone here. Give me one second to switch over.

Maybe if I put this one down.

Help, anyone. I'm trying to figure out how to close this. Planning. I'm trying to find ‑‑ this one. Here we go. Thank you. Okay. I'll make this bigger too. Hang on one second. This is going to be our draft in some of the same categories. Let me make it bigger. How is that? Where can I go to expand it? I don't ‑‑ I'm sorry. I don't usually have these many things going on. I don't want to make it too big. Oops. Sorry. Okay.

We don't need the completion date. Okay. The first area is the membership infrastructure building. We left on there to make sure that we contact states and territories that haven't been participating in DSHPSHWA and are not current members just to make sure that they understand what DSHPSHWA is. For example, I spoke to Missouri and their new ‑‑ you know she would fit into it. That's something that we definitely wanted to keep on here. We also have to collaborate with the different centers. National Technical Assistance Centers that they new states that are new leadership that we exchange that information back and forth so that again ‑‑ we can provide coordinator and provide a mentor and work with them as we go along.

Under communications and outreach I mentioned that we want to maintain the DSHPSHWA website. We had feedback that people are really encouraging us to do that as a way to keep up and put information out there that is available for everyone on our committee. We can do that. I know that in the past we had a website we actually had our directory on there which is very helpful for people. Especially even for our follow up coordinators and the folks doing follow up in your state it is a way to find out who can I reach out to in another state. If you have a family moving into another state and don't know how to help them that is how to connect. It is one of the ways. It is also nice because we always have our board members and contact information. That way you can more easily find us and be able to communicate with us.

Something that we talked about bringing back that we've done in the past was doing president's notes or monthly communication and putting information out there. Certainly some of our committees we can't share a lot of information, but at least if things come up it is a way for us to get information out to you quickly. We can do that electronically and distribution list or summarize the work we've been doing or collaboration that we have going on and you may not be aware of. I think that is something that we hope to bring back this year.

We are going to update our membership directory and disseminate. If you haven't gotten your picture please do so. We want to make sure that people can put a face with a name and things like that. It really kind of helps when you're reaching out or actually at the conference. It can be helpful. Again provide updates to key collaborating partners quarterly. The president and Co‑President and incoming presidents and all the presidents will talk about, will meet with the federal partners and continue that quarterly so that we can speak up and ensure that, you know, that we have a voice there because sometimes they don't always understand the challenges that we have in our state and so I think it is really important to bring those up to them so that as they're thinking about new things they keep in mind, you know, what are the challenges that states will be experiencing with this and how can we overcome those. Instead of moving forward without us and making assumptions.

So another thing is plan and provide education and networking opportunities at the DSHPSHWA meetings and EHDI meetings. In the past actually for those that are around for a while we usually have a full day of we do our business meetings and educational meetings and we're exploring that as something to do again. Different breakouts and things like that. Really to do more education. We've also done where we've provided some education throughout the year. A Webinar in an area of interest that you have as well.

Public policy. Basically we want to continue to participate and be members on those committees that we talked about. One that we was not on our strategic plan last year but actually we are a participant on is participate in the Parent Choice Group and our past presidents currently represent us on there now. We wanted to make sure we got that we got that added. Strategic relationships. That is our other parents. If you feel we need to reach out and include let us know that. We talked about additional partnerships like AAA and DeafBlind Community. Any entity that is working to improve outcomes for Deaf and Hard of Hearing or DeafBlind Children.

Last but not least this is the new area. Our category and strategic area that we added. That is for the needs assessment. We want to be able to identify gaps related to the emerging requirements for the state hearing and our speech and hearing programs.

We feel there is a lot of data out there. You probably remember the painful survey that you did for The National Technical Resource Center. Many hours for some people. We want to review that data and really see if there are some themes or areas that we could learn more about and you know bring back to all of you and figure out how we can support state and territory programs better in those areas. We also talked about, because our federal parents really haven't defined language access stuff we would like to review the different language access and currently being collected throughout the state and jurisdictional programs. If the data already exist out there we want to grab it and look at it and then figure out how we can be a part of the entity that moves those things forward. Or moves that area forward and expands on it a little bit. Those are the kinds of things that we came up with for just kind of a draft. I'm sorry. My computer went off. Next up we want to take up an opportunity for you to have some time at your round tables to talk about things that you want to see. What support do you want to see from us? Did we capture it already or are there things you want to see? Or educational opportunities that you like to have. Those are the kinds of things that you can let us know. Let me check. Are we using ‑‑ okay.

You should have pads of paper on your round tables. If you want to take like 10, I don't know how much time I have. Okay. So if you want to take 15 minutes to talk amongst yourself and write some ideas down we will come around and collect those. We're not going to go through them today and stand up and we talk about what ideas you came up with. If you can take the next 15 minutes to come up with some ideas or things you feel we didn't maybe capture up here we would appreciate it.

Two things. You can either do it anonymously or if you want to make sure that we ‑‑ in case we have we and have a way to get back in touch with you if you can include your name and contact information that's great. Certainly we don't want you to feel like you have to put your name and contact information. Certainly you can do it anonymously still as well. We will take it both ways.

>> Even if you put somebody at your table that we can reach out to. That might work.

>> Tammy O’Hollearn: Okay. Take the next 15 minutes and talk amongst yourselves.

(Table Discussion ‑ Brainstorming)

>> We're going to give you a three-minute warning.

>> TAMMY O’HOLLEARN: Okay. We're going to come back together.

>> Do we want to collect those first?

>> TAMMY O’HOLLEARN: Yep. Whoever has the little pad of paper or things at your desk ‑‑ at your table. We will have board members come around and collect those. Liz is going to finish up the gift exchange.

>> LIZ SCHARDINE: Arlene Colorado. Do we have to call them all out?

>> TAMMY O’HOLLEARN: No. We don't.

>> LIZ SCHARDINE: Okay. Whoever doesn't have a gift, go to the table and get your gift.

>> TAMMY O’HOLLEARN: Okay.

Michelle I'm going to pull up ‑‑ I'm going to pull it up. I want to pull up your ‑‑ well, you know. Well, I'm going to pull up, we don't need that. You can just ‑‑ I just move it this way. I'm sorry. You'll have to manage this too.

>> MICHELLE JOHN: It will be more like every time I do it, it will be like this.

>> TAMMY O’HOLLEARN: Okay. Let's go ahead and get started again. I am very excited about this next presentation. We have Michelle John with the Vermont Hands and Voices. She is going to talk to us about assuming competence.

>> MICHELLE JOHN: Thank you. Good morning. I'm going to go off topic just a hair and let you know that I hold you all in high esteem. I don't want you to mistake my outfit for thinking that I didn't need to get dressed to come here. I did. I would have loved to. I bought a brand‑new outfit for this. Guess what? It got stolen with all of my clothes in my luggage. I've been wearing this outfit for 24 hours. I owe you all appropriate clothing and that is what I would have done if I could have. I'm sorry. I wanted to give you a trigger warning. This session could cause tears and changes in your outlook with a child you worked with in your EHDI work. This is a raw vulnerable presentation about a child that I love and adore. This can be given and emotional and blunt. I feel like honest facts are going to be the best practice here for you to get the most out of your time. It won't be doom and gloom. It is important to have these facts in order to understand how practitioners and service providers and even family members can be influenced by what is often considered the standard and limit the child's connection, progress, and interactions. Some of the items I share may be strong emotions and ranging from sadness. I'm sorry if you cry. Some of you may know me as the President of Vermont Hands & Voices. I'm double timing. Assuming confidence. We're going to learn more by watching the next video on the next slide. Sometimes it is assuming to not know. Naming those feelings within us can help us to take action and improve our connection level and skills and professionalism. If these videos play I have a terrible mom voice. We're going to be nice to me about it. Maybe.

There we go.

>> Momma. Good job. Momma. I think she wants to borrow your toy. Nice job sharing, bud.

What honey? Nice job talking.

>> MICHELLE JOHN: I'm sorry. I have no idea how to reach the audio. I have no idea how to reach the mic back to the speaker. We're having technical difficulties. Okay.

>> Who did you see? Is momma taking videos of Tyson? Yeah, you see something over there. Who did you see? Is that your sister? Or your brother? Oh, you hear your brother? Yeah, you want to see. What amazing thing. Do you want to go and look? Yeah. Good job. Go see your brother now.

>> This is the video?

>> MICHELLE JOHN: Did you all get the general gist versus having to play it again? Okay. The captions helped enough that you can ‑‑ we're okay. Thank you. Nope. That's it. Okay.

So hopefully you could hear, see what you needed to hear or see if you have the capabilities of doing so. You can list the emotions while watching the video. Happiness or feeling connected or overwhelmed. Feel free to investigate those as well.

So who is that child from the clip? Tyson DeafBlind child. Revived after 17 minutes of no oxygen. Put on life support on a cooling mat and expected to die immediately. The EEG showed minimal or no brain activity or seizures. No breath. Surprise he lived. He is a vegetable with no awareness. He was brought home at six weeks to die. Some of the many diagnosis included cerebral palsy and quad bilateral sensory hearing loss. Oxygen and ventilation overnight. Suction and feeding tube and wheelchair and multiple hospitalization and have a short life expectancy. How life went and I only listed some of the many diagnosis that Tyson has. After being told he has no brain activity and the brainstem we were informed that he had had no awareness of who he, we, or anyone was. Where he was or any anything. He was in a vegetative state. Brain function was used for heart function and to breathe. Sometimes even forgetting to do that momentary. Basic and voluntarily sustaining measures. Due to the significant brain damage he would soon forget to breathe and keep his heart going and had he would die. Any second now. Wait for it. Wait for it. Any moment. This could be it. First it was to be a day. Then one‑month, two. Three. Then six. He won't live a year or see age 2. After turning three they stopped saying what age he would survive to. I wish more of what more day would look like. As soon as my first-born child and that terror is now known as PTSD and birth trauma created a mother and anxiety was on over drive and 24/7 for years. Unable to sleep and think and super hypervigilant. I was no medical professional. I could not possibly know how to take care of this failure to thrive baby who could not see, feel, hear, or know. His eyes would be opened at times. Of looking through things never at. No recognition of things. Just like they said. What do you do with a comatose kid. I would be the best damn caretaker. I would be the team of professionals it took. All wrapped up into one person at home. This is all relevant and important medical history to have. Is there more and things that are equally as important? Too many computers.

So while the information on the previous slide is critically important to understanding the history of how a child became who they are let's reflect on the possibility there is more to said child. Let's look at the next two slides together. Who is Tyson from the clip? A DeafBlind + child. Baby Tyson with a limited life expectancy and medical equipment. He is adorable and sweet. Enjoys to listen to music. He likes feeling toys and going for walks. Parents think they're projecting. Needs warmth and comfort. His favorite nonhuman cuddling companion is Gena long old white-haired cat. Ponder for a moment. What is here? Is it a little or a lot. Do you know baby Tyson very well? Can you convince yourself that you do know Tyson? Does the family? What if this was your child?

So now let's look at information regarding older Tyson. You will immediately notice there is a lot there. Visually busy. You will notice a key work shift. We will go through it. Still Tyson. My DeafBlind + child. Limited life expectancy and multiple diagnosis and medical requirements. He is an amazing sense of humor. Loves to laugh and smile. He loves listening to music. Classic rock he enjoys feeling toys and going for walks stores and shopping. Watching the iPad. His siblings. Looking at and listening to stories. Loves favorite providers. All things water. Everything to do with his hair. Loves snuggling and lava lamps and my parents. Silly voices and getting haircuts. Being complemented and picking out clothes that he deems cool looking. He hates poppy diapers. Old school music and being cold or alone. He hates jacket and schoolwork he doesn't enjoy. He hates seeing providers that don't get him and he hates blood draws. When you compare baby Tyson with older Tyson, is there a difference in daily. He is now a rounded individual for you? Perhaps an expanded version of baby Tyson. How do we get from the first slide of doom and gloom ‑‑ excuse me. Doom and gloom medical history to learning Tyson to really knowing Tyson. Perhaps you notice the big child description. He is not a child. He's my child. Does that change the meaning for you? Interactions with words and families. Excuse me. Interactions with families, words, and behavior matter. Families with significant or multiple diagnosis may be overwhelmed, confused, or scared. Your words and child’s incapabilities and your views have a stronger view than you release. I'm going to give you examples. Start with a simple one. Calling me not by my name but Tyson's mom. I don't mind it per say but no one has ever actually asked. I don't go by mom a lot. I chose momma. It is my preference. I don't love being relegated to just Tyson's mom. Although I'm extremely proud of that title. I'm more than just a mom. Don't assume people's comfortability with names or labels. I'm going to go bigger now. During the first two‑weeks of patient stay after birth. They allowed him to have donated breast milk was literally the only thing I had control over. I could not manage to do that correctly. Breast milk was best I heard. My body killed my kid, and I could not feed him. I was utterly defeated to stand and watch my child die. During rounds I overheard this unknown doctor shared to a large medical team and slew of residence. He could not understand why the other doctor was allowing to waste the donor breast milk. I wasn't able to hold or touch Tyson for a day of life five. On day of life eight Tyson was going to remove his life support, as they say let him go. I had only three days to touch him and holdings. A few minutes prior I was holding him skin to skin and chest to chest. It was a lot of work to get him skin to skin and keep the tubes in. I knew the hours were upon us. Read all the books and picked the grass and leaves to experience the world outside. I took the picture in the opening slide. I was saying my lengthy goodbye. Squeeze. He wasn't really squeezing my chest. Squeeze. It is just a reflection of action they said. During my ridiculously drawn-out goodbye we love him no matter what. We would never be upset or disappointed if he could not continue. He was in charge. I shared we understood if it was too much for his body or brain to go on. He was enough for who he was, and the situation and we were so proud of him for trying. You lead son and we'll follow you anywhere. We had no understanding at that time that moment was assuming confidence. As the entire medical team and my parents and Tyson's father circled around. I squeezed so tight while the tubes were removed. Not one breath. We waited. And then it came. And again and again. Involuntary reflection. This makes no sense. He never took a voluntary breath. It did all the work. Now realized it was completely accurate. He is just resting. No need to work when you don't have to.

As Tyson continued to live we were often told we could assist him by no longer feeding him by a nasal tube. After all, it was what was keeping him alive. Did we really understand what type of life were we choosing for us and him by keeping this going. His father and I were appalled. We were determined to be switched to a he was two weeks old. He was not there. They gave him no pain medicine whatsoever. He kept making this tiny noise. I never heard him make a noise. It seemed voluntary. It was barely audible if there was too much background noise, but it was a noise. I just knew he was in pain. I paged assistance. How would I know if my child felt pain. When they did the pain response test pinching him he did nothing. Have you ever had a whole and had no pain medicines? That was what my baby was enduring. He's been one way and now is different. The residents thought I wasn't projecting. The reality is my child was not there and did not know a surgery occurred. Low and hold to appease me the postpartum dramatic mother. They gave Tyson pain medicine and the noise stopped. During the outpatient visit they told me what type of mother I could be if I thought Tyson's seizures could be controlled. Did I want to be she questioned why I was insist ant and he should suffer. Let nature take it instead. I should evaluate what type of mother I should be. You have issues.

Within that same office on a different visit I stated I knew there was something wrong with Tyson with the neurologist. He could not move involuntary for lack of a better explanation a mal functioning robot. She scoffed and told me that was impossible. She said I wished he could do something. I was the one that made the appointment. I was concerned. I know you think you know. I know you wish you did know. I have the medical degree and my background in specialty is the brain. I promise you he is not doing anything. I got a second opinion. I was more concerned by the functioning robot that were increasing and consistency. When I called to inquire and was desperate for a second opinion the doctor called not even an hour later. I must bring him before the office opened so he could see him. He knew that the specific brain injury was associated and susceptible to a disease known infantile spasms. He received no care. In case you were curious we do continue to see that second opinion neurologist and he is an amazing practitioner.

Remember these stories I'm sharing with you are happening in rapid succession. We're talking about weeks. Tyson is going to die any second now. By now I resuscitated my child twice. Local emergency room knows us by a first name basis. We have our PCP's personal phone number. She is unofficially officially on call for us 24/7.

While enduring all that an untold number of medical and service providers asked how I knew he was in there. The thought of him being in there was nice. At times the feedback affected my parenting. What I did and held him. It made me question if I was literally losing my life. Was I living in an alternate universe? Could he be in there? Could the for the first-born shadow the truth? I had the providers tell me my brain-dead son was given way too much credit and was not able or capable to do. Love him to death crazy mother. There is nothing more for him and you at that. My mouth is getting dry. I've been up for clearly two days. I will try and change this one now. There we go.

Computers. Okay.

Early interventions and actions with family. Words and behaviors still matter. It is easy to forget the intervention the family is dealing with the terms diagnosis and having a variety of emotions and relation and now being told that their child needs early intervention. Most families don't know what that is and could and should be. They don't know if they are best practices or relevant to their child. The more diagnosis and less likely a family is to make sense of it all. There are rotating cast and crew and medical providers in your home. Can you imagine they are judging the state of their home. For some it is your job. They are judging how you look. Have I showered? Definitely not. The rest got stolen. The dog bark every time. What is this person's name? No clue. What is their specialty and why are they yet again. Some use jargon. My higher education made it easy to follow. I can't stress to say enough to learn the terms and families can use it and plain language. To know both to have competence. It is the more nourishing conditioner. Rinse and repeat.

Upon our first meeting with the case manager Tyson was asleep to prevent aspiration of secretions. Plumped herself down on the couch. I'm Bethany. First question. Is he always like this? While pointing like this. Do you ever hold him? How often? Every couple of days or less than that. I remind you he was asleep like so many babies do. This is the person that is going to write our IFSP. Try to remember you're in their home and in their minds, not just houses. This is their child. They're trying to notating this new landscape and capable of making the informed decisions with the best interest in their families. We relaxed to the family itself and the child. Those are actually two different relationships. Assume their competent, capable, feedback and interjection. You might think I said that advice for a reason. You're right. During the intervention and physical therapy and visit the PT flew through the door clearly not knowing what she was walking into. Tyson was in a reclined baby chair. He was a month old and failure to thrive. He is not moving because he can't. He's just chilling as we called it. All this woman does and pediatric PT. She has done this for 30 years. Laid one glance upon him and pivoted her upper body and said I don't know what you want me to do with this. And that hand motion is a real thing. I'm going to say it again so you can really take it in. I don't know what you want me to do with this. This thing that she doesn't know what to do with is my terminally ill baby. My first born and terrified loving and I don't know what I'm supposed to be doing with. Like most I expected a healthy perfect baby but instead I got this. This professional doesn't know what to do either? He is not even a person to her. What am I thinking about thinking him as a person. Is he right or wrong? Questioning my a baby that doesn't see or hear me or doesn't know where he is or who I am. Or does he?

A provider who specializes in Deaf and Hard of Hearing is here in the conference. Ms. Emma. I just a questioned her about Tyson's capabilities and availability. Assume confidence. You already are. Keep going with it. Take it further. Always assume confidence. He understands and paying attention even if he can't show it. I was floored. I probably looked like the emoji with the head blowing off. It made me question my ability as a parent. She assumed in many Tyson and me. She assumed we needed to boost the skills and confidence to grow. How did I know Tyson was confident? One day sitting in our recliner and small dog and baby Tyson resting in my arms I was watching in the TV. I felt someone looking at me. Many of you probably know what I'm talking about. I'm home alone or am I. I gaze down on my left. There is Tyson. Are you looking at me? Do you see me? Not through me, not nothingness but me. Momma? It was eye contact. He'd found me and I saw him too. He was in there. I wasn't crazy. I wasn't wrong and I wasn't a bad mother for wanting him in there. He was. We built that immediately. Awarding attempt to eye contact. It was the first connection. I assumed if I was making it up. Assume confidence. Tyson used to smile when he was having a seizure. I didn't bring those video. To think I would only see him smile on those occasions. Tysons fourth birthday. The trauma often suffocated what could be a special day. On this birthday on the late afternoon I did something, and I do not recall what. Tyson smiled, but he didn't seize. He just smiled. I loudly swore holy sh. . . questioning my sanity again I tried to replicate the smile. I came into his view for something, and he smiled again. It was real. He was capable of emotions. Glad to see me. The dog came over and licked his hand. I cried for hours. Happy birthday to us both. As an aside amazing moments like this don't ruin that he can do something now that that should be the switch movement. Never should an emotion should be a training to the twitch hit. Let the families enjoy.

Last example. For a child that was to live eight days his birthday and the following seven have been difficult. Deep emotions and anxiety. As you recall I wanted to make it to one year, two, and three. I want the five because it is half a decade. As time progressed. Eight years. Could it be possible, and it did. This child lived his entire 8th year and is now 10. So this kid is truly something. What does all this mean?

So lessons and takeaways. When best practices according to the professionals conflict you need to have a strong belief in your own confidence. Silos stay in your lane but have awareness of the cars around you. Is there an exit coming up? Prepare the family. Nonverbal does not mean non‑communicative. If you assume confidence the family will follow suit. It is okay if they need encouragement and self‑esteem. Assume confidence in both the child and family member and to yourself by leading by example. It is easy to follow your own specialty. It is important to know who else is involved with the family. What are the cards around you. You may be given suggestions and homework to the family. Is there a traffic jam? How many others are giving suggestions to do and work on daily and fit in alongside household duties. Medical and work and don't forget to connect with your child. Families hear conflicting messages. Do all of the things in the best interest of their child and don't do all of the things to avoid burn out. Connecting with your child number one. Also important to do X, Y, and Z because you will get no progress. For some of us doing told to do something we will at the expense of many other things. The awareness and teamwork needed amongst all providers is critical to find a balance. We're just trying to keep our highways clean. Regular communication with anyone would works with the child and family. Attention the stress off the parents to not play intermediary. You are building better prototype with families and colleagues. Remember when I said you are taking space with homes and minds. It is a ten-lane highway. Sometimes we're emotional or irrational. Try not to life has become more complex. Sometimes you show up on a bad day or tough moment. Things happen in things of emotions. Sometimes it looks a bill of irrational like this haircut I have. Don't make a hair appointment when you're upset in case you are wondering. Life has hard time when wondering. Adjusting to this new life things will fall apart. Sometimes family will tell you everything is good or fine even if the kitchen is behind me. I definitely meant them not me.

Others will wear their emotions on their sleeve. It is difficult. I implore you to keep in mind. It is likely not you. It is them. Their life. This is the one time it is not you; it is me is acceptable. For instance while some are prying in our life and not accept good or fine or some did I was getting fat from not eating. When I did eating garbage. My relationship with my significant other was falling apart and my parents announced their divorce. I got what I deserved, and these things were my own fault. I should have been the one to die, not Tyson. Those lanes had fiery accidents. Some of them said why didn't I fight with the insurance company or fill out this form. It might be because at night I cried a lot and also terrified that Tyson would die. It is not you. It was most definitely me. That guy in the first slide in the lovely picture is my children's father and working hard at being my friend. These just that. He is not my boyfriend or husband or parent or significant other and hasn't been for years. He is the father to our three amazing children, and they really love him. People talk about how I'm a vault for them. I can be a vault for myself too much to my own detriment. I don't trust you're going to help me with roadside assistance. Things I'm saying for you today are new for me to share. As my friends in many Arizona know, if you ask me on the wrong day and coparenting is under construction I will loudly tell you no, I don't have a husband. As my friends in North Carolina know, if you which with the construction is completed I will tell you we tried everything we could. There is a big different reaction depending on what is going on in my highways. Sitting in traffic wears on you. You might act a little different. Why am I being transparent with you now? This is my real life and sometimes it is easy to focus on your lane. Lots of people ignored the fires in my various lanes. The focus to be on the that providers lane and at what cost. The grieving process is individualized. Some will want to tell you nothing and others in between. It is really confusing. Treating them like there is an awareness is huge difference. Have compassion or avoid resentment. The more notice the better. Changes in providers, case managers are moving into the school system should not be a surprise whenever possible. Families need time to prepare the exit that is approaching. Jumping lanes isn't easy during rush hour. Children need time to process as well. By giving extra support if needed families can go prepared, confident. You are emphasizing collaboration. Independence and self‑worth. Nonverbal does not ever mean non‑communicative. Teaching families this lesson, they are not the same.

Communication will not necessarily using the language of the majority culture does not mean they don't have the ability to communicate. It may be via oral language, sound, sign language, body language, behavior, eye gaze and so many other ways. Tyson communicates by vocalization. Eye gazes, tongue movements and or attempts at making noise and only air comes out. Other variables Tyson will use one or multiple modes of communication to get his point across. Each and every one of these bids to respond he made the connection that I understood. Noises change over time. Are you sure? You're fine. Just tell me if I'm running over on your time. This says noon. Okay. Oh, okay. Oh, my God. How long have I been up here? I know how long this presentation takes. That's crazy. I'm sorry. Didn't mean to distract everybody. Noises changed over time to clear repeated sounds to yes or no. These are not the same sounds used positive or negative. He has a small communication. Communication partners are not recognizes these they're losing as an incredible opportunity to get to know Tyson. You must lead by example. If you assume you are confident the child and family members are confident. With dedication and best practices and hard work the sky is the limit. Children like Tyson are not going to get up and sing and dance and do a handstand. They may enjoy touching and listening to music. These are huge milestones for children with multiple disabilities. Never estimate the power of reaching a goal and ensure that you know basic wait times. It can be long but worth it. Respond to changes and communication bid. The child when assume confident can make the connections after much repetitive work. If you believe in your own capabilities and seeing it in others your work grows and expands. You are a competent and well‑rounded provider. Practice being responsive and reactive.

What can I do? Action steps. Assume confidence. Child and family are able, available, and capable. The child is capable of communicating. The burden is on you to recognize it. The best in yourself. Are you seeking best practices for your profession or family? Check in. Are you having positive interactions? Are you truly enjoying your time? Believe that the child diagnosis do not prevent them from connection, learning, changing. Any child is a whole being with thoughts and being and currently able to express them or not. If you feel that this is an area that needs work, trust you can start the change now. Start big, small, just start.

What are the systems that require changing to make assuming competence a natural part of EHDI, EI, educational systems and families? Individual throughout processes agency organizational leadership. Policy through DOE, AOE and legislation. Educational institutions. That's where everyone gets their education and the medical systems. What are the benefits of assuming competence? Increased members and professions. Increase self‑worth. Increases communication and connection for and with the child. Appropriate policies, rules and regulations. Legislation that supports individuals with medical and complexities. Increased funding for programs that serve them. Changes in medical providers, staff, service providers and terminology and suggestions and decision-making processes. Perhaps most important. Changes and or shifts in societal views. More positive views and acknowledgement that every person is not only capable but actual is a productive member of society.

Did you notice a theme? Increased? Positive results. Assuming competence is a natural policy and position has untold benefits for all. Top-down bottom up is the most productive way to create change efficiently. We should not wait a trickledown effect. Utilize the theory that a larger collection can have change. Policies and procedures and best practices and assume confident will all create change in society. Something seemingly small and one family or child can create ripple effects. Something that cannot be ignored. The same for the learning process. One notice for the bid of communication and show understanding increases the possibility of it occurring again. Positive reinforcement.

So I don't know what to do. Take a breath. It is okay not to know. Give yourself permission to know that you are not positive or assure the information. Don't shame yourself of the person asking. Be aware of toxic and positivity and awarism. Due your due diligence. Most importantly don't push away. Hold the individual and family towards you. It is about the connection. Trusting relationships creates safety for learning, trying new things and feelings of being accepted and understood. So many times when I do this talk people say I don't know if I'm doing it right. I don't always have the answers and I don't know what you're talking about Michelle. That's okay. You are not expected to ever know. You never will. You may have to say, I don't know. That really is okay. Take a deep cleansing breath and give yourself permission to be honest. If you give clear information on the next steps and when you will get back to them and follow through families will take you seriously and not question your abilities. If you panic. There is no shame in not showing. We're all learning every day. There can be intense shame in responding inappropriately. If you say something out of turn take a few deep breaths. Correct and collect yourself. It is okay to seek help from a counselor or mentor or coworker that you trust. I do caution you to be aware of the track of toxic positivity. Unfortunately it a has to be okay. Constantly turning a moment of vulnerability and everything happens for a reason. Every statement will server injure relationship you built. The family will feel unheard, unseen, and have feelings of rejection and isolation. In moments of vulnerability you can validate what is being shared. You might not be able to fix it but throwing out toxic positivity is not going to help. I want to acknowledge the newer negatives. Otherism. This can come out on views of the family and views on them. Influences one to one work and policies and procedures. If you discuss families as a collective they regularly as in why don't they just do X, Y, Z, I don't understand why they don't do that. They are annoying and time consuming. These are the nicer examples that have been asked of me recently. That doesn't sound too great to me. It sounds terribly offensive. If we made a negative connotation of the providers here I don't recognize you with your own personal highways. This type of relationship becomes an intrinsic power dynamic. I know it is hard and sometimes you won't agree with the decisions and actions that families take. Sometimes they are not going to agree either. Avoiding this situation from a team standpoint you will feel a sense and assuming confidence.

Lastly try to assume the best situation. Ask yourself what should I do? What feels right? Believe you are capable of making an informed choice. Trust me family members know when you are faking us. We know when you believe in our abilities. We know what feels real and what feels fake.

Ask yourself, how can assuming confidence help you personally or professionally? Can you think of ways to incorporate it in your life. Shame and mistakes made and not assuming conversation assist you and have you ever had an experience when someone in the position of power felt you weren't seen and believed. How did you feel in that moment? Additional questions to reflect upon. Are you willing to let others to take the lead and know what is best for themselves and family? Recognize assuming confidence you are leading and following. Can you learn from your missteps? Give yourself to say I'm not sure. Vulnerable. What is she talking about when she said Tyson tough. When Tyson was born we attempted to rally our emotions. Tyson tough is what we landed on. A nurse thought we were Bonkers. When I felt I was spiraling. Do you need a feel-good slogan and happens to include assuming confidence and centers you in stuffer times. Use it as much as you need. Don't let it be embarrassing and shameful. If it works it is great. I don't feel you're bonkers if it works for you. Thank you for your time. I know I did a lot of talking. I appreciate the time and attention and the invitation to come speak today.

>> TAMMY O’HOLLEARN: Yes. We have plenty of time.

>> MICHELLE JOHN: Tripping would be the icing I had in the last 48 hours.

>> Thank you. This is the second time I've heard it. I had my own fidgeting from crying. You remind us of what we do what we do. We get caught up in bureaucracy. This is why we do what we do. Would you be willing to speak. When do we reach out to families? When should be we as a state or part C reach out. Can you speak to that? When should we offer services.

>> MICHELLE JOHN: This is a huge topic and sometimes be considered controversial because families feel really different. Some want them straight out the gate. They want and need that support. Some are like me and closed off and not ready. My advice has always been try and catch them all at those times have a schedule and follow up. Have a scheduled follow up. Just keep kind of I'm here. In case you need me. Some are going to jump immediately, and some are going to wait to make sure that Tyson is going to live. I think there is something to be said for regular follow up without being intrusive. I would really start as soon as you're told that this family exists but just gently start. If that helps at all.

>> TAMMY O’HOLLEARN: Any other questions or comments? How do you follow that? How about a round of applause? Okay. Believe it or not we actually are going to finish early. That's a good thing actually. Hang on one second. I know that a lot of you as a part of the DSHPSHWA membership you are able to take advantage of the individual sessions today and I know that many of them start sometimes at 12:30. This will give you some time to catch lunch, take a break and do all those things. A couple of things that I want to do first is thank our interpreters for their assistance today. I also want to thank each and every one of you for engaging with in our DSHPSHWA community. Please seek us out if you have questions, concerns, suggestions. We're all here and very open to that. What else? I also want to wish you a happy St. Pattie's Day. One thing I want to stress is I know how hard each and every one of you works. So ‑‑ I'm sorry. I just want to say thank you. I want to ‑‑ one thing I want to say is thank you for lifting us up today and make sure you go out and do that for other people as well.

Another quick announcement. Board members current and new meet in the hall to get a picture. Last and not least can we get a emotion to officially adjourn the meeting early? I'm sorry.

>> You guys are great. All of you. I make a motion to adjourn.

>> TAMMY O’HOLLEARN: Is there a second?

>> Liz Schardine seconds.

>> TAMMY O’HOLLEARN: Okay. All in favor say aye. Oppose do the same. Okay. Motion carried. And then, um, this meeting is adjourned. Okay.

I was like wow! Overcome with emotion.

New board members and all board members we're going to do the picture in here since we're done early.