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CAPITOL6

Topical Session 7 & 8: Capitol 6

March 19, 2024

1:15pm – 4:00pm

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[1:15pm]

[Live Captioner standing by]

>> There we go. That's a lot better. Good morning, everybody. I am Randy Winston. I'm happy to see you here and looking forward to talking about EHDI Pals today. I'm an audiologist, a pediatric audiologist, I call myself an EHDI-audiologist. And my work is primarily around the one and the three. So, newborn hearing screening and EHDI Pals. And so I'm going to just start with asking a couple of people who are here, who are audiologists, can you show me?

[Pause]

>> Okay, we have a few. Any EHDI-state Programs? Okay. Thank you. And parents? Families?

[Pause]

>> Great. Anybody who is new to EHDI Pals or has never seen it or not familiar with it?

[Pause]

>> A few of you. Okay, um... so... I like to always start out with the commission statement. To just let you know a little bit about why and what we are doing with EHDI Pals. EHDI Pals was developed to be a searchable database of audiology facilities for families and professionals, so they could identify, very quickly, pediatric audiology facilities, in their communities that have the capacities to serve young children, ages birth to five. And age-appropriate services. So because of the national dilemma of loss to follow-up which became very clear to all of us back in 2008 or' 09, EHDI Pals was developed to address the issue so state EHDI programs could provide the EHDI Pals website to families in the state and would quickly be able to find appropriate services and get their children into... a diagnostic audiology facility that had what they needed. As a result of the work done in EHDI Pals we have developed more things, developed family resources and developed professional resources. Lots of resources and back-end tools for EHDI programs, so I'm going to show you some of those things today. We talk a little bit about updates and enhancements. Past years updates was we improved the facility survey. The facility survey, as many of you know, is more than 65 questions. And an audiologist goes in and have to fill out all of this information about their facility, all the services the facility provides, and the services, the pediatric audiology services that they have. So, it's very detailed and it's long. What we did this year was able to minimize and streamline process for people who, maybe they are not -- maybe they are not fitting hearing aids, maybe they are not doing cochlear implants. Maybe they are just doing hearing screening or diagnostics. They would indicate that at the beginning of the survey and it would streamline you and take you right to the area you need to fill out. So we heard a lot of complaints about people, from people who said it takes too long, so now we have really shortened the process which we are excited about. We have family resources that we enhanced EHDI Pals with a couple of years ago, professional resources last year.

We now have the capacity to enter outpatient screening facilities in EHDI Pals so we are hoping more and more screening facilities will enroll. We have new website layout for optimization of phones and tablets. So you have really good vision and view of the screens. And we've improved the look and feel of the family pages.

So, I'm going to show you, really quickly, a couple of things on the website. Let's see if I can get there easily. Just to share, really quick, because we don't have a lot of time, here are the family resources.

When the family comes into EHDI Pals, they are going to search for services. Let's see if I can get my mouse to work.

I use a mac, so I know I'm not doing something right. Can you help me. It's not scrolling well. Oh, here is what I did wrong.

Okay, if they look for services they will come here, and we will go through that in a second. One of the great things about EHDI Pals is we have lots of family resources. We worked on a project a couple of years ago with many of our Advisory Committee members, to actually add all of these wonderful questions and answers that families might ask about any given subject, having to do with their child, from age birth on up. If they have concerns, if they didn't pass the newborn hearing screening, there's just -- it's just got lots of great information and resources in here in all of these different topics. So, I encourage you to take a look, get in there and take a look.

The other thing that's really cool is -- are the professional resources that we added last year. And this, I'm going to show you for example... what we did was for years, NCHAM had pediatric workshops over the country and these were to help audiologists who wanted to update their skills and wanted to learn about pediatric audiology, we would go around to different cities in the country and even outside of the country to provide these workshops with national experts. Well, we had so many materials and so many tools and so many resources that what we did was we took them all and we -- it's a treasure and we put them in EHDI Pals so professionals, audiologist, anybody had access to this information. So for example, if I'm looking at the diagnostic test battery, we have all of these different topics, and you can click on any one of them and you can see all of the information that we have provided: Presentations, videos, clinical practice, guidelines.

We are very excited about that. We have tools for families, professionals and EDHI coordinators. I'm going to show you chose in a moment. So I'm going to scoot out of here. See if I can get out. Okay.

Back to the presentation.

It's here, it's just not being my friend. Yeah, I can't get back to it. You see it here; right?

There we go. Okay. So... one of the up dates that we added this year, in fact we just completed the functionality for it, is called: EHDI Approved Functionality.

And this is a really cool thing, because we've been getting requests from State Programs for quite a while, to add the ability for EHDI programs to go and designate the facilities that are using the best practice guidelines to you know, all those facilities that have the equipment, that are using the best standard of care and identify them in the EHDI Pals directly, so when families coin and they are searches for service, they can identify those that have a star next to them. So we are excited about this and I don't know if anybody is here from Utah, but they really helped to encourage us to do this and we are going to be doing a pilot with them because we just finished the development of this. So, um... on the website, we have various statements for State EHDI Programs and for families and professionals around what this is. And instead of going through it right here, what I'm going to do is I am going to go back to the Internet, and I'm going to show you how this looks. So, if I'm a family, and I'm searching for services. I'm going to come down here, and I'm going to put in the information about my child and let's pretend they want diagnostic testing. And they live in Logan Utah. And let's... show you... --

So they would come in here, and they would see right here, the explanation of what the stars mean and they can come down and see that this has a star next to it.

At this point they are going to click on the facilities they want more information on and I want to show this to you so you can see how much information EHDI Pals provides to families. Um... we've got you know, the number of cases that a given facility has had in the different modalities. We have whether they have had teleintervention, teleaudiology service, insurance they take, the services they provide in their facility.

So all -- I'm showing this to you because I think it's important to know how much information EHDI Pals provides families. So, when they are in here, they can find the right match for their child. But as you can see, here is the one facility, for example, that has the EHDI-approved status.

So let's go back.... And let me just show you, if you're an EHDI coordinator and you want to see how this works, I'm going to do a very quick...

[Pause]

>> You want to see how you can designate a facility. So you would come in here and these are back-end tools for the EHDI program, so they get to log in as their state and they can come in here and they can quick on any facility, like for example, this facility. And they can decide whether they want that facility to have EHDI-approved status. The one thing about EHDI-approved status is you have to have an updated facility.

A lot of facilities have not updated. Once they become outdated they show on the website to the parent or the family or the professional, in red, that the facility is outdated. So we don't really know if all the information in their facility profile is actually accurate, so we won't allow those facilities that aren't updated to be displayed with the star.

But this one is the last update -- oh, this one isn't. So we wouldn't be able to update it. We wouldn't be able to provide EHDI-status. So, let's just use this one. If I were an EHDI coordinator, I could come in here, click this and see the star when I closed it. It's that simple. And right here, if you click here, it's the -- all the definitions of what EHDI approved is, what it means for families, as you can see. What it means for audiology facilities so that they know and also for state-EHDI programs what they need to do for using this feature. What they need to do. And my recommendation is always that is state EHDI program, if they are going to be using this feature, that they actually provide a document to audiology facilities, so they can see exactly what that state expects, what that state's guidelines are. And that very, very specific detail is very important for audiology facilities to see.

And that goes into reporting, and that goes into so many you know, laws to follow-up and so many other things that we really um... we really, really want the state to, when we encourage states to provide this to us, and then we can share it with audiology facilities. There will be another eye and they would be able to click on it and see this document that shows the state guidelines. So I think that's pretty cool.

So, that's EHDI approved. And I'll have a -- hopefully have a couple of minutes for questions at the end, if anybody has any around this.

We are going to do this pilot, like I said, with Utah. And then maybe bring in a couple of more states and slowly roll this out and see how it goes.

So, this shows a registered facilities, facilities that are updated, facilities that are disabled and facilities that would complete submissions. So in this blue line, we have 1,594 facilities enrolled in EHDI Pals and we continue to you know, do things, different strategies to try to encourage facilities to enroll.

1,500 of them right here, this orange line, have complete submissions. In other words, they completed -- they didn't just start their facility account. They completed it and it's existing in the EHDI Pals directly.

711 of our facilities are updated. And that's where the biggest issue lies in having facilities keep their information updated as I was saying before. And we will talk about that in a moment. 632 of them are disabled. And we disable them if they haven't been updated in a year. We -- and there are many efforts that we make to try and get ahold of facilities. But some of these haven't been updated for you know, 5 years or so. So we want to keep our database clean, we want to keep the integrity high of the facilities that are in there. Um, so how do we do that? Um... we... oh, this is not -- yeah. I'm missing a slide. So I'm just going to talk to what we do. Um, I have an assistant with NCHAM and this assistant helps me by looking at all the facilities that are outdated on a weekly basis about what he does, his sends an e-mail to the facilities that have not been updated and asks them to update again, once more. This time he has changed the username and password because very often there's turn over. Very often we have no idea who is in that role. They may not even know they have an EHDI Pals account at that facility. That's one of the biggest issues we see. And so if you send the information to a number of people in the facility account, because we ask for more than one e-mail, we are hopeful that somebody is going to get it and we are hopeful that they are going to update the EHDI Pals account. So we are constantly working on things like that. The other thing that I have recognized is how important the EHDI program is in all of this. The EHDI program is the gate keeper for all the audiology facilities in their state. And right now the majority of them use a paper document to hand to families. This is really not sustainable because facilities are always -- there's just turn over, there are always changes. And what is great about EHDI Pals is it has the ability to have the information updated, all the time.

We have both English and Spanish. So families can search in Spanish, all those resources that I showed you are in Spanish. So, it's just so much user-friendly than having to update a paper document. And more and more states that I'm working with, have recognized this. And are starting to change their practice from handing out that paper document, to also sending their families to EHDI Pals. And... I'm hopeful that more and more will do this. What is really important is the EHDI program can help me identify facilities, where there has been turn-over and who the new contact person is. So we also send a weekly e-mail to some EHDI programs, and we ask those EHDI programs for the new contact F they have any idea who the new contact is, if the facility is -- should be disabled, because maybe they have closed, whatever the status is, we ask the EHDI coordinator: and we have found great outcomes: we get information back if we e-mail one-on-one.

So we are just working at this constantly and trying to find ways to keep this information updated and to get more and more facilities to enroll. I want to talk about linking badges. They are awesome. We provide them on the NCHAM website. Excuse me, in the EHDI Pals website and let me see if I can show them to you. If you come to the bottom of any page in EHDI Pals, you can go to link to us and you will see we have these postcards and I brought some of these today if you can't to take them. Yeah, they are great to hand out. Stakeholders in your state. They are here, you can come and grab some. I can also send you this file if anybody wants it with the QR Code and you can personalize it with your state, which is cool. Ohio just did that.

So, this is nice. We also have all of these badges. So if you are, for example, just a state, any state, Department of Health Service, you could put one of these badges on your website and we provide the coding which is great. Because you don't have to figure that out. But we have a number of them. We have them for families and we have some to inspire audiologists to enrolling. We have a bunch like, depending on the size of the space that you have on your website, you could have your choice of all these linking badges.

Let me show you a couple of ones that we have. Register your pediatric audiologist facility in EHDI Pals. You can put that on your website, too.

How is our time? Five minutes? I want to leave a couple of minutes for questions. Get back to the presentation, hopefully. My finesse with this is not great, so I apologize.

I think that's it, the badges, the promotional and questions. Does anybody have any questions? Yes, hi.

>> Audience: I'm from South Dakota. I had a few questions. One of them is for sites, looks like you can enter in two contacts. Is there the ability to enter more?

>> Yes, we have added more fields.

>> Audience: Because sometimes I want to add as many as possible to get to them.

>> Yes, absolutely and we have asked for a main e-mail that might go to a secondary or administrative person.

>> How have places with telesites handled that? How do you define them but fall under another clinic so they know how it's set up?

>> Presenter: Yeah, you can actually -- can't really search for "tele sites" specifically. But you can pull up the facilities closer to you or you want to see in your state. And as you scroll down, there is an area, regarding what their teleservices are. If you choose a facility to get more information on, like earlier I showed you those comparison pages and I was scrolling down, there's an area in there that has all kinds of teleaudiologist diagnostics, OAE, tympanometry, the whole gamete of teleaudiology. But you're saying that you would rather see like, the ability obviously, to search for the services; right?.

>> Audience: I can talk to you after.

>> Presenter: I love working with states and hearing state requests. We take them and use them and do our best to implement them, so any other questions?

>> Audience: Keeping the information updated is important for EHDI Pals. All of us have to update information for bank accounts or job. Do you have this strategy that audiology facilities receive just one e-mail a year just to said is this information accurate? Yes or not. Just a simple message that they can easily said yes or not.

>> Presenter: What we do... what we do is ever facility that is enrolled, what we do is 3 weeks before the expiration date of that year, we send out 3 consecutive e-mails. They are automated, they tell them it's time to update their facility, it also has a link so they can reset their password and it automatically sends the pass word to them so they can do it that way.

When we don't see an updated facility after those 3 weeks, we wait a month and then we start to go after, in more information, we research, we google, we look on LinkedIn. We try and find out who the contacts are and send another e-mail with the re-set password.

>> Audience: Perfect. Thanks so much.

>> Audience: The mic is right here. What are -- I know you went over the updating strategy. What are your strategies for identifying pediatric audiologists that aren't in EHDI Pals?

>> Presenter: Yeah, that's the EHDI program. We recently developed an MOU with ASHA. One of the things is trying to get cross-reference list. Find other entities where I can get, you know, information. But yeah.

Thank you so much. Here is my information. Please contact me with any questions, if you have ideas, if you have things that you think would be wonderful to enhance EHDI Pals, I would like to know. It's been a great collaboration and that's what this is about, so thank you.

>> Yeah, please do. Yeah. You can take both.

[Pause]

[ Session Concluded at 11:06 a.m. CST ]

[Live Captioner standing by]

>> Good morning, everyone, I am one of the two co-coordinators for the California EHDI program. And my esteemed colleague here, my partner in crime, take it away, Sherrie.

>> Hello. My name is Sherry Farah. And I am the EHDI coordinator for California. And the name of our program is: Lead Kay family services as you can see here.

>> Yes, you can see our very amazing logo on the bottom right of our screen. Today what we are going to be talking about is what California is doing to improve early language acquisition opportunities and what we have done historically. We received the HRSA grant in 2020 and just notified that we received the HRSA grant again for five years so we are thrilled.

So we have been working from 2020-2024. However we did a lot of preliminary work prior to 2020 which is what I'll talk about right now.

>> I'm curious, how many of you here are from California? Raise of hand?

>> We have a couple. A few.

>> I see hands. Yeah.

>> Great. And they all sat on one side, okay.

Those California people, sitting on the east side, not on the website.

>> How many of you are from the East Coast? East Coast is on the west.

>> We don't have a lot of time so we are going to briefly touch upon what we have been doing. As you know, historically deaf children have been struggling academically. We hear often and throughout this conference, that deaf children are often capped at a 4th grade reading level. You hear this statistic often and it's not because they are deaf it's because they were denied early language acquisition opportunity. So does deafness within itself cause the delay? No, it's the system that causes the delay. So language deprivation causes language developmental delay and it doesn't matter if they are profoundly deaf, unilaterally deaf, it doesn't matter, it impacts them at all stages. An important aspect of our work is we are focused on the 0-3 early language acquisition.

>> I'm skooch over here. For parents... deaf children with hearing parents, there are significant things to remember, the age of identification of their deafness, having the access of early language acquisition services, having family engagement in those services, and having deaf coaching services.

>> And so many of you are familiar with part C which was instituted in 1986, prior to that, it was just an ambiguous element of part B, but part C clarified the 0-3 segment. So 1998 in California, we instituted a newborn hearing screening law and the work that was required to institute this law which was tremendous was spearheaded by the deaf community, because the community wanted to see deaf children learn and exposed to sign language as early as possible.

Do you know who opposed us? Can you tell us, Sherry, when this was passing? Who opposed us?

>> The medical community.

>> It was, the medical profession. In 19 --

>> And just a little added tidbit here. When we introduced the bill, the governor at the time... um... Pete Wilson... liked it so much that he said he wanted to take that bill and make it part of his legacy.

>> $6 million of state funding that backed this legislation. And so now fast-forward to 2010. EHDI law.

HERS funded all of your states including California at the federal level as well. And now looking at 2015, we passed the first lead cay law in California which was the language milestone, looking at the ages of 0-5.

>> So what is important to know about this bill, is that five years prior to this time, option schools had academies of audiologists and there was a bill where they wanted to have new program information and brochures that were given to parents when they had children identified as deaf or hard-of-hearing at birth, giving them information regarding cochlear implants. Through all of those brochures, they add all this information and one statement that talked about ASL and we were like, wait a minute, this is bias, this is tainted towards the medical profession and the medical perspective. Not just one sided. And so we had to combat that battle and finally we were successful in changing that through a bill. And then... at the final moment of that bill being passed, the governor declined. Vetoed it.

So then we had to work with legislators and we were like stop lying to legislators. They are going to find out.

So audiologists were telling the legislators "we were working with the deaf community, we have them involved, sure, they are a part of it."

And so the current -- the president of the senate at the time was like "if you're not including ASL in that bill and if it doesn't have it specifically delineated, then the bill is not coming on my floor."

So then it changed. That was the Academy of Audiologists that had to come up with the bill they wanted because the bill they were working on didn't. The governor ultimately vetoed their bill and what was important for you is to understand that the option school then re -- withdrew from that bill.

Later I approached them and said less talk about that. I want to see what is in the best interest of deaf children and we want to see these deaf children succeed. Let's work together to make this happen.

So we worked together and created this bill which was Senate Bill 210 and that was out of a collaboration of both groups working together to find the best possible and still working together today.

>> Absolutely. It was exhausting to have responses so let's be proactive. The two of us along with many others, let's emerge and get into the driver's seat.

So, this is part of SB210 so that each family in California gets this parent profile and so when they start their early intervention services, EI services within State of California, this is the most important segment of the service, because before this, there was discussion of hearing aids, batteries, device a week check in, cochlear implants, checking on that. It was very auditorily focus, no focus on language acquisition and the auditory aspect was causing a diverse from the linguistic aspect. So this changed the direction of the discussion at the IFSPs to institute language goals and you know, at 3 months there's language, there's communication, are they smiling, making contact, now they are at 6 months, producing signs? One to three years, increasing their motor production, are they ready for kindergarten by the age of 5? You see this girl here with the superhero, the captain America, this is what we are looking at. This is empowered. She's a superhero, kindergarten-ready.

>> To add to that, the language milestones what's important to understand about the bill... is that it says that these language milestones have certain goals, regardless of what language is being utilized, whether it's spoken English or ASL. It doesn't matter. There isn't an I equivalent to it.

>> Absolutely, so we have the link which is embedded in the PowerPoint and certainly you can look at it there. But we also have it variable in Spanish, ASL, English and other languages.

So, if you need to find different changes you'll use the link at the bottom, Mandarin, and so forth. I believe we have it translated in 8 different languages. And so now taking a look at 2020. We got the EHDI grant and it's important to understand that before that, we were a -- working as PI under the California Department of Education and it was a very lonely position for me. Because I was the singular deaf individual there, and I was reaching out to the bureaucrats and you know, there was tremendous turn-over within that department and I would get somebody who I could finally connect with and educate and understand and they would leave. And then I would spend my time, quote unquote, reinventing the wheel and my work was becoming unsuccessful... the education and the turn-over made it ridiculous.

And so when the time came to apply for the grant, I realized that a non-profit organization can apply, it was not just a state sanctions agency. So naturally I reached out to Sherry, the CEO of the Norcal services for the deaf and I said, let's partner with the Department of Education and she said, "No."

>> Well... you know... I -- yeah.

>> Just, remove the knife from my heart. And she's like "that's a lot of work for not very much money."

>> I mean, you guys know that, it's true.

>> And let me tell you, she's very smart. And I accepted that and at some point what we did was we just recycled some of the grant language, developed the grant and then she got pissed off at me because my higher ups continued to forget to provide interpreters for meetings Sherry was present at.

"You she what I'm dealing with?"

And she came into my office "is that grant available?"

Yes, we have one month. We sat and made magic happen and we took out the old language for the newborn hearing screening project and developed Lead Cay family services. Because the L of course, what does the L stand for? Language.

E? Equality.

A? Acquisition.

D? Deaf.

K? Kids.

Kids. Yes.

And so it's right there on the logo and of course, the acronym is LEADK Ready. So we were bringing language back to the forefront, the original intention of the newborn hearing screening law was now brought to life. And here we are.

>> We changed that for CHDHI.

>> Yes, Sherry and I are co-coordinator, both deaf and I believe we are the only state within the entire country where both co-coordinators identify as deaf.

>> So you see the logos for all the different state entities.

Previously the Department of Health care services had their bill. Not the bill, they had their grant.

And then went to CDE California Department of Education. And then now it came to us.

So, when we showed up as a non-profit organization, we were you know, talking with all of the different state entity, these 4 entities and nobody wanted to continue to work in silo. So, I said let's come together and let's all work today to do this. And we asked them to be involved and to be part of our California stakeholder group. We've recently changed the name about that, for that, but we will talk about that later. Anyways, so... all of these entities plus the schools for the deaf, plus the option schools, plus the mainstream programs, plus this, that and the other, the parents, the families, everybody was there. All to support one child. And so everything was there and every child that was identified as deaf was getting the support from the early start programs. They were getting referral to reach -- to match with the right school district. And they were being notified for the school district that there's a deaf baby that was just born in your areas. Start providing them services. And then at the same time you would get the information for the regional center for the same child. They would get the information if there was a deaf-plus baby.

We also employed 4 hearing parent mentors. Is Kira here? That's one over the parent mentors here at the EHDI conference. And 3 were trilingual.

We contracted with 7 different agency, California is a big state so we had 7 different agencies that we contracted with for deaf coaches services.

And they coordinated their own deaf coaches services, each of those 7 areas, they have to go through fingerprinting, background checks, etc. They have a curriculum that they have to learn and screen through before they can be involved. And then the deaf coach works with the school instructors, the DHH early education intervention teacher or teach of the deaf, whoever it might be, they work with that for servicing that child and their families.

And that's just touching the surface of what we have done. We have had wrap-around services from 0-5 for these children.

>> So the NORCAL services for the deaf is part of the California coalition of deaf and hard-of-hearing agency, 7 sister agencies that comprise the California cluster. There's Norcal, Dacara in the Bay Area, DHHS in Central California, GLAD greater LA.

We have the Orange County, OC, we have one in Riverside, ODE and we have deaf Community Services of San Diego. So these are deaf-lead non-profit agencies. Which -- do you want the talk about the LEADK literacy event? Do you want to take that, Sherry?

>> So... EHDI is required for families to identify deaf children, they have the one, three, six program. One month, 3 months, 6 month program. So, we have added a little bit more of enhancement to that with parent mentoring that is happening prior to the 6 month period. And with the deaf coach, prior to the 9 month period. So those goals are still brought over through our next grant cycle we will continue with that. One thing there's unique to share, there's a lot of families and family engagement and that's important that you're well-known about. So what we have done is, on -- we had one day, it was recent, March 9, we had each of the 7 different locations throughout State of California, we established from 10 a.m. to 2 p.m. all on March 9, simultaneous, throughout the state, a love and literacy event.

We welcomed families from 0-5. They were given swag bags with book, information, resources. We worked with our local vendors, local hospitals, audiologists, TODs, family, Hands & Voices. Everybody was in. It was all hands on deck and each of these local areas throughout the state and local people came, they had face painting, they played games, did activities, they had balloon animals. It was carnival atmosphere, and they were storytelling. We were teaching parents literacy and how to read to their deaf babies or children. It was fun. Over a thousand families came throughout the 7 locations last Saturday. It was amazing, a one day event. Huge coordinated effort and amazing.

>> These are our partners, do you want the talk about the new name of the partnership?

>> So, the, we have an Advisory Board, or a learning community board in each state and in California we have one, and it used to be called California stakeholder group.

That's who we have a meeting with. But yesterday we met in person, over 50 people show up in our room for the California stakeholder meeting and it was wonderful. Yay for California. That's huge that that many people came out here. Anyways, while we were there, we decided, because that name stakeholder is politically incorrect at this point.

It's not okay to use that terminology any longer. It applies to the Native Americans when they long time ago would use a stake to claim land as their own.

So we wanted to get out of the appropriation and change the name. Last night we had a discussion and we decided to change it to the Coalition of Partners. So, this is what we are now, the California Coalition of Partners.

>> These are pictures, from the love and literacy event.

>> Each of the different locations, all the different locations where we had our events.

>> And now we are at 20....

>> How much time do we have?

>> About 3 minutes. Okay.

>> 2024. Right now we are in the process of updating the cause of the grant that we received from HRSA. We have an amount we work on to improve our language milestones. How we approach the assessment, how we upload that data to a database and so that is our work in 2024 and partnering with the California Department of Education. Would you like to add, Sherry?

>> Our core team is to ensure that we have representation on that team, with teachers, from mainstream, teachers from the schools for the deaf. Teachers from option schools, family, parents, because we are also hiring researchers to help us to develop these assessments. So right now we are in the midst of getting everybody on board. We are almost finished with phase one.

>> Yes, yes, so the assessment aligns with the language milestones that have already been developed. So rather than developing these two segments in silos, we are going to incorporate and embed them so it's more detailed. And that we understand the correlation with deaf children's language acquisition.

>> Once that assessment has been completed, then of course we will share it out with everybody, statewide.

>> Next year, come on back to the conference. And this slide is the information about the amendment to the grant that we just recently received.

All good? Picture? Sure. Got it? Okay. Great.

Oh... go ahead.

Popular slide. A lot of cameras coming out.

>> What is important about the language milestones and why we are sticking with that is because we are seeing that those milestones help families to understand better how to work with their deaf babies and their deaf children. When -- a family has been informed and they have identified that their child is deaf, often they are grieving, blaming, upset. Nobody is stopping to think about "my baby is never going to be able to work, my baby can never be independent."

There's all of these things parents go through through the grieving cycle and then we introduce them to language milestones and say: That's what your baby and can and will do, thousand they develop language, this is how my baby is going to succeed.

And it changes and it's very empowering.

>> It is incredibly empowering. Very, very empowering. If a baby is not meeting these specific language milestones, that means additional services, as soon as possible. And this does help families feel empowered and these in-person services, these ASL resources in the past were not easy to identify, but we have definitely improved and grown the resource base, of course the early language milestone resource, strategies for teacher's who are teaching speech to create a fun approach to speech instead of this rudimentary rigorous design. System of you may be following on Instagram, a Raised Hands Therapy what is it called again?

>> Rise and Sign.

>> It's on Instagram and there they are demonstrating different ways to teach speech, without this archaic method of sitting in front of each other. Let's go out and do other things. It's creative. Play, let's bring books, let's get involved. Let's use books that have representation of people that look like me. And so families are asking their EI specialists for deaf coach and deaf mentors. IFSPs and IEP teams, the schools pay for that. And so next year we are going to be talking about how you can get your LEA to pay for deaf coach services through the IFSP or IEP. Now we have one minute left. Are there any questions.

>> Who wants to give their 5 cent presentation. This is our 5 cent presentation. We couldn't give you the full 25 cent tour.

>> We did the best we could.

>> Are there any questions?

>> Audience: How do we contact you?

>> Here we have it.

>> There you go. Take a picture of that if you need.

>> Also there are going to be different e-mails as of next week, so at this point use Sherry's e-mail. Contact Sherry.

All right... thank you for coming.

>> Yes, thank you so much for being here.

[ Session Concluded at 11:38 a.m. CST ]

[Live Captioner standing by]

>> Hi, I'm Julia your room monitor and I'm waiting for Meridith, your room speaker. Please don't leave. She is coming, 3-5 minutes late.

[Pause]

>> There are a couple of seats up front and in the middle if anyone doesn't want to sit on the floor. I would like to give people a minute to read this.

Welcome, we are going to be talking about children with microtia atresia and share parents. My voice has been going in and out for a week, I so I apologize in advance if it doesn't.

Hello, my name is Meridith Burger, that's my new favorite professional photo. My favorite drawing stage is arms coming out of the head so this is perfect. And this is a topic personal to me, I was interested, as a parent I've spined this from the other side to have fence. And there's a lot of work to do.

So... I'm trying something new, and if someone has their phone out and can check if the QR Code actually works when it's this distorted, that would be great. Anyone in it's working? I'm doing this presentation and then one right after it, also on microtia atresia. All of the PDFs for the literature that I'll cite in the second one are there, working on one that is I refer to in this one getting them there. But usually after I present on this topic, I get a bunch of e-mails from people asking for the articles because it's so hard to get research if it's behind a PayPal. So, I thought I would try it this way. If you end up using it in a way that helps in a job or community, I would love to hear those stories from you after. Otherwise Betsy will think I just make work for myself by spending time saving things as PDFs.

Before we get started, it's hard to know at what level people are entering this conversation. So, if you -- if microtia atresia is completely new to you and you don't know the basics about it, and you're comfortable doing so, if you could just raise your hand? Okay, there are enough people so I'll go through this and I'm fine with interrupting, New Yorkers talk over each other all the time. So if you have a question, if I miss something, if I've gone too fast, let me know, within 25 minutes. Microtia refers to the ear being small, atresia, there are lots of kind in the body, it's something that's supposed to be open, but it's closed. And in this case when we talk about children with microtia atresia, we are talking about a small ear and closed ear canal. There are children who have -- don't have microtia but I tend to use microtia atresia to include everybody. There are levels to talk about it, grade 3 is the most common.

Grade 4 is known as Anotia and if you look on the CDC website they have birth defects registry. So those are the pictures you'll see. And in some of the prevalence types of data from public health views they will use the word Anotia.

But microtia atresia could also be oral atresia, unilateral oral atresia. Bilateral. Unilateral conducting hearing loss. Atresia is always oral atresia. But conductive hearing loss could be from other reasons. And so the fun part about digging through research is figuring out who they are talking about. Because it's not always clear.

We not talking about today -- about single sided deafness. Not really talking about a stenotic canal, meaning the canal is open but narrow. And not talking about middle ear infections. Unless we talk about I as a child that has atresia. I'll give you a second to look at this. I tend to put a lot of text on my slides, despite the fact that everyone that tells you how to put a presentation together tells you not to, because often people want the information, they don't want me just talking about it and trying to keep up with notes or what have you. I found it fascinating because in research of incidents and prevalence and risk factors and all of those things we talk a lot about several South American countries that have significantly higher rates than other parts of the world. And study just came out that confirmed that there were 17 children per 10,000 born with microtia atresia which is the highest in the world. And many children have hemifacial microsomia. There are a variety of other syndromes that have some -- may have microtia atresia as well. What is interesting is you'll see in research and hear people talk about isolated microtia atresia or only microtia atresia. There's some growing research and evidence that that's actually the mildest presentation of OAVS where like a golden hemifacial microsomia is the other extreme. So that will be interesting.... To see as we go through.

This is probably familiar to people. This is the pathway for sound through the ear, that does not have conductive hearing loss or a sensorineural hearing loss. So it goes from the hair, funneled into the canal, the eardrum in the middle ear, turn it into mechanical energy, there's movement there. Stimulates the fluid in the cochlea. The hair cells in the cochlea send the signal along the auditory nerve to the brain.

But... [clears throat]... excuse me... you can see here is "a normal ear."

And you can see the sound going through and getting to the eardrum. But in atresia the canal is blocked. The middle ear may or may not be there, the bones might be there but they might be loading, disconnected from each other, or from other parts of the ear.

And sound can't go from the outside and into the ear and follow the path along. What is interesting to me, kids health, I think it's Numors in Florida for this picture because almost every picture that you see is of white children, even though they are not the majority and it's hard to find a picture of diagnose gram of hearing that shows an atritic or microtia ear. So image for parents when you try to find info and you don't see pictures that look like your child. But there's a natural phenomena, when sounds get to a loudness, our skulls vibrate. We don't feel it. But what that does at about conversational level, it acts and sends to bypass the middle ear and stimulate the cochlea directly and so for most children with microtia atresia, they have full access to the rate of the various frequencies of hearing. The issue is getting the sound loud enough -- yeah?

I'll get to that. So most children have a normal typical cochlea. I'll get to that.

Once they have access to sound, their hearing is more like mine. Not exactly, but it's more like mine. Compared so some of the thanks that we are playing around with, with sensorineural hearing loss and technology, to make up for where there's damaged hair cells.

And so, and ABR doesn't get -- you don't see results for an ABR like this. But we are going to pretend you do for the sake of discussion.

I'm not an audiologist but I like to think I know things. When you test someone with microtia atresia from sounds in the air, ABR or in the booth, they are going to come out around here. And you'll often hear people refer to it as a maximum conductive hearing loss. Because at a certain point when your skull starts vibrating, your cochlea gets the signal anyway. So you can't have -- unless you have a neural hearing lose, it can't be more than the maximum conductive hearing loss.

And the way they rule out whether it's a mixed or conductive hearing loss, is that they test using bone vibration.

And so... if it's purely a conductive hearing loss, you're going to get responses here. And you'll hear people talk about the air bone gap, related to cochlear function. And so if there's an air bone gap, it's a conductive hearing loss. The problem is, that when parents are being counseled about results of an ABR, an audiologist says there's normal cochlea function, parents hear "normal hearing."

They don't realize that the normal hearing, which is up here, is because they were essentially using bone conduction amplification and it's important to keep in mind that, and you may not be the person in the hospital or the audiologist. You may be the first interventionist, evaluator, in the EI system, whatever your background is. But some of the hesitation that you might see from parents is they have been told their child has normal hearing, to them.

But, if you remember, their air responses were down here, that maximum conductive hearing loss. So if they are not aided, look at everything that miss in the middle.

The CDC has something called the national birth DPEKTs prevention network and they have started doing surveillance, they look at different things. Microtia atresia is a small part. I know from New York state, where I'm from, at some point there is a birth defects registry, separate from the newborn hearing screening stuff. And it said information on this site is unreliable, due to and consistencies in reporting requirements. So it's sometimes hard to know if the numbers we look at are accurate or under reported.

But this gives you a sense. These are the locations where um, Clark is located. And so you can see the variation in Florida. They estimate it's 1.3 per ten thousand. In future, 2.6, in New York 2.2. And you can look for your states, how can there be ten minutes left?

That's because I don't practice enough. You can look for the states recommendation, in the most recents recommendations in 2019, the recommendations related to microtia atresia is to skip screening, if you don't have an ear canal, you probably can't get a screening anyway. It just is set up diagnostic testing appointment right away. You can do the ABR in theory, while the child is still inpatient. And immediately, refer to EI.

Raise your hand if that's being done where you live? One. Two.

For us it varied by hospital. To me this is one of the most profound quotes related to why we are here these couple of days. There's no point in early identification if we are not going to do something about it. For parents that oh... it's completely understandable that they would immediately start asking about how do I fix this. Right? Because they are not thinking hearing loss. Many parents are self diagnosing in the delivery room. They google "my baby has no ear" or something similar.

And it's gotten better, but it used to just come up with surgeons who do reconstructive surgeries, and it would say if you have one ear, you don't need to do anything unless a delay develops.

Dissipate that none of the surgical interventions that a parent may be interested in can be done earlier than 3 years, and then you think about language learning, listening, all of those things that happen before 3. So... again, not that those questions aren't important, but helping parents to understand the importance of auditory access and language opportunities is a critical part of what we do. There's a big discrepancy between what JCIH and what EHDI recommend and what part C IDEA talk about regarding children who have diagnosed conditions.

There's a general comment on the federal level about children with diagnosed conditions being automatically eligible because those conditions are known to have a high risk of developmental delay, but on the federal level they leave it up to the states to make the decision. And there are 38 states that refer to it, in their state policies and many just use the language from the federal statute. New York, Massachusetts, Florida have more descriptive language. In New York we have the GIFT that early intervention will cover the cost of hearing aids, accessories, bone conduction device, sound arcs, whatever it might be. They don't cover surgery. So cochlear implants, surgical implanting of a bone conduction twice, things like that, but everything else is considered a hearing aid and is fully covered without an out-of-pocket expense to the parent. That's a huge, huge benefit for those families. So, when you meet these families as they come to you thinking about all the things they have on their minds, in addition to complementing the things you're used to counseling about for children with neural sensory hearing loss, a big thing to me is that they get a lot of mixed information and there isn't a lot of research to necessarily support it. And so they need time to understand why we say what we say, in terms of the impact on language development.

Families also get mixed information regarding medically what they should follow-up on, but there's enough evidence to suggest that kidney, heart, vertebrae issue, soft pallet issues, and genital anomalies are higher in the population of children with microtia atresia than general population. Genetics is way back to where we were many, many years ago with sensorineural hearing loss. So there isn't allot, unless it's syndrome related. There's a lot of research happening but this is a low incident population so you don't have a critical mass to necessarily have great answers for genetics. But I'm all about parents being informed. If they can find a good geneticist, I know parents that have gone every year, because what they know changes. Parents need to know that they should look for a hospital that has a cranial fatialty. I spoke to a mother two weeks ago, who was born in a major New York City hospital. It's a hospital that has the largest crane ya phatia clinic and nobody told her about. So don't assume that someone else talked about it and don't assume that people give information to the flames of children who really need it. You know?

It's luck. It shouldn't be luck, but it's luck of the draw and so it's good for you to just be aware of that.

Um, you know, I'm sure for those of you who work with families in the early years, almost every parent asks at some point about bullying or expresses their concern and there's a study that was done two years ago, that actually showed that not all children but percentage of children with microtia atresia experience bullying and in both countries there are different ages with children start kinder and the incidents of reporting of bullying starts at that age of entrance into school. So thinking about the work we need to do with whatever the school is, where a child might be enrolling, how we work with families to instill a healthy sense of self in children.

A lot of families are struggling even years later. So that might be the family that the child's hair is never up in the ponytail. Or that they take the amplification off before class pictures. Things like that. But that sends a message to the children about you know, how they should feel themselves about their bodies.

There's also growing research that even for children who don't have red flags like facial asymmetry, that they might have some issues with their soft pallet. They do. A high number of them. So it's important to consider how you're going to assess. Especially if you work with kids with microtia atresia, you will have kids with not errors consistent with the types of errors you would hear in sensorineural hearing loss of the same degree. There's something that doesn't make sense. So it's something to look for. I'm going to skip that because I don't have time. I am grateful to the people who worked on the clinical consensus document for fitting nonsurgical transcutaneous devices. Because there's many audiologists and insurance companies that need to see it in writing. This is a great resource for parents that need to be convinced. And the girl in the top who is 12 came in on her first day of early intervention when she was 3 weeks old, fit with a loaner device.

You don't need an ear mold which is always the weak link for first hearing aid fittings. So it's really a matter of access to getting the device. Psychosocial needs. This is a child who their Baha's are part of who they are. Infants with microtia atresia become adults. And the things that we say or do mean something, whether we intend them to or not. And so be aware of finding therapists that may have experience, that families are dealing with questions in some way similar to those with hearing aids and implants and in some ways different. And that there are challenges like ear thermometers at the pediatrician. Masks before COVID but also, during COVID that are hard and they crave connecting with other parents to find tricks that work.

But it's also a paradigm shift. It doesn't have to be negative. We are all different. We don't look like anyone else in this room and celebrating that. My daughter is 13 and has microtia atresia and has a running list of all the benefits, including the fact that she was able to focus during the state test because she just turns her Baha's off. She thinks being hard-of-hearing is the best of both worlds. When she realized that bugs can fly into your ears she was like, one more reason I'm happy I have atresia.

And there are lots of resources. Hopefully, you stop by the Ear Community booth and helping to advocate for federal coverage of bone conduction devices for these children. There are a bunch of Facebook groups. My face and the little baby face foundation provide financial support to families that need to travel for medical care. I'll give you that. Try to find, it's hard to know sometimes if someone has microtia atresia because the amplification options are fairly new in the last 25 years or so in terms of these. But they are out there. And so try to find those... those role models for parents, for therapists for the kids themselves. And there are a lot more books that feature characters with microtia atresia. I love the I'm Me series and the mother... I lock Ricky the rock that couldn't roll because Licy in the top right corner, it's not about her hearing loss, it's not about meeting new friends or advocating for herself, she's in the back and a parent in the Facebook group posts and said I think that rock is carrying a bone conduction device and it's there, it's not the moral story that is going to help everyone be better people. It's just someone in the crowd. Which I love. Um, some of the books along the bottom are newer. Some of them are self-published. I don't know if they are good or not good. But you know, if you're like me, you buy one of everything because it's something.

I recently came across the artist, Priscilla, who is an adult with acquired single sided hearing loss and using an implant and she has illustrated -- I wish I remembered to bright it down. A children's book on -- that has deaf character, she has a son who is deaf and implant user. And she does custom artwork but also, does things like this, where you see characters or Disney princesses with a little ear. And it's really validating. So her Instagram is my lucky ears and she has a website also. So... um, hopefully you'll like her work as much as I do. And so let's of references. I'm speaking here next so I can stay and answer questions for anyone who wants. Boys like me, yes.

So there's a site Called Toys Like Me that you can custom order dolls that have devices or physical differences that look like the child. Any other questions?

I have to go back because I never say it right. There we go. VPI is here. Someone is going to say it better than me. It is... I never say it so I like saying VPI.

I'm going to go back to the QR code if I can find it. Here is the QR Code, the papers that I base this presentation on aren't all in there yet. So give me, like... 4 or 5 days. You can e-mail me if you're like "I've been waiting."

Other questions?

Does everyone have the QR Code that needs it? I'm going to show it in the next presentation too, if you're staying. And if you know of people I've missed, tell me. Trying to find younger people was hard. Because kids don't care as much.

>> [Off mic]

>> Did everyone hear that? We were talking about the slide that showed the diagram of what an ear that has microtia and atresia looks like with the middle ear component, because so many family vs. A hard time officializing that and there aren't that many resources out to get those images. Even the companies with devices a lot of times when you're looking at them, it's library a beautiful big ear with device, whatever device they are doing. And it doesn't look like kids and parents need to see that. You know? The only way -- like, I love my daughter's little ear, she has no interest in surgery, she used to let me rub her ear to help her fall asleep. But for many parents, that's not -- not going to feel like that on day one. And to get to that point, you have to kind of be desensitized somewhat to it and start to see it as your normal. Right? Any other questions? And then I think I have to change the PowerPoint. You've been great audience. Thank you. And now where did the gentleman go that was going to help? He's coming? Oh, I need -- I think he was going to do the... let's see. I don't want to mess up the captions.

[Pause]

>> I'll try to close this. There we go, close... save... did I mess up the captions?

[Pause]

>> Nope, I didn't. All right. What time do we start?

[Pause]

>> 11:30? Oh, there we go. Okay. I'm going to pull this out as if I'm going to look at it past the very beginning. I apologize to that tree. From research to practice. Raise your hand a second if you were here for the last one, too? Okay, a couple. If I meant for the people who weren't, if I refer to something and it doesn't make sense to you, pop your hand up so I give you more context. So if you are like me, you have a lot of questions, that's why you came here. You're either the parent of a child with microtia atresia, a therapist or teacher, you might be one of the people within the EHDI system and you have kids that you don't really understand their needs or people asking for research. And it's harder to find information. We are here because we have questions. I'll show you that.

I want to start by showing you two studies so we can set the stage for what we talk about when we talk about research for these children.

Now let's look at study two. Now the part that is still -- still stuns me is the first one is from 1979. And the second one is a review, so looking at all recent research from 2018. So, we have a long way to go. We are getting there. It's getting better in some ways. But... there's an interesting paper that came out in 2023, focused trends and developments in craniofacial microsomia from 1992-2022. It was the first time I knew that there was such a thing as bibliometric analysis.

It can be called first and second brachial arch syndrome. Otoo -- I should have practiced saying that word. Distosis?

Sounds good; right?

Golden Har and I'm going to say OAVS because I still struggle pronouncing it at times, that's why I didn't two to med school, I guess. And so they did this analysis of research, journals, keywords, topics... that have been done since 1992. And the good news is, that in 1992, in the year 1992 there were 16 and in the year 2022 there were 60.

So that's really nice to see. But when you look at the top ten topics, the things that I care about are nowhere on that top ten.

And when they say pediatrics, they are not talking about intervention, language outcomes. Social/emotional development. It's more related to surgery. And I've said this for a while, that that's the case. There's a lot about surgery and not a lot about kids in development but it was still shocking to see it. And so the common questions that parents ask when they have a child with microtia atresia and they are trying to get information, something along these lines but in the last two years or so, there isn't research on those topics. There's some research like, an article from 3 years ago or 4 years ago. But we look for more recent things. We don't want to think that that thing that is now several years old is all there is that is out there. But sometimes it's true. And I've got the QR Code back, same as the last presentation. For this presentation, all of the studies that I talk about or have talked about are in the Google Drive that that is linked to, if you catch something that is either missing or I uploaded the wrong thing, let me know so I can fix it. Everyone got it that wants it?

And for those who aren't here before, if you end up using the studies and they help you in some way to you know, spread information, advocate for a child, convince someone to do something, whatever, I would love to hear that. It would be nice to know. And so the question of what caused this is something I did is probably the research I come across the most. I don't pay as much attention to surgery. Um, in terms of reconstructive surgery. It's not -- I'm birth to five focused. For my own child, I do. But professional...

She's not interested in surgery so I'll catch up on the research if she is. But what we already know is this information, and I'll give you a chance to read it since you don't need me to read for you.

[Pause]

>> And most of this stuff has been known for a couple of years. So what's new? Some of the stuff was on the list before it but there's more information. So they are finding that Teritagenic drugs, drugs that have harm the fetus are a risk factor. That makes sense. It's interesting to see the roll of fathers. Autism is one of the few things relate today father's characteristics, so they should take some of the responsibility. I thought the Lauri 2023 article showing that between 1997 and 2019 there was a significant increase in microtia atresia. And the 2024 is the study from Ecuador that showed the 17 out of 10,000 births were children with microtia atresia, so the highest in the world. 99% had hearing loss. Sometimes you hear in discussions of microtia atresia that some children have hearing loss. I don't know how you could have an atritic canal and not have a hearing loss. But it's nice to see it confirmed. Sometimes people need the statistics to get on with the rest of the conversation you need to have. So 83% lived at high altitudes. To give you an example, this is in meters. Denver is about 5,000 feet about 1600 meters. So, the 83% of children in the study lived at higher than that 2,500 to 3,500 meters. There's research about hypoxia with lots of different developmental things in birth issues: in the case it wasn't considered statistically significant because of the numbers. They didn't have a broad enough range and also, um, in the US central and South America, those who are Indigenous to the area, tend to have higher rates of microtia atresia and that was true in this case also, there's -- Indigenous Ecuadorians had higher rates, but Ecuadorians in general have higher rates of Indigenous heredity. In general when we talk about birth, Black mothers and children fare worse than other groups. But... Black children are -- have the lowest chance of having microtia atresia. And so in this case, there wasn't a relationship between microtia and race, but there was for Asian children. So, I thought that was interesting, too.

>> Audience: [Off mic]

>> So the question had to do with the detail in the study about the cause of the prematurity and I would say, one of the articles the Shihan article is one to save to double check because I can't remember.

I have it here too so I can look it up.

A lot of mothers want to know why they had the nice ultrasound and they "why" didn't someone see it? We used to say they don't look for that, they look for things that affect life. But there are a couple of study that is come out recently about how can that be done, how can that imaging be used when a mother is pregnant and how accurate is it. So there are 3 study that is come out in one they discussed using ultrasound and said 2D is preferred during the second trimester because that's when you have the chance to best see the fetal ear morphology.

And the other with MRI accuracy, that they were able to pick up slightly over 93% of microtia and 93% of atresia. And so they did that by looking at imaging that was done while the mother was pregnant. And then babies that were identified after birth and comparing. For accuracy. So it's kind of interesting. Again, these are not widespread, they are really eliminated into where they -- what countries are looking into it. But I think it's something for parents who are kind of... really grappling with that, but why, what happened, to know at least changes are coming. Especially because parents will often ask about inheritance and if we have another child. So I think being able to give them information is always good. Other questions about are there other medical issues. What we know is that children with microtia atresia are more likely to have renal anomalies than the population and cardiac issues. Children who are not medically fragile or have multiple anomalies at birth often don't have something like an echo cardiogram. But these are kids who are likely to have other surgeries like reconstruction or what have you. And so if they look fine... other than their ears, and nobody has done a cardiac work up because they might not necessarily do that for whatever the level procedure is, and they have anesthesia, that could be a real problem. And so the authors recommend that if a child has not had a cardiac exam, if they didn't have it early at birth, that they have it before they have any surgery that involves anesthesia.

Vertebral anomalies are higher in children with microtia atresia. The reason this is significant aside from... is that one of the reconstructive techniques is called rib graft where they remove parts of ribs to construct the ears.... Which could cause significant other health issues if that child has some issues with the vertebrae. What's new?

So I've been in the field for a while and I was told that cholesteatoma were more common for in his can MA. And I've come across one, but it made sense to me, they said it's children with atresia, there's a slight increase but not enough to do ongoing surveillance to make sure you catch it. So they have an open canal, but it's not the right size or shape or what have you, it might affect their hearing loss, might not, they are more likely significantly more likely to have a cholesteatoma.

18% had spinal imaging. And so... and the rate of scoliosis is higher in this population. So, I had -- I've heard of this before even as a parent, but I've never heard it phrased in a way that made me feel like I was neglecting my child if I didn't go and do it. But if I found out now that something was wrong, that I should have done something ten years ago, and nobody told me, I would be upset. And I would feel guilty and responsibility even though I didn't know. So I think these things are important to um, to look at.

And so the next two are related to genital, urinary tract types of malformations and the first one is more common. Um... in boys, and the second one is more common in girls. And so it's definitely worth being aware of. And then going back to the VPI. There's a higher rate of VPI in children with microtia atresia even from the outside their face is symmetrical, they don't have any signs of internal issues, they don't have cleft palette. It's still worth monitoring, especially if you start hearing atypical patterns in speech production.

Amplification and parents needs. We flow a lot more and we know there are barrier, particularly for families with limited English proficiency and those without private insurance. There were a lot of systematic reviews of other researcher that I didn't want to get into but I've listed them here and shared them in the drive folder so that you could read them. But again, I think sometimes because of the wording or the mixed information, or contra directory information parents get among all of the people they might need, they might need to see evidence of the child having hearing loss, but that hearing loss impacting the child.

I thought it was interesting that Lou et al looked at the different between the soft band option for the add here and there's a different in functional gain. So it's something to think about. Especially with young children who can't give us feedback on what they are hearing. And really, at the heart of it, parents want to make the decision they think will take care of their child now and their child's future and parents consistently say in studies what they need is accurate information at early points so they can make the decisions themselves. One of the studies on the previous slide compared using the mini mic that comes with or the personal mic that comes with the bone conduction device, compared to using the mini mic paired with the receiver of a Rodger mic. Some of the signal interference and the more points that the information is going through I guess creates problems and so the perceived benefit of the Rodger technology isn't realized. Again, QR code if you missed it. And my e-mail address so you can tell me how you changed the world with some of the articles that you read. Or one person's world. I have a low bar. Does everyone have this? I don't want to -- and lots of references and these are all in -- or these all should be in the drive. I wish I had more disclosures. Do we have time for questions or am I at the end?

I've got one minute, any burning questions?

>> [Off mic]

>> The question is about 500 per year of babies born with microtia atresia in the U.S. accurate, every time I say that I share that somebody asks that question and the answer is I don't know.

I think there could be an under reporting in terms of the microtia piece. Um... Hollands 2022 goes through it and says that if you look on the EHDI -- CDC EHDI site that has the reporting data and look at conductive hearing loss compared to sensorineural, it's about 10% and about half of that is related to malformations of the ear. So that's where I get the 500 from, just doing the math on that. But I think there's probably an under reporting. But I don't know. It's hard to know what is confirmation bias. You know? And what is real. So I think it's a really good question that I'm interested in researching at some point if someone gives me money to do that. Because I think we all want to know that. 10,000 or 11,000 is still rare. But if it affects you, it's not. Other questions? I have a different sense of what a minute is. Thank you very much for coming and enjoy lunch or the talk, whatever you're going to next.

[ Session Concluded at 12:57 p.m. CST ]

[Live Captioner standing by]

>> Hello, my name is Michelle and I'm the Michigan EHDI follow-up consultant. I've been with the EHDI program for 17 years. Most of my role within our program is related to the database and tracking and surveillance part. My presentation is on our work with Medicaid which is outside of my normal role. I do not work for Medicaid. We are in the same department. I know a little bit of knowledge about Medicaid, but not a ton. So just a little disclaimer, I will do my best.

Also, I want to say that what I'm sharing today is kind of like a mini celebration for me. We got really, really lucky. What I'm going to share today is a great example of how collaboration can really work well for families but also, I got very lucky. So, the contributors not necessarily to the presentation, but to the work, there's someone who is the Medicaid policy specialist and she's been phenomenal with being my go-to person within Medicaid to answer all of my questions. Dr. Tim is Medicaid medical consultant. And he's also EHDI chapter champion right now and he was -- involved in some of this work. But mostly I give most of this credit to Dr. Berry, she used to be a neonatologist, was our EHDI chapter champion, retired and started working at Medicaid as a medical consultant and she's the one that dragged me into system of this work and was instrumental in creating this collaboration.

So, I just want the learning objectives as to gain insight into Michigan EHDI program and Medicaid in the efforts that we have done. Our strategies that we use to update our policy and reimbursement rates, and then just learn initiatives about increasing the number of healthcare providers on Medicaid. So to give you a bit of where I'm coming from, so Michigan has a little over 100,000 births of year, 76 birth hospitals. We are doing -- sharing two years worth of data, along with the national rate, so you can compare. So we are doing really well with the screening. And then we just kind of... for diagnostic testing we have a lot of work to do. Obviously if babies aren't getting diagnosed within the 3 month timeframe it's hard to get them into early intervention by 6 months and then it's about 10% higher than the national.

I don't have to share that. I had a printed here. Okay, so we get babies diagnosed with permanent hearing loss. Parents make the choice of getting hearing aids. But if they are private insurance couldn't cover hearing aids, we run into issues. I don't know if Michigan is alone on this. I don't hear it talked a lot about it. So that's what I want to share today. We have a lack of providers, we have low reimbursement. We have provider's who have limited experience with infants. They will see children but won't see infants. So we are working hard to get babies diagnosed but then we don't have the providers to fit them with hearing aids if the family chooses that. Sometimes families have to travel a great distance, in order to get those services. And then in Michigan, we also -- so we have Medicaid, which they call fee for service. And then we have Medicaid health plans where they contract out with health plans, and that causes some issues, perfect example of this is I hear this a lot, is... if a baby or child has some other type of medical condition takes this health plan but the baby has hearing loss or has hearing aids and this provider and that area doesn't accept that health plan.

So the family have to choose what condition do I want to get help with? Otherwise I have to drive a long way to get a hearing aid.

In Michigan we created best practice guidelines. Once infants were identified we wanted to make sure there was a group of audiologists that were following best practice guidelines for ongoing management and hearing aid fitting. This was created back in 2012. We had certain requirements for the facility of you have to have equipment, and staff requirements, like the staff had to have experience of pediatrics to be on the list and recommendations regarding monitoring and management. We have a very small list of providers for that. It was like 6 or 7, very small. So here is our map.

It starts off confusing. Anything with the black dot across the state, our facilities will accept children special healthcare services for hearing aids. The ones with the pink circle are the ones that follow our EHDI best practice. The blue lines are the ones that will see infants and the red are the sites that have special rules. So, we have one center, where a baby has to be born or live in the county and the family has to be on Medicaid in order to see them. So if you have private insurance you can't be seen at that site. It's really weird. So one center, had requirements they would only see babies in Southwest and they couldn't go up to the closest center because the center wouldn't see them. And there's no sites in the state depending on where you live. So in 2014 I feel this bubbled up as an issue. This is ten years of work that I'm sharing. In 2014, we are having our EDHI advisory meeting and we had a stakeholder who brought I up at the meeting about the issues. The nice thing is we have children's healthcare rep on the advisory. The other thing I didn't share is we had a parent who sent an e-mail to a very high-up person within our government complaining about the fact that she had children with special healthcare, paying for children with special healthcare and had to drive two hours for services and that wasn't fair. So from that, we started the collaboration. So we had a lot of meetings with Medicaid staff, children special healthcare and EHDI. Because we had to figure out what was going on. One thing I've learned is Medicaid is very complex and similar to EHDI where someone can say they just don't give us money, they are not reimbursing, they want to know specifically who, when did it happen, what exactly happened, they want to look into every individual case to see what exactly happened. So we have to go to our community, our audiologists and say please send me any -- what is happening, what information do you have, give me specific examples of why you're frustrated. Which they responded they were great. We had meetings talking about those.

The other thing is we created this hearing aid provider list. Our Medicaid data list is confusing and they don't have a magical that you can click a button and it will pull all the providers who see infants and children for hearing aids. Instead I got a list of 2050 different providers. But not necessarily all of them will see, they are just providers of Medicaid who have the hearing services eligibility. So we had an EHDI student who works at EHDI call every provider and say do you accept infants? Do you accept Medicaid?

A lot of them had stopped. And that's how I -- we got that map, that 2019 map I showed you. So that took a long time. Um... the other thing we did is um... we created a provider survey. So we created a survey asking questions about their thoughts on Medicaid, what issues they are having and from that survey um, our Medicaid area has an education and outreach section and they created an only training, based on the feedback and some issues related to reimbursement that they had seen. So that was nice and they kept it on the website so people could go back on it.

Every time we complained about something, the Medicaid would say: We have this group, this quality assurance group, you should talk to them.

So we were going around to all the different Medicaid groups talking about what the issues we had and we didn't get a lot of feedback or change from that.

So, we did all this work, a lot of the work we did was audiologists giving us feedback about what was happening. And from that, in 2019, our Medicaid area agree today increase reimbursement rate maximums for hearing aid devices. So our state is part of a 5-state contract where they have a list of hearing aids that they can pick from and they increased the amounts so they have more options for hearing aids that they can pick for kids.

But in 2020, that's kind of where the real work happened. So that is where Dr. Barry invited me to join this Medicaid group. And they updated our hearing services chapter. So that's all of the policy related to Medicaid and children's special healthcare and what they cover. So this 80-page document, every two weeks, we spent two hours and we talked through every section. When I sat down and I didn't know anyone in this group besides our former AAP champion and I said my goal is to reduce as many prior approvals as I can to make things easier for providers and ask our providers every step of the way what they want the see. And they were like "okay."

So after every meeting whatever section we were on I would send it to the pediatric audiologists and say "what do you want changed? What do you need differently?"

A perfect example is the cochlear implant section. I nailed all of our cochlear implant providers and said what do you want to see?

And they changed it the way they wanted it. It was pretty awesome.

Another change we tried to do is we had a lot of feedback about hearing aid batteries. A lot of frustration with families could only get batteries for certain time frames, so if they came in 4 days before that timeframe, they couldn't get the batteries. And then the clinics didn't want to mail the batteries because they only get reimbursed for the price to have battery and not the shipping cost. One way we tried to do this was um, they allowed pharmacy medical suppliers to dispense hearing aid batteries. The thought process is that the family could go to the local pharmacy, hand in the script and get the batteries. That was a fail.

We were like -- I was like, this is a different option. It did not work. To get the script, to go to the pharmacy and have them understand that they could bill -- "no, we're not doing this."

And even though we talked to the corporate people at the pharmacies and they sent out e-mail blasts to their different areas, stores they still wouldn't do it.

So that hasn't been as successful as we hoped. The other thing was increase the timeframe for the batteries. So we were able to get a 6-month dispensing cycle. A family can get X amount of batteries within the 6 month timeframe and it's not limited to you know, like 45 days. So they have more flexibilities of doing in and out of audiology to get their batteries. The other thing Medicaid increased reimbursement rates by 25% for some of our ancillary hearing aid services. The best one was the ear molds. I had an audiologist make a chart for pediatric fittings of every company that they used and then the different modifications of the ear molds that they do for children in their clinic, along with percentage they do it and the approximate cost and show the negative amount every time they did an ear mold for a family, how much money they were losing. That was so instrumental in getting Medicaid to make these changes.

Part of the provider manual was hearing aid supplies so they updated that information and allowed more hearing aid supplies for families. Initially when I sat in on meetings, oh the provider just needs to do prior approval.

"Stop making them do more work, why do they need to do a prior approval to get it?"

So we were able to remove that: and then because it was 2020, they also allowed hearing services to be done by telemedicine because that was COVID.

Okay. So, we have been working on this for like five years now, and we haven't done a survey. We are like, how are things going? We got rate increases. Um, people have been really... with COVID, not sure they noticed. So, let's ask. So we sent out a survey just asking, you know, what kind of plans people were accepting, what age groups. If you're not offering service, why not. And um, what else do you need to see to be a provide center we haven't seen an increase in provider, what else do we need to do? We had 19 question, 80 respondents. This is hard because you know, you learn things from doing surveys. So like that might have been one person responding for a huge clinic. So we should have done it based on clinic, but we had personal e-mails so you know.

And then from that survey, we did another, or Medicaid did at provider training. So and that kind of went over similar things that they had before. Related to just the changes in policy, billing resources, and then they also did analysis of um, what are the top claim issues and denials, just so that providers could learn from that.

As a small group we met frequently to discuss the provider training and the survey and then Medicaid started pulling more analysis over reimbursement rates and from that we were request -- they were able to increase reimbursement rates 24% and 25 for visits. Our big issue, that audiologists were complaining about is the hearing aid dispensing fee billing code included the cost of an other mold. So if you only -- I don't remember the amount, $150 to dispense the hearing aid, but your ear mold, then that was less money that you're able to get for your services. So they remove that out. And then some other follow-up services that they included in the dispensing rate, they separated out. They also updated it so we can continue our telemedicine. And the increase reimbursement rate, 75% for diagnostic audiologist testing and cochlear and Baha services.

Almost all the hearing services have been increased in the past few years. Unfortunately, I don't think all providers know that. I've sent e-mails during my diagnostic site visits I talk about it. During the state conference I talk about it.

I just don't think the information is known. So there's more education to let providers know there have been a lot of great positive changes in reimbursement rates for Medicaid.

The big issue is provider doesn't want to say yes I'll do Medicaid because what is going to happen? Everyone is going to flood. Everyone goes straight to the site and say we within the do this anymore. What we would want is to share access to multiple providers in a certain area would be willing to see kids. My personal thing too, is I'm concerned about the type of providers who are willing to do that. I also want to make sure they are following best practice and families are going to get good care. We have an issue with our hearing aid battery access unfortunately, our cool idea of Medicaid -- or the pharmacy supplier didn't work so we need to continue coming up with different solutions for that.

Even though we had great work done, it's slow. So we want to make sure that we can keep an eye on increased price of goods for providers and make sure we are staying in line in trying to give them more money so they can keep their doors open. We are thinking about doing another type of survey to just do an analysis of how many providers have decided to join Medicaid. Because that's our goal, we need to increase the number of providers. Um, as we are preparing for the session when I was talking to the Medicaid group I was like I think what we have done is make sure that the audiologists who are seeing kids don't close their doors. So they haven't stopped seeing them. Now we just need to gain.

Just reach out to Medicaid children's healthcare, advise them to your EHDI advisory, request the meeting and utilize providers. When I send out e-mails about I need your feedback on Medicaid, they come out of the wood work. They are there, so it just -- send out e-mails or make phone calms to the audiologists and say how is it going for you? Anyway, that's all I have. Do you have questions? Any issues?

>> Audience: If your ongoing work to increase providers who accept Medicaid, I'm wondering if you've talked to audiology schools? I know central Michigan has an audiology school. If you could access the newly licensed or newly graduating providers and get -- I feel like the young people have that spark to change the world and if they would be able to, it you know, make change that way.

>> Central is one of our centers, I hope that the audiologist there sparks their interest in pediatrics. That's great idea. Can I follow-up with central and see if they can... work with their students. Hopefully, they stay in Michigan. That's the first thing I ask, are you staying in Michigan? Yes, that would be amazing if they could go to different communities throughout Michigan. Another question?

>> So you only had a 7.5% increase in diagnostic reimbursement rates, is that right?

>> Um-hum.

>> Audience: So it's sustaining, keeping your providers.

>> Yes.

>> Audience: Did you see that policy -- in Texas Medicaid is the -- the handbook is so outside of our statute and the points of referral where we lose the ball happen a lot. When you remove those referrals, what did you remove? Like, is there referrals needed now in Michigan if a baby passes, doesn't pass their outpatient hearing screening? Do they have to have a PCP referral to --

>> Yes, they have to have a referral for the diagnostic test.

I feel all the insurances have that. When I said during the process of updating the policy it was the prior approvals, so it was -- for some reason for certain hearing services even though it's a covered thing for Medicaid, they need prior approval, so you show the need, they say "yes" and then you can get it. So that's why we tried -- I tried to get to remove. Thanks.

>> Audience: Thanks, thank you.

>> Um-hum.

[Pause]

>> Audience: Hi, I'm from Utah and I'm just wondering if though the way that we kind of have combatted this is having an EHDI medical director and so that provider has now, we have a form that is as long as any baby fails the hearing screening process, they use this form to complete their CMB testing and their diagnostic ABR and it works for any of our diagnostic facilities is that medical referral process. Just an idea.

>> That's a great idea.

All right. Thank you.

[ Session Concluded at 3:09 p.m. CST ].

>> Hello, we don't have the right PowerPoint, I'm so sorry. We don't have the right PowerPoint presentation up yet, so I'm going to start talking about some things that we don't need the PowerPoint for, because...

We don't think it's here.

>> We don't know how to pull it up.

>> But it was here this morning.

>> Well, here is our friend Lilas that that will be working with us. Okay, our presentation is early child had services for children who are deaf, hard-of-hearing, and their families. Oh, Lila's found it. Awesome. How do we advance? Do we arrow?

>> Right arrow. Okay, we have here Sharel Johnson, part of the audiology deaf education consulting group and adjunct professor. [Off mic]... Najwa, the Vice President of Arizona Hands & Voices. The Phoenix hospital cochlear program coordinator and the mother of two children with hearing differences. So what we will talk about first of all are the needs of deaf and hard-of-hearing, infants and toddlers. Arizona is a unique state. For those of you that have never been to Arizona, Arizona's huge. And I'm from Ohio so I'm trying to learn Arizona. But Arizona is huge. It is bigger than all of the New England states and the state of Pennsylvania, combined. Huge state, lots and lots of rural areas. Most people live in Maricopa county, which is more Phoenix is located. 68% of the population live there. There's also the most -- the greatest amount of Indian reservations are in the state of Arizona. So there's not so -- so most of the populations in the center to have state, then there's a lot of rural areas after that. Arizona early intervention, provides services to the eligible children in the state of Arizona. What happens is when a child is identified as having hearing differences, the audiologist let the Arizona early intervention program know and early intervention talks to Arizona School for the Deaf and blind which is ASDB. And ASDB is the part C provider for listening and language services and there's a whole process where they assign case managers and decide the service that children's need and all of that stuff.

Well, we had something interesting that happened a couple of years ago. In that ASDB had a contract to provide -- had a contract with service providers to provide intense, services through two organizations in the city of Phoenix. The contracts ended and parents were upset because they were like, where am I going to get the services for the children? Who else can provide these services for my children? And they were asking the audiologist where do I go, what do I do? And the audiologist were not the right people, they didn't know what to do or what to tell the parents.

And we decide to meet and figure out what to do next. So we started having a series of meetings with Lilis who is right there. Lilis. Our EHDI coordinator me, I don't think I introduced myself. My name is Wendy, I'm the director of audiology at Phoenix children's. Lila, Kendra and Nesha, the first thing we wanted to talk about is how to have better communication between agencies to tell the parents what is going on.

Then we invited more people to join our group, because oh we can't forget to include Desert Voices. We just kept growing and growing and growing.

And um... finally what we decided to do was... to create a... to look at the state of Arizona, which as I said is mainly rural, and figure out who was providing services and where parents get these LISL services just as a place to start. And then like for the next phase of this, we want to look at ASL services. Just looking at as a state how are our children communicating, how are parents learning about different communication modes. And options.

So formally, as you can see on the slide, the purpose was to identify services, gaps and services and a community based approach to identifying needs and supporting opportunities to improve services for young children who are deaf and hard-of-hearing.

And as I said, this first project is focusing on LISL because that's what the parents wanted. That's how all this came about is because of parents needing more information. So we engaged every agency, every provider who we thought would be interested in this, and who we thought would have a um... who would be interacting with the parents who would have the questions for what was going on. It was very, very grassroots. And then um, as more people came up, yes, join, join. Come and join.

And so what we are trying to do is just to identify needs and supporting opportunities to improve the LISL services and create a framework for future -- for future endeavors. So I'm going to hand this off to Sharel who is going to tell you more.-I got involved with this project as a facilitator, as it became bigger. I think Lilas wanted to take this totally on because she has many projects at our state. I came in as a facilitator of this group. As Wendy was saying, we have our main Steering Committee team here and then we, from there, identified all the other groups and individuals throughout the state, who anyone really who had an invested interest in early education for deaf and hard-of-hearing children. But the goal really was to create something that -- a process that we would be able to use when we needed to access and learn other information. So this is a bit of our timeline. We started last April, with our Steering Committee. And then we invited all of our stakeholders and started having meetings, a plan which I'm going to share with you and developing the surveys were different because we needed to have a parent survey and we needed to have a provider survey, in order to actually identify what challenges were, what is the state of services across Arizona. And Kendra is going to talk about the actual analysis of the data and kind of where we are today.

So, this is the partners that participated in the group of stakeholders for the project. And we were really focused on different perspectives from different groups, whether they were in private practice working through ASDB as an agency provider early learning programs, hospital, clinic, parents hands as voices. So, the commission, Arizona commission, we wanted everybody involved. And I think that's critical. Any time you embark on any kind of project that you want to have some systemic change to, you need to involve everybody and get everybody on board for that activity.

A the impact we want to have is that all children and families have access to desired intervention services provided by highly qualified providers.

So inputs were all the groups involved the activities were the survey. Identifying the providers, analyzing all of that data and preparing a report. We have a report that details all of the results which is online in the handout so you can look at the data we collected from both parents and providers. And our outcome is to have this community based approach that we can use as we embark on other quests and the next one is ASL services and support for children throughout our state.

And again, as we mentioned most of the states Phoenix, Tucson in this little their owe alley, but we have all these rural areas and Native American reservations. So there's challenges to get input from all of the families that we want to serve throughout the state. So I think, Cendra.

>> Thank you. I shouldn't have moved my hands a lot.

Does that work?

Key findings, I do want to say one more time, bear in mind the numbers of our population, and the state where most of it lands. In Maricopa county, more than the half of the states population is in central Arizona. So, when you see percentages over other areas of the state, you're going to expect that to a degree but there's under representation from various areas of the state. Stars the overall key findings, in regard to the professional survey, we had the total response number, where was that? I thought we had it on here. I don't see it. We had about 90 providers. 30 providers of those that responded about 90 about a third asked for training and listening services. They were giving them and they were wanting more support in that, bear in mind we have about 5 or 6AVT certified listening and spoken language therapists in the state and overwhelmingly a lot of these folks are providing these services. But they don't have certification. So that's one of the barriers or challenges we'll talk about later. Confusion from terminology was a finding, from the provider survey, as far as what is listening as spoking language certified, what is AVTED. All of these different terms. Seem to provide confusion for not just parents but providers alike. We did have well over 100 parents respond. The majority were in Maricopa county. 73% of those parents that responded had children that were identified between 0 and 3 months. Pa 30% amplified between 3 and 6 months. You can see the break down of the children of the families that responded and primarily they were using a listening and spoking language approach to language development. Some were using a combination of both visual language and spoken language. And then there was a small portion that were just using a visual language ASL. This slide again, I know it's tiny, the PowerPoint is available online. This one just highlights the age that the children were fit with their hearing devices and how often that they wear them. Obviously, we are looking if these families are wanting to use a listening spoken language approach to language learning, how early are these children being amplified, how often are they using their amplification.

We highlighted the funding sources to access LSL services and barriers to accessing those services. You can see that as far as funding, most of it was either insurance or self pay. I'll tell you right now that with the new contract that ASDB has entered into with two local private listening spoken language therapists, the state is covering that for the families. And it's not something that early intervention program that we are a part of with Arizona is a team based model. And um, so the Arizona early intervention program AZIP, they do not reimburse us for these zests. This is coming out of ASDB general fund so that pulls from other areas of the programming. But these -- we go up to grade 12. So birth to grade 12. And these services are only available in Maricopa county. They are not available anywhere else in the state. One of the providers does allow for teleintervention, and so with that we are able to reach broader of an audience. So of those providing services in listening and spoken language you can see here that only less than 20% strongly agree that they have a lot of confidence in their ability to provide services. So, a lot of these are speech language therapist, teachers of the deaf providing these services and doing the best they can because access to training, to become LSL certified is one of those potential barriers. So how are these providers supporting families since they aren't able to have consistent access, to these services statewide, a lot of parent-to-parent support which we of course have heard a lot about this week, online learning, handouts, videos, during COVID our staff made wonderful videos for families so they could reach them more often, modeling how to use those strategies with their families.

The challenges that we ran into, like I mentioned, the definitions of LSL and LSL-S Cert and AVT. Getting to not only rural areas but to... -- I heard the world "cultural broker" was mentioned at a session this week. I found that interesting because we have a lot of reservations. So there's certain level of trust that's not necessarily established there. And it's hard to get information from some of our communities. And then as parents again, definitions, parents understanding the vocabulary. Language barriers, obviously we have a lot of Spanish-speaking folks around the state. And the distribution of the surveys. It was the Survey Monkey, it was available on -- you could do it on your phone, computer. But it wasn't printed in Spanish. We allowed for um, we would have a Spanish interpreter made available for families to sit down with them and do it. But we didn't have a printed version. Oh, we did?

Oh, okay, we did. It just didn't get out.

Oh, it did get out. Okay. We are looking at every moment. Anyhow, we did feel the number of responses we got was a positive. It brought together -- Wendy mentioned lots of people from different agencies working toward a common goal. The first thing over its kind in Arizona and giving us foundational steps. We have a long way to go but the only way to do something sustainable in a field like ours that is low incidents is to build capacity, now that we have identified where those greatest needs are, hopefully we can bring those two things together. And allow for capacity building in those smaller communities.

>> You heard the theme throughout, so I'm going to quickly say it, the language and the terminology was one of the biggest thing we struggled with. And we spent one or two Zoom sessions on our own, deciding what we meant by LSL. That by itself was a challenge and then really thinking about meeting families where they are at and how to connect with those families. We have been talking about that as well and one way we were thinking about that is being able to dig deeper by maybe having a project manager as well as a facilitator. If someone could track the surveys and say we are not getting any from this area.

If there was someone reaching out to providers to get the families we were missing a large number came from Maricopa county and one preschool that a lot of the families participated. We wanted it to be more comprehensive. If we had someone paying attention to those things, that's something we want to look at in the next round of this. So our next steps we are wrapping up this first year of the brand, and so now what we -- thanks for the second round. We got another grant to do the ASL portion so we want to do the same thing, take the lessons we have learned alie it to the ASL services in our state and actually work on what we are missing for some of the LSL. So maybe while we call providers and looking back we can touch base on getting the families and more information. Thinking about calling and interviewing families over the phone and reach out better. So we are going to work on the training and the action items based on the survey results that we finish, so we know for sure providers want more training. We are looking at that, they are going to level what we have in the state. We just found out about a program where they may be providing certificates not certifications. And now we are going to move on and replicate this for ASL and see where it goes from there and work on other communication, total communication. Who knows, we will see where it goes but we excited to do the next part of this. I think we a couple of minutes if anyone of you have questions about the project.

>> Thank you, my question is about the trainings that you then do with your providers. Do you know what that looks like? Have you done that already? Who is going to be providing that training?

>> We going to have Kendra answer that but no we have not started.

>> In an official capacity, that's our next step. But right now what we currently do within the state School for the Deaf and the blind, we have a listening and spoken language certified individual who recently retired. She comes back and provides training. In-house individual who is listening and spoken language certified, sign fluent SLP. We have a build in-house training and we have 3 people, 3 or 4 currently in their now third year of this so she provides the one-on-one mentoring and training. And then they will be certified. They will be ready to take the test that they have to take to become fully ADT certified so we have one more year. So that will give us 3 more people.

>> And just to add to that we were pleased that so many said they want training and they wanted it because they realize the kids goals on their IPs would be facilitated if they had better training. If we can do a basic level or on our way towards certification, that's a step towards ABT because that's a rigorous process that not everyone has time to invest in. If they do the first level and gear up to do the actual ABTcert. More questions?

>> I'm curious do others of you have this issue about parents understanding when you tell them they are getting LSL services, the difference between a certified ABT-Cert LSL?

What state are you?? I guess no more questions. Anything else? Anybody wants to add?

>> Thank you for listening.

[ Session Concluded at 3:39 p.m. CST ].

>> I guess I'm going to get started. My name is Kristy and I'm going to be presenting on use ago multifaceted approach to increase enrollment in early intervention. Um... I sort of am going to go through 3 different things today. So first I'm going to share some baseline data, um, looking at enrollment in early intervention, in Baltimore city. From 2020 and 2021. And then I'm going to share the efforts basically, so all of these different approaches that we have worked on, to increase enrollment. One, and two, to add a knowledgeable provider to the team.

So not just increasing enrollment but making sure somebody is on the team. I put results in quotation marks, I'll show you the numbers but I feel there's always more to do so it doesn't feel "done" in the sense of results are final. So, before I start, this feels important in the context of the information I share later. So in Baltimore city, our infants and toddler program is housed under the Department of Health and so you can see there's a bunch of different bureaus and programs all under the Department of Health. And then Baltimore cities infants and toddler program, city schools holds the lead contract for providers. So, Baltimore infants and toddlers program, hires the service coordinator and all of the related service providers are hired by Baltimore city schools, so that's me. I'm a Baltimore city school employee that solely does early intervention through the infants and toddler program. So, the first thing that I wanted to do was show you baseline data from 2020 and 2021. When I first started thinking about what made the most sense to present, I wanted to obviously look at enrollment. Where were we before these efforts started. And so, I knew I had offered and wanted to be working with these children, and my background is working with children with hearing impairment of any configuration. They weren't on my case load so I didn't know where they were. So again, looking at those services from a knowledgeable provider, were they enrolled in receiving speech service's from other people? Right? I didn't know what was happening. So, we are going to look at the enrollment data from 2020, and 2021 first. Um, and it was not great. I looked at the number of children enrolled. Out of the total referred that year.

And so you'll see both years 4 children were enrolled. I assume that ten on the total referral number for 2021 is related to COVID. I haven't dug into that in any capacity. You'll see later the other years are closer to that 17. Just in Baltimore city. So this was the enrollment data and I wanted to look at enrollment by 6 months thinking about our 1, 3, 6. So, the first slide is overall enrollment. This one is looking specifically um, at enrollment by 6 months. You can split it either way; right?

Out of all the children that were enrolled, how many were enrolled by 6 months were referred; right?

So it's one out of 4, or one out of 17 or one out of ten.

And so yeah, that made me think we needed to do something.

And looking at services from the knowledgeable provider, we know there's the AGIH. Not only do we want children to be enrolled in early intervention.

Who is knowledgeable on their team. I'm not going to read all of that to you. Looking at the same data, of out of those 4 enrolled in 2020 none of them were receiving services from a knowledgeable provider. One over them was actually only receiving service coordination which should equate to a phone call every 3-6 months from a service coordinator. Baltimore cities system is not doing well and we are short 6 service coordinators. So I'm not sure that was happening for the children that were receiving service coordination only and 3 receiving speech services. Out of the 4 that were enrolled in 2021, two were service coordination only. Not receiving any support other than a check in phone call. One receiving speech.

One was receiving speech from me. That's the knowledgeable provider and she was a 26-weeker global delay, super premature. OT, PT and speech. So, I want to spend the bulk of the time talking about the efforts that we have made over the last -- it's been about a year and a half total. So I think what is important to share is that all of this really started because post-COVID, my role had really been coaching other providers on coaching. I wasn't doing a lot of direct service provision at the time. And post-COVID, our case loads had to increase. There was this huge influx of kids coming into the system. Toddlers received upwards of 2 hundred referrals a month and all the kids were eligible and my supervisor was like: All hands on deck. Everybody is providing services because we had a lot of children that needed support.

So I was like, selfishly, I don't want any kids, I want to see these kids because this is the population I'm passionate about and it's what my experience and background is in. I'm going to walk through what I did with each of these 4 bullet points. Um... the first part and probably, what allowed me to do the other 3 was figuring out how to run these data reports. So, I actually contacted our MSDE rep. So, the state rep and asked: I have access to all the kids that have IFSP, but how can I find the children diagnosed with any degree type configuration of hearing difference? And she showed me how to run these reports. So, this is just Baltimore city. This is not the EHDI database. This is our IFSP system. I started playing around with the filters.

There's a lot of different ways you could run it and I just started making my own kind of spreadsheet list of these children. So referral source from audiologists was a big one. You can look at the dates. One of the trickiest pieces is that I could on the run these reports. If you see at the top, category, it won't show inactive children. So that was a barrier to finding the one that is weren't enrolled buzz these are the ones active. So... I looked at it different ways, we can mark off eligibility, so if they were marked eligible under the high probability category, and deaf and hard-of-hearing was marked off, I could find them that way. You can mark off past newborn hearing screening, yes or no. Um... diagnose conditions. So there's all these different ways that you may or may not catch all of them. Um, most of them are caught with that audiologist referral because of the EHDI system but we found babies coming from the NICU that wasn't always the point of referral, they may have gotten referred by a NICU follow-up clinic. This was the start. This is where I started figuring out who the children were. And then I started doing some training and professional development. So there are about 25 infant and toddler speech pathologists in Baltimore city. And that was kind of the first group I presented to. Mostly because they were my colleagues and sorry the fastest access to them. And so I presented on EHDI, a lot of them didn't really know what the EHDI program was attendee all. I presented on JCIH and this knowledgeable provider piece. Um, and then one of the trickiest pieces in our system that I would say is 100% a barrier, is this eligibility that's just this concept of eligibility and prevention base services, and so when I started five years ago in Baltimore city, I was told if a child showing a delay before 12 months they don't receive speech services. They can receive special instruction and then at 12 months we can do speech. And I had come from working in EHDI and I was getting all these 3 month old babies and I was like what? So shifting there, if they are in the high probability, category, not just for deaf and hard-of-hearing, like there's high probability for all of these parts diagnoses. We can be in there early and we can assign speech services if functional outcomes align. And we can do prevention work in early intervention. They don't need to be showing a delay. And so, that was a hard shift for people, I think. And just not what they were used to and comfortable doing.

So you can see here this is a report from a child that is now on my case load. But at her initial eligibility, she was 9 months old, she had age appropriate expressive and receptive language scores and the recommended frequency is none, not eligible and no services recommended at the time.

So I found this, this was happening right? So... this is from one of my colleagues. And this is over a couple of different months, I think I presented to the speech pathologies in March of 2023. It was scheduled for their training week in August, when schools are coming back at the end of August. I talked to them about EHDI and theirs was a more like, logistical services. Because they are doing intake and it was important to keep in mind that there are 200 referrals a month; right? Overall. And we are talking about maybe one or two per month system wide that this would apply to and they short staffed and there should be 12 of them and there are 3. So, the presentation was brief, it was like: Here are two take homes. I'm here if you get these kids or see them coming up. And we talked about. I talked about device retention, we can talk about that in supporting babies this young. Just kind of what we would be doing if they are at an initial eligibility for a baby. Because I think it was just unknown to them. Um, and then I've worked pretty hard on collaborating. So, I collaborate closely with the Maryland School for the Deaf. So, we have teacher that is do home visits and teach sign language for family once or twice a month they have parent child preschool play group class. That's once a week. They have a classroom for two-year-olds that is in the mornings that you can go one day a week or five days a week. So you have a bunch of supports available. So I have collaborated with them for some of my families. Um, I collaborated with our DeafBlind project. The little one that I mentioned earlier has some vision loss as well. And so I found that person in our state and started collaborating with her. I reached out to our Johns Hopkins audiologists because I had the referrals, when I found them in the IFSP system I could see who referred them and see the audiologist report linked. "Hi, I'm here, trying to get these children enrolled."

So worked with them and then connected with our state's EHDI program and that was kind of what really unlocked everything because then I got access to EHDI database as well, which helped find those other ones that I didn't -- hadn't found before.

Some of the system or procedural changes is that my supervisor has been incredibly supportive of me doing this with my time. And so our initial eligibility teams are usually zoned, our city is split into 4 zones and she's given me permission to attend any initial eligibility independent of zone, if we know a baby is coming that has any diagnosis. Working on IFSP development with our functional outcomes. And I -- so currently my case load is in all 4 zones and I work with the children throughout Baltimore city.

I have about ten minutes left so I want to share the results of what I've done so far. So again, I wanted to look at enrollment and services from a knowledgeable provider. So if you'll remember, our 2020 and 2021 data, um, 23% and 40%. And since then, we have increased it.

2022 is tricky. All of this started in December of 2022, so it was like who was still open, um... haven't had the capacity to work backwards in the way that I -- I don't know, doesn't feel great. But just trying to work proactively. Enrollments by 6 months has also increased. A lot of this is dependent on the age of referral, too. I didn't factor that in. So again, the 2022 piece, like that, I was too late basically to change, refer much of that to be impacted. But that's increased, um... like the one for 2024... the little guy who was not enrolled by 6 months moved from another state and is 29 months. Like, he wasn't even referred. So, these -- take what you will from the in your opinions. But it's increasing. And then here is one of the pieces that I found really positive, is that these were numbers from 2020 and 2021. Once I presented to the SLPs they wanted support. So even those numbers changed in a positive way. So receiving service coordination only, and then all 3 SLPs asked for some support. One of the... one of them ended up switching providers to me. The other ones we collaborated because the kids were close to 3. One of the one which is are for 2021 so some next steps, I talked about the IFSP coordinator. All the things you can mark off to identify the babies, they are not the most thorough about and so they might not be marking high probability for eligibility if the child was showing a delay. Right? They might have marked that they were eligible because of the delay and not because of high probability. So that wouldn't come up on my list. And then again those babies from NICU. Um... I am not reality reached of out to any other disciplines yet. Um... so I think that will continue to be exciting work. Continued work with the service coordinators. This one, I just put in here because it made me laugh. If anybody else is a presenter, you'll know that our presentations were due on March 1. And as I was working on mine on March 1, I got this e-mail from a service coordinator. And I just thought it was a really good example of she attended that training a couple of months prior, um, some of this doesn't completely align with part C. She didn't need to do all of these things and we will work on that piece. But if you read the last paragraph, like she did remember that. Right? Like, that stuck, I'm on this e-mail and she wanted to know if I could be the provider. Um... for the family. This is interesting, so this is another one that has been pretty recent. Um... this was a January e-mail. I don't have "data" data, but they e-mailed me for a NICU baby. I think this baby has Down's Syndrome. That isn't even through diagnosis yet. And so the question was, should we add sessions so that you can support follow-up and diagnosis? Which is cool. This is another one like that. Again, we are not quite there with primary service provider and a lot of part C things that could be in better alignment. But look, I'm CCing me because of the hearing. This normally wouldn't be an e-mail to me. This would be an e-mail between service coordinators and the infant and toddler program. But she put me on this. So continued work. Collaboration, more audiologists. So, a bunch of my family, the majority are at Johns Hopkins, but we do have University of Maryland. I met one of them here, so I feel like I'm working on those next steps. This is an e-mail from one of the audiologists. Again, super recent. He was in her office, mom says this, it says they contacted them 3 times and then closed it. But independently of all those things, great, we refer while you're sitting there, and we can work together.

And thinking about even more next steps, um, thinking about that initial point of referral, the intake phone call, calling families to remind them of their initial eligibility meeting before it happens. And sometimes they cancel. Right? And so thinking about who is making that phone call and what could potentially be different about it. And then capacity building with other -- not necessarily SLPs. My case has increased drastically from 2 to 23. And so just thinking if we have 17 a year, that's not really sustainable and I don't have a good plan for that yet. Um... I think that's all. I did it in time. Any question? I think she has the mic. Talking really fast. In the back.

>> I'm curious if you've done in fluff in terms of retention of those kids? Especially like the 2023 kids that you saw, where that's where your um, improvement starts to increase. It seems like the graph information that you have shows that you've got them enrolled and they are seeing a provider. But do you know if they stayed with a provider once they got enrolled? I would be curious to know about the retention.

>> So all of them are on my case load. So I have a very easy way to measure that. That's actually not true for one of the 2022 so I have two that go to the MSD, the School for the Deaf preschool and I counted that as a knowledgeable provider. It's not just me. There are other ways to support and so... it's not just me and that knowledgeable provider. But they are receiving their services there.

>> Congratulations on being the change.

>> Thank you.

>> And when are they hiring the next person.

>> Right?

>> To help you.

>> I don't know that plan.

>> Do you have any suggestions on how to... professionally have that discussion with service coordinators to explain why speech services can be provided under 12 months? Because I'm having that struggle right now, really badly.

>> Yes, so most of our service coordinators were following provider beliefs, that's what I found. It was the special instructors beliefs that they were the best ones to do prelinguistic language. And then the SLPs beliefs too. So our SLPs have done a lot of professional development on prelinguistic skills and that has helped them feel more confident in that. We found that once the providers feel confident doing it, the service coordinators fell -- they don't have the educational -- background. So once the providers felt confident, I can do this, this could be my domain, especially if we think long-term about who the best provider is and shifting into the primary provider model for a child with nothing else, it does make more sense early. So... we've done a lot of really intentional professional development. Does that answer your question? It's hard.

>> A lot of that can be parent education pre that young age and parent coaching and talking about the importance of language acquisition from 0-3. And that first 12 months and I think that parent education piece and coaching is really that piece that is hard to see. Because the child is not talking and all of that.

>> Another piece is feeling comfortable writing a family outcome. Um, on the IFSP and not a speech and language outcome; right?

And so if you can shift the IFSP development outcome to more align with that piece, too, like, the parents will understand. Thinking about that type of language, that's also helped.

>> That's a good point. Thank you.

>> In 2021 did you not think of going virtual to help your numbers? Or was that an option?

>> I was not doing any of this in 2021.

>> Oh, was that an option for that data?

>> Yes, so all of our speech services were provided virtually. But I was not tapped into this population at the time I was coaching other providers and so when I was asked for my case load to increase, in 2022, is when I kind of started doing all of this data.

>> So everything you do is virtual, is that what you said?

>> It was during COVID but we are all in-person now.

>> Do you have a registration charge? Does that make families not want to sign up sometimes?

>> No, it's completely free in Maryland.

>> That's awesome. We have a registration fee and it's a disaster.

>> We are really fortunate. I think there's one more. Sorry.

>> Did you have any resistance from any of the folks who were already providing services, that they didn't want to make the change?

>> I wouldn't say resistance, I would say finding the value. What can you bring that I'm not already doing? Like, what is that piece? And so really presenting to those SLP, I talked about the auditory hierarchy, about device retention and they were like "oh."

They may have been working on receptive and expressive and it was like "oh, there is more" and so they were my colleagues that I had enough of a relationship with that they were pretty receptive. My time is up. Thank you.

[ Session Concluded at 4:33 p.m. CST ]

>> Good afternoon we are going to get started. Thank you for being here, last session of the day. We are really grateful for everyone joining us. We are going to jump into our topic today which is um, a partnership between EHDI and part C here in Wisconsin.

My name is Lauren, I'm a speech-language pathologist and on our EHDI team my role is I'm the communication specialist. And....

>> I'm Chris, and my background is as a teacher for the deaf and hard-of-hearing, I'm the early intervention coordinator for our EHDI early intervention team.

>> Chris and I do not have any disclosures to share.

These are the objectives for today, they are on the online program.

>> So joint commission, on infant hearing specifically, early intervention supplement, provides guidance for best practices for little one's who are deaf and hard-of-hearing. When we are thinking specifically about those early intervention providers, this statements has given our state EHDI teams a call-to-action.

Every single EHDI state program has its own landscape of unique strengths and challenges. We are briefly going to explain a little bit about what is happening in Wisconsin early intervention system so you can better understand the partnership we have. In our state we do not have a centralized program that provides deafness specific early intervention.

We do have professionals in our state who have expertise in working with this population. However there's not too many. And geographically, it's pretty limited. But what is variable in every corner of our state is part C program. In Wisconsin part C is called birth to three program so you hear me refer to it as that. We are a local control state when it comes to our birth to 3 programming. So that means that each of these counties, there are 72 different counties. Each of those counties are responsible for providing those birth to 3 services for families that live within their county. That means the policies and procedures can all look a little different when it comes to services this unique population. As a whole, our state utilizes the primary coach to teaming or service model, which means primary service provider is in contact with the family that one person is then supported by a team. A few counties again, because every county does things different, might choose to have a teacher for the deaf and hard-of-hearing brought in but it's just a few counties that have chosen to do that. Um... and in some of our more rural areas the access to those specialized providers is just not available. So in many cases here in Wisconsin, if a child is enrolled, and the birth to three program who is deaf and hard-of-hearing, it's like they they might be matched with a primary provider who has limited or no experience in working with a child who is deaf and hard-of-hearing.

So, with that landscape in mind, where we build -- where we have built this partnership. Wisconsin's EHDI program, and within our team, we have a cares team. Our acronym is here. Two of those team member social security here, Chris is the early intervention coordinator and I'm one of two communication specialist. Our other communication specialist was supposed to join us. My background is as a speech pathologist. Of our teams I'm supporting families pursuing amplification, looking to support the auditory learning, accessing spoken language. Do other member is an ASL specialist. He has been promoted to a leadership position in another area of our state for deaf and hard-of-hearing so that's a position we will be filling. So we are a small team, just the 3 of us. Um... and let's talk a little bit about how we are doing this work.

The cares team is a full participating partner in the birth to three program. What that means is that we are considered a full team member on any IFSP for any child who is deaf and hard-of-hearing in the birth to 3 program. This successfully functions because we have a memorandum of understanding between those two different programs. Utilizing that primary coach approach to teaming, the cares team members are one of those support team members that can be brought in. As a joint visit support person on any IFSP so we are not that primary service provider. We not locally located in every one of those 72 counties. But we can be brought in as a specialized support person to support that primary coach.

We can participate anywhere from that intake phone call through initial valuation, IFSP updates. Joining joint visits, all the way through -- and when a child has the cares team as part of the IFSP we have an assessment protocol so every 6 months we are collecting assessment data on their language development, both from an auditory standpoint and also visual communication.

Again, we are a distanced team member so we are not located right in their county but we are able to join virtually for all the support.

So that individual primary coach may not have that expertise. That's okay and that's reasonable given our landscape. But they have that expertise in this team available to them. Not only do they have their support but their interdisciplinary team includes an audiologist, an SLP, teacher of the deaf and hard-of-hearing and ASL specialist. And we align this support with that coaching program so we are coaching those primary service providers to raise their capacity and knowledge for best practices for this population.

So we have built a system here in Wisconsin for building capacity of those primary service providers that work with families. Let's learn a little bit, we have data to share about how that is working.

>> So we started this process of partnering with part C program in 2021. And we started with just one region of the state, there are 5 regions so we gradually expanded across the state. So it's only been 3 years since we started completely and then we -- it's been a year and a half since we've been covering the entire state. So we need to know how it's going anecdotal information from the providers with whom we are working, families. But we do send out surveys. And we have a Qualtrics survey that we send out to parents and then to both the service coordinator and the primary service provider. And also to the cares team member and we send out that survey at IFSP update. So we send it out at the first -- at the 6 month update or review. And then at the first annual and then annually after that. We want to see initially is this working right away? And then ongoing is this how -- how is it helping? How is it becoming the family and also the service provider. And just to give you an idea. So this gives an idea of the providers. We have gotten responses from the primary service provider as well as service coordinators and there are some that have a dual role.

We have 49 total responses, I look back at how come they have sent out and this is not individual families because some might have been sent out to the same family and providers multiple times based on the different IFSP but we have sent out 59 sets of surveys. And um, so possible 59 family responses but possible 118 provider responses. This is a fairly decent return rate. First I was thinking it's not that many but it's a good percentage. And so there's the survey is 12 questions. But we are not beginning to go through all 12 of them. There's a couple that are the most potent, I guess. One is, you know, I feel more confident in supporting families of children who are deaf and hard-of-hearing. This is part of our mission to increase capacity and we are getting responses that 94% of the providers are saying they agree or strongly agree. Which we think is pretty good endorsement that it's working pretty well and we've got some comments that um... there was a spot for comments as well. And I'll let you read those.

I'll pause just to -- do we have any -- oh, ten minutes.

We wanted to look at some of the strategies that we use that might be supporting these positive comments. We -- I reached out as a coordinator when they get the referral, I reach out and send the diagnostic ideology report from our we-ing system. I send that along with the type of hearing difference and also in that e-mail say: Let us know how and when we can support you.

We also have a protocol our cares beginnings. We modeled it after the main 6 visit policy. So it's -- these are topics, parent education topics, that parents have told us that are super important for helping them make informed decisions going forward. So that's helpful and one of those is going through the communication opportunities which is been commented on there. Um... yeah, so those are a couple of the strategies or policies we have put in place. Another question, is that I feel more competent in supporting the families. This one, 84% agree or um, strongly agree, a little bit less percentage. But we looked at some of the comments and some are you know, service coordinator, they don't attend the visits. The ongoing visits. So one said I can't say I feel confident -- or competent in sharing the strategies, but I do feel more confident in sharing the kinds of support that can be offered. So that's -- and also some of these might be after just 6 months, the provider might not be feeling more competent, yet.

I understand the impact of the hearing difference, I better understand on different areas of development. Um... this is particularly important to us. Because yeah, they can feel more confident and competent, but about what? So in the other -- this also relates to one of the questions from the previous -- it's like, the provider that is are unfamiliar with deaf and hard-of-hearing children, as we all say they don't know what they don't know. And so they are frequently resistant to enrolling children that are not yet delayed. And we still run against -- run up against that and in Wisconsin we do have automatic eligibility for any type of degree or configuration of hearing difference but the providers are not in the habit of thinking in terms of risk and minimizing risk. They are thinking in terms of treating a delay. So this gives us feedback that we hope some of the providers with who we've been working, are starting to get it. So um, understanding what can be done to early -- to support early.

And then we have provider comments. Some of what we do that we feel really contributes to this is we have a 3-part visit when we do joint visits. Um, that 3-part is you know, initially we meet with the provider to do some joint planning. And then we have the joint visit and Lauren mentioned before we are a distance partner. When we join the visits via Zoom or teams. So, the provider is there in the house but we are joining virtually.

So then we join the visit and do reflection where the provider afterwards and planning -- join planning for the next one. This may, as we goat the know providers and families better, happen through e-mail later. We also send our visit note summaries to that provider, so I know they take notes but we pretty much outline almost everything that we have covered in that visit.

>> Reminds us of the ultimate goal in the EHDI system. We screening for a purpose. Screening so that we can intervene. By empowering the part C provider that is we have in our state, through coaching and collaboration, this EHDI EI team were able to promote language acquisition, in our state in ways that have not been accessible before we have heard nice feedback and also have data from families to share. Because increasing confidence and capacity for providers is great but not enough. We want to see that parents are growing in their understanding and advocacy for their kiddos. Parents are also sharing with us overwhelmingly that they are feeling more confident in making decisions related to their child's hearing, communication. And education needs. We similarly asked parent to dig deeper What are they learning more about? So parents shared following the support from this deafness specific EI team, I have increased my knowledge about the impact of my child hearing difference on their overall development, social/emotional needs and communication development.

We have some family comments to share as as well from the surveys.

>> The top quote mentions options for different communication, that's something early on Chris shared. We spent very specific time at the beginning when we first work with a family on communicating in an unbiased way, different communication opportunities and it is a topic that comes up again.

With those two different communication specialists that we have on our team, there are times where a family might be pursuing listening and talking and so I may be the primary cares team member supporting, there's other times where visual communication and ASL is their priority. So that other communication specialist is their primary contact. But wouldn't you know it, we have a lot of families who would like both and so they are absolutely times where both of our communication specialists will be a part of that team, maybe for bilingual, by cultural, maybe mostly spoken language but we want key signs added in so we talk a lot about language planning and blending the support for what the family feels is their best fit.

>> We have talked a lot about the model. These are strategies that we find from provider feedback, family feedback and our own experiences what has helped to make this partnership successful. I believe we have touched on all of them, maybe accept for the top one. Again, remember that state, there's 72 counties so when we rolled of out our services we did the job to each individual program. Some of them are tiny and some of them have not had a kid who is deaf and hard-of-hearing for some time. But we wanted to make sure they met us, understood what supports and resources we had so they know that we are available.

>> We understand these are just surveys but giving us feedback. The -- we are not capturing whether a provider has worked with us with more than one family or if the particular survey is after 6 months or two years of working together. So that might be something we could um, do to change to get better more accurate information. We also want to re-evaluate. We know families are busy and multitasking all the time. But maybe re-evaluating the survey to make it more family friendly and we are not -- we did capture a little bit of what specific knowledge providers are and families are increasing their awareness about, but we probably could do a better job of that as well. Our next steps. We want to, as I said, increase the response rate from families. And make sure that we are -- that the cares team is added to more IFSPs for every child, or every child that doesn't have another specialized DHH specialized provider on their team.

Explore more ways to provide on demand and just in time for counties and just improving, making that automatic that we are added to the team.

The last slide is a wrap up. Our model, it's up and running, and we've you know, it's looking positive and we are continue together gather feedback and... did we do that?

That was basically the end. We are still working on improving.

Any questions?

>> Thanks for sharing that information. I was wondering, you alluded to this at the end about the automaticity of getting added. How is that currently, are they reaching out to you based on the meet and greets? How is that happening now?

>> It starts with me sending out the referral information. I mean, they get the referral automatically, but then I send out more specific information. And yeah, if we have not worked with that county before I specifically say let us know who to get in touch with, who is going to be contacting the family and sometimes they do and sometimes they don't. So, we have worked with, I think, 27 counties, it's about 40% of the counties. Which we think isn't too bad for a year and a half of working the state. Still working on it.

[Pause]

>> So when you're Zooming into these sessions, what are some of the most common things you see that you want to provide coaching on? What are some of the most vulnerable areas for provider that is don't have experience with DHH kids?

>> This is a great question. Do you want to start with that one?

>> I'll share, from my perspective a lot of times when I'm joining it's families utilizing amplification who might be just exploring if cochlear implant candidacy, they are in that phase so we will talk about again, that different complines opportunities. Early access, if they are utilizing amplification, retention is 100% what we talk about and meeting the child. Developmentally where they are at, in age appropriate ways and finding different strategies for retention. Um, that auditory hierarchy is often something that is unfamiliar, even to language specialists, like SLPs. But I often work with PTs as the primary coach or OTs and so we are really starting off with giving them some baseline information about auditory development. So even once those maybe implants are activated giving them that information that this is not you know, immediate access to hearing like we may expect. So, a lot of those things, similar topics that parents are interested in, those primary service providers as well, really benefit from.

>> And I usually do most of the cares beginnings topics with the families before once they choose a communication path then I transition out. But so, I'm helping them understand their child's hearing difference, understand the audiogram, but also, what does that mean in their environment? What -- supporting that parent child relationship, because we know that's the foundation of language and communication.

Communication opportunities. And so all of those different topics are -- it starts out most of the providers are like: I had no idea. We want today use -- I know baby sign. Let's use baby sign with this family. That's not a language.

>> Thank you so much. I think this was really valuable. I have a million questions, but I guess you could start with how are you funded and do schools pay for this? Or do... yeah. Just start there. And I'll find you after.

>> Yeah, so we are in Wisconsin. The -- our EHDI program and our part C program are both under the Department of Health Services. And we are -- our EHDI program contracts with a... we are really part of the EHDI program. So we are EHDI, providing early intervention which is unusual. We are not just getting the families to early intervention. We are supporting the intervention. So we are funded by the HERZA grant, the EHDI grant, by our state title 5 grant and that's pretty much it. That's why there's only 3 of us and we are supporting, I mean the part C birth to 3 is statewide and so by supporting and um, increasing their capacity, we can hopefully spread more knowledge and awareness.

>> When you provide the support virtually, is it to providers at the same time? So it's provided to the provider and the family simultaneously?

>> Yes and no. So, again, that joint visit has 3 parts to it. And especially when I'm working with a new primary service provider, I really emphasize the importance of us meeting before that joint visit. So whether that's a phone call, or a short Zoom meeting, we do some really purposeful planning ahead of time, who will start the visit, what will the flow be, what is my role, really spelling things out for that person and we will have reviewed some of those topics ahead of time, that maybe that provider has big questions about or that we might talk about. An example could be a listening check. If the provider is understand shoe how to do something, she and I may do planning and preparing so when she's in-person with the family we are still coaching and doing education, but that person has had sort of a pre-session with me to talk about it. And the third part is reflection, if it's a text or phone call or another Zoom to just say: What follow-up questions do you have? You were in person, what did you pick up on that I did not. Let's have reflection time.

>> Thank you, everyone. Thank you for the great questions.

[ Session Concluded at 5:03 p.m. CST ]