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 EHDI Annual Conference

 Topical Session 3 & 4: Mineral A

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>> Really quick housekeeping before we get started or emergency exit behind you and in front you, all forms and course evaluations are on the app to ship take it away Stacy.

>> I am Stacy, the buttons aren't working. Hopefully the technical issues are better now. I am an audiologist, and a mother of 4-year-old Addison and 2-year-old Benjamin who was born with a charge syndrome. I've been married to my husband know what for six years. We live in Las Vegas.

I always wanted to work in healthcare originally, I was interested in speech pathology. Quickly became more drawn to ideology. I got my Bachelor of Science and communication disorder at Central Michigan University in 2011.

Then, my doctor in audiology at East Tennessee State University in 2015. Regiment will be three in May. He was born with charge syndrome. He, really gets around by crawling, and playing in water as you can see. Or in his day trader.

He is one 100% tube feeder he uses total communication; he wears a hearing aid in the right air and a cochlear implant in his left ear. He uses 20-30 expressive words that he signs or vocalizes. We are hoping to send him to total communication classroom in the fall.

Benjamin was born in May of 2021, had been a normal pregnancy, no complications. We were expecting a healthy child. I went into labor spontaneously. Benjamin his delivery was uncomplicated.

Pretty much the nurses were concerned because he would paint up when he was crying. He would turn blue when he was not crying. So immediately they suspected and they took him to the intensive care unit. Two hours later they came back to the room and they intubated him to stabilize his airway. They also found heart defects, and abnormal outer ear shape and other things I don't remember.

He was transferred to another hospital, with the children's cardiac program is located. The first week we received additional diagnosis such as horseshoe kidney, bilateral optic disc and matrix brain bleed.

Before coming home, he had four total surgeries, so one was a heart surgery, to airway surgeries, and then one surgery for his tube placement for feeding. In the first year, he spent a total of 14 weeks in the hospital. Being an audiologist and comfortable in the medical field was helpful along this journey .

Today I would like to share things that I learned from my son Benjamin that I did not learn in my audiology program. So, the first thing that I learned hearing is not always the first priority. When a child has complex medical diagnosis they can be managed first. So first he needed heart surgery.

Then after that he was sent out of state to open up his airway. There was not an EMT in Las Vegas at the time that was able to take care of his airway. Still is not. Then we had to get a feeding tube so we could take them home and feed them safely.

And Las Vegas and other areas in the country, there is not an audiologist available in the hospital to diagnostic hearing evaluations. On inference. They have screenings are being completed, but the child has to be discharged to get diagnostic testing done.

Think about the implications this has on kids who are in hospital for an extended period of time. There are some kids that have been in the hospital over a year. So they are not given the opportunity to receive an appropriate diagnosis and timely intervention.

Number two, how much parents had to advocate for the children. So here is the picture of mama bear and I have hospital as mama bear on one occasion. Especially early on when Benjamin was a few days old. They did a CT of his nasal region. The bones in his face.

Also of his heart, to prepare for heart surgery. So I knew he probably had hearing loss and structural ear abnormalities. Due to the syndrome. So I ask the doctor to to his ear imaging at the time as well. While they have them in there.

She refused to do that, mostly because there is not an EMT in the hospital. So the EMT is affiliated with a different hospital. Uneducated regarding EMT care. The effects of the that getting delayed, that delayed his him getting his cochlear implant by about a year.

Because he was only two and half-years-old, and we were having to manage other health issues. And then coordinate travel out of state. Because he goes to primary children's for his EMT care. So managing health concerns and arranging travel.

The same doctor refused to do was hearing screening. Because he would probably fail it. I was like well, what you were doing every other test under the son and he's not passing any of those. Why would you not want to do a hearing screening because he would fail it? He did not pass any other tests. That was baffling to me.

So, after his first heart surgery he was transferred to primary children's for his EMT care. They did not want him to see other specialists because they wanted to establish care in Las Vegas because that's where we live. But I was able to convince them to do hearing tests and the genetic testing while we were there as well.

So, number three access and care in the community is not always easy. After he was discharged from the hospital I was left to navigate his follow-up care. Apparently he has 13 doctors on his care team not including therapist.

So he had a follow up with cardiology, G.I., general surgery, ophthalmology, neurology, at the top of my list, as an audiologist was to get him who is hearing aids. So at the time the insurance is restrictive with where he could go for care. They kind of one provider in each area.

That is the only place that you can go. So I called that college year audiology office to set up an appointment to get his hearing aids. And they refused to schedule the appointment, because for our insurance, he has to see this particular EMT group in town before going to audiology.

So, I told him they were not appropriate and he had been sent out of state for care. So that was not what needed to be done. So I ended up telling them we will come in as cash paid pick once we got in and saw the audiologist we got everything sorted out.

Benjamin got his hearing aids when he was four months old. Look at the situation from the perspective of someone that is not familiar with the medical field. They do not know that you can ask to do that. Or it may be there is a language barrier?

It would be easy to get frustrated with the situation and just give up. Another challenge we encountered was with early intervention. So, I pretty much once he got out of the hospital set him up with early intervention right away.

He come up when we talk to the DS, she said he was too young for a hearing test. So, I was like well, we should probably do it now and he's going to sleep through it and not wait until he is older and not sleep through it pair

So we did get in with audiology with early intervention. But, just you know just important to keep staff trained, make sure they are actually trying to help people. And provide frequent services you know just to keep everyone up to date on current protocol.

So, use best practices, so I don't want to pass our DRL just we are all human stuff happens. But I do think this is an important.to make. When Benjamin got his hearing aids, they were connected to the test box. They were meeting targets everything looks fine.

After we got the hearing aids, we connected to the software, you know, to my supper and was looking at settings to make sure everything was okay. And I realize, that the hearing aids were not connected to the computer together.

They had two different fitting formulas in them. So they were never actually paired to the computer together. So I was not able to read all of the signs. That makes me wonder how often this actually happens? In the real world. And the patients and parents may have no idea.

I also interviewed for an audiology position with the school district in Las Vegas pick one of the questions would come up how what I handle inappropriately it fit hearing aids. So this is a bigger pair problems in our experience.

Something you are not comfortable doing, let's say you are in a rural area paired and start providing service because it would prevent families from having to travel. What you are not really comfortable doing that.

Just refer them out to where they can get appropriate care. We try to travel to Salt Lake City a six hour drive for care. Right now we are going every three months because it is just got his implant pick that should move to about every six months. It is a lot of work, but it is worth it, to you know get care in a facility where everyone is comfortable with Benjamin and what he has got going on.

So, just so you are aware, Benjamin is on a Medicare waiver program and actually does cover travel for that type of thing pick so the hotel, gas, food, is covered by insurance.

If you are an underserved area keep it in mind. So, choosing communication approaches can be complex. I did not realize he had a complex until I had a child who was deaf/blind with other disabilities. As I mentioned earlier. They are pictured here. Basically it means his eye is not completely formed, like it just not completely develop.

So both eyes are affected but more so the right than the left. He probably does not have much central vision in the right eye. But he does pretty well with his left eye.

Initially we did not get much information about what is functional vision was like. He said they had colorblindness and they will make and they're covering the object is pick out with that diagnoses how could he possibly see anything? So I am thinking he cannot see anything.

It wasn't until he was about a year end a half old, that we were confident that he could see. We also did not know if he was able to see well enough to read or if he needs to use braille. So when we are trying to figure this out the most helpful thing that anyone said to me, said watch how is it interacting with his toys. If he is looking at the toy before reaching and grabbing and interacting with it he can probably see well enough to read. If he is feeling for it before grabbing it and interacting. Then he has to probably use braille.

I thought that was helpful. The next concern was vocal quality. So, after Benjamin's heart surgery, when he was nine months old. His left vocal cord got paralyzed. So for about two months we did not hear any sound out of them. No crying or nothing. Since then his vocal quality has improved significantly. But at the time we did not know if he was going to use his voice? Also the motor milestones are significantly delayed. He did not sit until he was about one year end a half old. He was a little over two years when he started crawling in about two and a half when he started pulling up to stand.

The average age of walking is 3-years-old. Our fingers are crossed. Hopefully he will do that soon. But all of that, goes into choosing a communication approach that makes it difficult. Kids don't keep their hearing aids in. Holy cow, I did not realize how true that was.

Until having a child with hearing loss. Pictured here is Benjamin chewing on his hearing aid. One of the things I found entertaining was the OT checklist.

Going through a thing does he remove his hat or socks? Yes. Well he can't do that pic and you want me too keep his hearing aids in? Yeah, so number one topic and hearing loss space groups. My favorite answer is first you put the hearing aid in 500 times a day. [Indiscernible] that is so true.

Rings me to the importance of teaching so I actually didn't learn this in school. I think it is important to teach families because, sometimes it is hard to keep the hearing aids and. It has been helpful with Benjamin as well as his grandparents. They are not fans of worry hearing devices.

This has been the most consistent communication approach our family has use. And so this picture sums up the typical day in our home. Benjamin is wearing a cranial helmet. He has continuous oxygen on.

I am doing one of his tube feedings. So there is a lot of accessories to manage and the hearing age is just on top of that. And during this time when he was wearing the helmet, the hearing aid did not get used a lot. It was hard to manage all of it.

And so during hospitalization you know it is hard to keep technology on. It can get lost. And the reality is, not all families including mine have the time, energy, or patients to put in the hearing aid 500 times a day. Especially when there is additional needs.

Sometimes it is more practical to use clear speech or sign language to flip rather than flipping the couch over to find the hearing aid, don't forget about that. The importance of support network spirit so we met Martha's family. Here is moth with my daughter Addison and Benjamin.

She also has chart syndrome, so we went with them through the chart syndrome foundation. They have state liaisons. You can connect with them. Ours happens to live 10 minutes from us. So, it was really helpful to reach out to other families, and to just meet someone who has been through I was she was and it was been through this experience. So the chart foundation has family support groups. There are Zoom meetings monthly for different regions. So with the West one is for Pacific time zone pick

There is a three support group. And then there is by annual conferences. The next one is in Phoenix in 2025. Navigating insurance can be a challenge. There have been definitely days that I went to bed and was like wow, my head did not explode today. And that was a shock. So, the biggest thing that is help me through navigating insurance is being a case manager.

With primary insurance we have a case manager she is able to help coordinate out-of-state care. And help with anything that we need. And then number ten how rewarding it is with a hearing loss. So when we said his first work with meeting of course was daddy, so when he started requesting. By crawling over to me ends and he says mom appeared to the time we were sitting together as a family and my daughter was blowing bubbles. And I said bubbles, and he said it immediately.

We were all shocked, we would like really? So, it is so much rewarding when it's your own kid and it makes all the work going into helping him with it. Are you finding best practices are you people in your area don't hesitate to look for a second opinion if your child is not doing well with amplification. Are you referring to all newly diagnosed patients into the hands and voices chapter? And letting them know about the Facebook support groups those are helpful too. Is it easy for vacations to make appointments with your office?

Are you providing as much help with possible and navigating certain insurance coverage for devices. Are there any opportunities to give services in the community regarding hearing loss in pediatric population. So. I don't know if I have time for any questions but. I will be around if anyone wants to ask anything. Yes?

I am, I'm not, I hate pediatrics. I want to specify that yes. Yes. I work with adults, so I kind of do the hearing itself a little bit. The cochlea implant is out of my wills. And so you know too much. Like yeah. Yeah. Any other questions? Okay.

>> All right everybody will going to go ahead and get started. Just for safety reasons, everybody is aware, there is an emergency exit in front of you and behind you. All CEU information and course evaluations will be on the app this year, there is no paper to fill out for each session. I will let the team take it away.

>> My name is Arlene Brown, and it's great to be able to share this topic with you. There will be three of us talking. I will give background, then they will make it pertinent to families and Allison will make this all pertinent to state systems. And that is what I just said.

This assessment has withstood the test of time. I started it in the late 1980s, and I wanted to give you a perspective on how it has withstood the test of time. Because we have hit on many different reasons for this assessment.

I think that among all of them, maybe someone, or two, or three come that will resonate with each of you. So, in the 1980s. The early intervention program was run through Colorado Department of Health. That was unusual.

The joint budget committee come up for safe legislature thought it was unusual. They said, why are you spending money on direct services? How is this money being used? Can you show its effectiveness? If we are going to continue to find it.

So I was hired as a consultant with the health department and created this assessment with this acronym. The acronym is meaningful, because it tells you everything about the assessment components of the assessment. The family helps, participates they don't help in completing the assessment.

At the assessment covers receptive in a special language, vocabulary, speech, listening development, pre-verbal communication. Pragmatics, and more, because it is multidisciplinary. So we can screen for the cognitive level of the child, and we can screen for gross and fine motor skills as well.

It is interactional, because part of the assessment, even today in part, but in days gone by always. Included a videotape of a parents interacting with their child. So we got real life interactional information. That was analyzed.

It all applies to the learning of the young child. So that is how the acronym came to be. And in the 1990s, we were trying it out with a bunch of early intervention is. We made a video and had protocols. The interventionist could collected the data.

Then they sent it to the University of Colorado, where the data was stored in the videotape was analyzed. We had a lot of training then, to give back to the interventionist to say, now you have this information what you going to do with it? That what Lynn is going to talk to about.

We stand by the notion nine month growth nine, six month growth in six-month time, call it what you will. This assessment was predicated on pre-/post data. And posts, so we could see the introductory of the child's development in the different areas over time.

The health department did continue to fund it. Back then in the '90s, we also got money from the Colorado school for the deaf and the blind.

We got money from different grants that were written. The University of Colorado where I worked at the time. Allison still does, contributed a lot to the assessment as well.

Fast forward ten years, we have used the data in lots of different ways. I want to make the point, of this seminal study, 1998.

The data from our assessment, which was used to just look at the effectiveness of the program was used by others to look at the effectiveness of early identification An early intervention. As well as other citations that we have included to that effect. Not always using our database.

We also use this database to document the need for services for children with unilateral hearing differences. We tried to replicate this in other states one other state in particulate the whole thing protocol family, the videotape, it was cumbersome. More about that another time if you are interested. But replication has happened in the next decade through the National early childhood assessment project funded by the CDC. And currently the Odyssey project all of this is both of his projects are a smaller package of the family assessment if you will.

There is no videotape, there aren't as many assessments there is part of the lesson that we learned when we try to replicate the entire project in other states it seemed to be much. I think Colorado kinda grew into it. And when you start fresh eight smaller package seems to be more appropriate.

So coming up, as so many of you know, HERSA has gotten very interested in language income data. And every state is in a different place of having the assessment protocol and collecting the data. And the same data because we have so much data what our plan is for the next grant round is to investigate the child language outcomes, because we have the data according to health disparities.

So, let's say it is teen moms whose children may show a health disparity. Gosh, you know, as an intervention program in the state, why don't we look at getting some information and training about how to work with team moms as a group. So we want to apply this assessment data to look at any health disparities that we identified, and identified those health disparities would happen through both supplemental grant that we have in the supplemental grant that we applied for.

I don't know about you, we do not know if we got that are not yet. That is the kind of work that we will do, again, to inform training. So if we have a health disparity it's good to know. What are we going to do about their health disparity within the system due to address it. So, that is history to date. Lynn? Hi everyone.

>> Fun time after lunch my name is Lynn Whisman I am a Colorado hearing at Colorado school for the deaf and blind. There is eight of us in the state. We divided the state pick our job is to work with families once they are identified. Audiologist calls us, we call the family, and we are in.

You know, sometimes that knocked on the door or zoom meeting we are the first people to me kind of makes it real paragraph so we get all of the fun of taking this assessment, and how do we do this with families?

I am in charge of that ship facilitators that go in four times a month working with families. I have figured out, and this wonderful mass, once these babies are identified at birth maybe we have 120 hours before the kid turns three. So those 120 hours are really precious.

And for those of you who work in this like you are in the home. It is rough, wild, crazy, and amazing and we are supposed to do in assessment? I will have to tell you what the three of us represent in my mind as part of the reason white families in chip are so successful.

This to me is the backbone of everything. I feel like I get the best of and the hardest, because we are administering tests. On the go we kitchen table we are trying to find space. And what I like about this honestly, are a million different things.

Is advocacy for the parents, that is our job, is helping families, moms, dads, blurt out to be the best mom and pop a bear that they can be. But they do not how to roar in this language. Babies were tested in the hospital they already failed the test. So the family is hearing medical information, educational information, everyone is testing my baby. What this is what I love about the assessment pair

They are the ones who get to test the baby. And what is so powerful about this, is they learn how to be the best advocate for their child. And their child watches that mom and dad advocate, and they are training this child how to advocate on educational using educational language.

Using medical language, it is so powerful. I was telling Arlene recently, I was meeting with a new family on zoom. What is that a Monday? Saturday, Saturday right? This family did not want to meet with me. Because I would make it real. All of these different postponing, I get it, it's okay I'm not going anywhere.

We finally got to me, this mom could not come on the screen on zoom. You could tell it was that. I am explaining about hearing loss, we have all of this and we have an assessment, you know, and the game change in the room I said yes, it do you mind if we could do this is your baby doing this? All of a sudden mom participates. Yes my baby is doing this picks of the dialogue that you have went we do these assessments, it takes time, and I know sometimes we get antsy.

We don't have the time come up but it is beautiful what happens. What will be talking about holding things? I don't know, our baby supposed to do that? Let's do that. Will maybe that is the next stage.

 So families feel empowered to share their information about the child. They have a way to organize it. They have to see what is next. It is huge. It also takes time.

Sometimes I have to say facilitators I don't want to give up my time it be so much easier I could do the assessment myself. I am like no, this is the training process for the family. And what I get to see, because I have been here for so many years.

You know, I started young. I have been doing this for a long time. What is nice I meet the family in the beginning, for that very first assessment. Then I am with them through preschool. And I love meeting other agencies whether it is service coordinates for the ISP, or educational cities stone for IEP.

Our chip families can't do it. I tell them I will come with you to the evaluation, the transition evaluation. I will be there for the AUP. But if you hear me say nothing, I did not mean to. So family, well my child receptive language is blocked, and the next up are blah blah.

My child's motor skills are at blah blah. My child's skills are at blah blah blah and I sit there. And I am just so proud of them. Because they have learned. It is so nice, I am not leading them anywhere. I am just there for support, because they have learned how to do all of the steps.

If you can't figure out how to do magic that the three of us represent what we are doing. It is priceless. Especially I should probably look at what I said. What I think what is nice too is that you think. I love this, I am a mom. I think my kid is doing this? I think my kid is? Sure they are, when you get the data. I guess not.

So then you can have a really nice conversation about what is your kid doing? But I really like we send it to Allison and her team, and we get the results back. So the family learns how to read results.

So anything past us, when they get educational reports they know how to read them. Because that's what we are training. We now to develop goals, because they've already seen the development a progression in all of these assessments.

It is just fabulous. As cochairs we work with Allison, and we are trying to update what we have. So the six month packet does not look like the 27 month packet. We used to have videotapes, but we ran out of funding we cannot do that all of the time. It is amazing that we have enough practice. We develop tactics for unilateral families who don't have full-time services pick my favorite is the deaf plus communication matrix. I just love doing that with the family. They are so used to all of their evaluations but I don't know communication matrix we sit there and say yes.

They are doing this, they are. Then we have the goal. How is the kid going to formulae protest besides this? That is our goal and the parents develop that. So, parents they learn how to fill in all those forms because they get to do it. And now we have it on the computer so some parents are showing how to do that.

Statement what is age appropriate. I am asking my kid to do too much. It is okay my 1-year-old is not turning pages. They learn how to wash their child in a new way right? They learn how to recognize how moments.

I can do this right now in the back of my head I know this is the next goal. They learn how to get assessment results. They are not scary, they are not scary, because they are the ones who created them. They want to get them back.

You are taking out that, you will going to get control of that. How to use those to create goals? The service coordinators in my area, I am in the development pathway area. They love our chip families tell us all the time your family knows what they're talking about.

They know how to use language for assessments to figure out what is an appropriate place for these families to go? And teaching how the facilitators how to do this. Probably the most trickiest part is how to help parents understand the results. Some of those results are tough.

How do you process I know it is probably what you weren't expecting pick or maybe were you expecting it?

I thought so you have that conversation training facilitators kind of how to hold space. Let families figure out what to do next. So I think, what we do once we have it is we send it off to Allison and her team.

>> Hello, thank you Lynn. What I will talk about Lynn has talked a lot about how she and others on the team take the assessment and use it with individual families and individual children. What I will talk about is how we use the information more at the statewide program wide level.

And a little bit about what we do, also the collaboration between all of us, I don't even know how it got started? We are all just friends I guess? But documenting language outcomes statewide is something we have done for a long time in Colorado.

It is taken many different agencies within the state to come together and support each other. Not just with the work, but actually supporting each other financially. And taking a piece of this. To do a comprehensive assessment and do it on a regular basis. There is a certain amount of money involved.

If you take it beyond the individual child. If you want to look at statewide, somebody has to create a database. Someone has to collect all of the information from the people who are doing it with the individual family. Somebody has to make sense of it.

There is not a point in putting the numbers in the database and not doing anything with the database. All of that takes money. It's not money that is typically kind of they're ready to be used. So in our state.

Here in our state welcome, so glad you could have sunshine which we usually have your. It has been a combination primarily of four different agencies. Over time different agencies come and go.

Actually our current Colorado Department of Ed used to be a financial contributor. Based on their regulation they had to could be involved in birth-3 anymore. The agencies that collaborate and all make either direct financial contributions to the process.

Or in-kind contributions in other words, staff do the work. The Colorado school for the deaf in the blind where Lynn works and I also have a part-time appointment. Colorado EHDI, which is Arlene, the University of Colorado which is primarily where I work. And also not represented on the panel but represented in the process is the Colorado Department of early childhood.

Which is the part C agency, while Lynn works for the school for the deaf. Early intervention goes into the home every week, work for part C, contractors with local part C agency.

So that is the in-kind support. We don't get direct money from part C, but they are paying the provider who is in the home who is administrating the actual assessment. A combination of four agencies working together and supporting the whole process financially.

So what peaches do we each take and something that you can envision for yourself in a similar format. Is we have the part C early intervention is as I mentioned pair cap

The people that go into the home on a weekly or biweekly whenever it is decided. They were for part C. They are contracting with local part C agency the cochairs of the coordinators, who are overseeing those individual interventions. And they also were the first point of contact with the family and got that connected with the early intervention.

Both of those people are facilitating the assessment process. Sometimes it would be Lynn, for her region, that would go into it sometimes it would be the part C person who would do it. It depends on how much experience the part C person has brick if it is a new provider, Lynn will probably go we do it and bring parts eat with their. So they can't learn the process.

She might do that a couple of times a couple of different joint assessments. More importantly, she will go back when they were explain the results. Because that is the hard part. You know that you could train somebody to get the assessment that is not difficult. To go back to the family and explain the results, in a supportive way, it especially if it turns out it is not good news.

How to share that.

How to use it to develop your next goal and steps. So, so either one of those people might actually do the physical assessment. And then the school for the deaf, contract with the University. They provide direct dollars contract with us, to manage the whole process. Let people know time to do the assessment on the child. Send reminders to them. Send material that they need to do the assessment.

And then, we collected, score it, provide an individual child report to them. We provide graphic displays of how the child is doing, and we create the database. So we can not look just at the individual child but also look program wide.

And we also fund the part-time assessment accountability coordinator. That is me. I work for them part-time directly and get a salary for that. So they are sending subcontract money to help us manage a project but they are also finding an appointment for me on a part-time basis. So as I said we are scoring the assessment, we maintain a detailed database.

We give reports back to the program, so that they can see the kids as a whole how they are doing? They use of the information to determine needs and where strengths and challenges in the program. Colorado EHDI supports that piece of it. As Arlene mentioned we will look at health disparities. So, Colorado EHDI funds that aspect of the analysis.

Looking at subgroups other children that are at more risk, might need more services or a different type of service. Compared to other children who have more successful outcomes and how to use that to help other children also be more successful. Soap some of the benefits to documenting the language outcomes statewide.

Is that it does provide accountability and program evaluation which is required is part of a plan of a program. I said I identify strengths and challenges of the program which can form personal prep needs, do our providers need more information? On encouraging pragmatic language skills.

Encouraging expanding vocabulary, where are the areas where the children are doing as well, so maybe providers are doing well? We need to provide support to them so they can support the family. Aunt that we can't look at different risk categories. Which might mean differential service. And it gives us data when we apply for a grant.

So if we see a grant available, often it requires or at least desire is see some outcome data from the program. Are you collecting this? Are you monitoring progress? It all stems from a funding agency sink were not to give you money if this isn't working.

You need to show that it's working. If you can show that upfront, people are often more willing to give you money. It's nice to have that on hand when you are replying to a grant. For the EHDI program, responsive to the new grant.

A new grant coming out the next funding collect language outcomes. We are already doing that. We are super excited that we already are meeting those goals. So being responsive to the EHDI funding agency. It just complete the circle. EHDI is screening, detection, intervention, and then to meet the last piece of the circle is the outcome.

That is what we are doing it for we are doing a for early intervention An early detection screening to get better outcomes.'S we need to see if that is happening. Then the EHDI system can see if the child is meeting the benchmark pickup we seen outcomes? They can identify health disparities as we said.

I want to show you we do have some of the data in our EHDI information system. This is what the page looks like. We do a lot more at the University database what we have more details. To give you an idea, you know, in a single sort of screen and your EHDI information system you can capture some really great information. We do a lot of assessments and we don't put them all in the EHDI information system.

We use them for different purposes big database in Colorado, we have captured I want to anchor instruments, which are the days eat five domain assessment and the MacArthur. A specific language assessment.

Looking at percentile, age, score, which you can see up there. Super important,.out for those who are building database, you always want to have a field, circled in red out there. Where you are determining to the best of your knowledge, if the child has a an additional disability to a packed speech or language or not.

When you analyze the data at the end he will separate those two groups. If you don't have a field that identifies who goes into each group, you are going to have one big group. And you are not going to be very clear about the outcome is not looking great because of the impact of a hearing difference on language, or is it because we have a bunch of kids in the air with cognitive impairments. You will going to want to be able to separate those out.

Set it up similar to this, where it is yes and no unknown. Don't do it like we did in the beginning. Super sorry, it just said has additional disability and you would take it if they did.

I never knew what to make of the empty box? Because I don't know if that meant they don't have additional disabilities? That field is been overlooked the person didn't know so they had to leave it blank and it really turned out not to be used don't make that mistake like I did. That's it thank you. I think we ended right on time. I don't think we have time to take questions, if anybody wants to, you know ask individually we can answer appear. Thank you very much we appreciate you coming.

MINERAL A

>> We are a couple of seconds early the room is full that means we are starting. So glad you guys are here this afternoon. Hopefully the energy that we can bring in this 25 minutes will keep us awake and on the home stretch into the last planner recension and then dinner.

My name is Darcy still I am with a heart for a hearing in Oklahoma but I am a speech pathologist this is me as Mary Poppins.

I am listed as a spoken language specialist my current role, I have one Mary hats the current role is in chief of clinical collaboration and research. I get the pleasure of working with gifted providers, and collaboration and services for children with hearing loss.

In the state of Oklahoma. Let's learn about you, two questions, are you a parent of a child with hearing loss? Raise your hand. Wonderful. Are you a professional that works with children with hearing loss? Awesome, great.

This will be on a timer, that will be very interesting this is great. Okay. I am here on Bihar behalf of hearts for a hearing. We have a wonderful team of professionals, and I feel the great pleasure of getting to come to talk to you about their work and about our work.

In focusing on improving things with children with hearing loss what works well and what hasn't we will be very honest today okay? Okay what is in the research let's do our own research.

If you have a child with hearing loss or work with a child with hearing loss, we are keeping the computers on the tiny human in the birth-3. Was difficult raise your hand.

All right we all have this shared experience. Some of you are behind a column that is interesting hi to you. Don't forget to move around. So we have this lived experience and we note that there are. Reviewed research articles that show the same.

We have a hearing technology as a global issue. Guess what, none of the research says it isn't. Here are in the few the stats. When I e-mailed the handout to the program coordinators you will have all this. So it will be coming.

As you can see less than optical where time is a problem. There is not a quick fix. Her colleagues from UNC did a study with 40 children with cochlear implants and I looked at language outcomes. At the age of three, we learned that come up more than 57% took more than one year to reach full time use pair

30% took more than two years to reach full time use, and only 53% of the kids reached full-time use at three years of age. Not only is it a big problem, there are a lot of factors that affect where time. Those of you with parents of children with hearing loss know this to be true with you your single human that you tried to get computers on.

We could spend two hours talking about the factors let's highlight a few. One of them, and the work from Walker and colleagues in 2015. She noted, the caregiver estimation of where time exceeded data logging on average by two hours. That is nothing against caregivers that is a discrepancy in technology.

Maybe we thought it was on the head but not powered on, all of those things. Graded discrepancies when it was birth-3. Also work by Walker in 2013. Indicates three factors that hearing aid use. Age of the child, better ear PTA. And the maternal education level.

Other things noted from the article, there are situations that affect hearing technology use. Like concerns, for things like when we wear them in the car, playground, daycare, especially for kids were younger than two.

Children with a greater degree of hearing loss where there hearing technology more especially in a public setting. Okay, another caregiver survey looked at these factors. The retention or fit affected where time. Awareness, maybe not knowing what it was? What defines full-time use?

Maybe not realizing the benefit all worried about losing them. Or them being a hazard. Okay, the third significant factor from research is where time influence the influence and spoken language outcomes children with hearing loss achieved. We all know that don't we. That's why we are here.

We do, a few of those highlights we will not spend long. Work that showed us ten hours or more affecting the language outcomes later in my. And then the top two findings here, in 2019, of the 40 children who wear cochlear implants pick

All children who achieved a full-time use by 24 months of age have language within normal limits by 36 months. You should put that on a T-shirt. And you should put the next one on the other side. H at full-time use of a better predictor of outcome then age at cochlear implantation.

Okay let's talk about at hearts for hearing, the pandemic afforded us a little time to look at what is this problem? Why is it so prevalent when we identify babies early? They have access to incredible technology even as infants.

We are Starling An early intervention, why do we still have this where time affecting outcomes? And the answer is it is not one answer it is a complex thing. But we took the charge, we decided to be worth the time, the energy in the dollars, to figure out how can we help change and how can we support families more than we already are?

By launching eyes open airs on. Four key components retention, that is probably what you think appeared when you think of keeping technology on. Education, assessment and support, and where all of those intersect is at where time.

Let's start with the easiest low hanging fruit retention. We sorry I am trying to multitask that's not a good idea. We started providing every family with a pilot cap at the hearing aid fitting. On shameless plug, this is an at seat brand, they stretch and they grow with their heads. It is snaps not ties.

We have families that prefer that. We add a project, I don't up for the project who is the mother of one of our audiologist. So we did not apply for a grant, we did not take that funding elsewhere but we had an motivated motivated provider that said we will help take care of this.

Do pilot caps work with all children with hearing technology? No. We have a closet full of all options that we know of Eric and when the family teaches us a new option we throw some of their too. So they are all options to test drive we do that and listening therapy a lot.

We will pull out something new that they can try, or another family has said have you tried this?

They will ask us to have this so I can try? So having it assessable breaks down the barrier. Sometimes. Okay, education. We could spend two hours on this. We put a lot of effort into providing access to material for families of all reading levels. Of all learning style. So, and we are working toward having as many Spanish material as we do English.

We are not there yet, we are still working on it. And this is true for the research but it is true for the listening and spoken labor strategies. It is true for the what are some of those barriers? Sometimes we don't know how to put in a hearing aid if I am a daycare provider. In English and Spanish, that they can pull up when they need to come want to be able to have that resource. Okay, assessment. Don't glaze over. This is exciting.

All right, you can't really know if you are meeting a goal, until you figure out what is your goal? How do we measure it? And at hearts for a hearing how do we unify that protocol across all providers? It is not just two of us deciding what to do.

That was a big undertaking. The team from UNC has gone before us, and they dug into the data about awake hours for children. And helped us calculate a hearing hours percentage. And given us target which is 80% or greater of awake hours.

That is our target and that is the center of the target that we aim for. Okay, here is where it gets interesting. Did you know whistle providers can data log? Okay if you don't hear anything else today. I will challenge you start data logging in every session.

You might say I don't have the equipment. We'll talk about that in a minute to go. Let me tell you about hearts for hearing, pediatric cardiologist trained us. On all of the manufacturers and all of the cords or wireless tech that you might need. To

To connect it get into the software, and it was a learning curve, but it is proven to be extremely beneficial. For a lot of reasons, one of which it is no longer an elephant in the room. How long is the person wearing the hearing technology pick we are talking about it every single time. It is a data point, that we can't log every single time. And I am not an audiologist I'll explain this as best as I can. But when you get into the software, to data log hearing aids, for example it resets. So you don't have 90 days of qubit of data.

You have one week or two. Some of us we have off weeks. It is great when we get to push the reset button and started all over. So we have data logging stations with three of them to win Oklahoma and one of the Tulsa branch. And that laptop can loop move to the therapy room and stay there.

It is on a wheeled cart, we are constantly figuring out new ways to use this. We began data logging every session. Let's reflect on how that looked. In June of 2021. We started this initiative with our new work diagnosed babies and children. This was the easy step. It became a part of what we talked about at that hearing technology fitting.

And its a part of what we talked about in every listening session and every intervention session. We normalize it from the beginning. And parents were proud of themselves for incremental progress over coming out of the chute and never having less than up the ball where time. It gave us another reason to celebrate.

And then there was October. That is when we started data logging on all children that we had seen no matter, we had seen them. This was a little bit bumpier of a road. For some families it gave us because to celebrate what was happening.

For some families, they felt watched. If there are families that did not know, that the technology had that capability. And then you tell them for six years now, we have known about this. And by the way, it is a goal that we need to work on.

Talk about vulnerable and uncomfortable, we as speech pathologists and pediatric cardiologist had to step into that uncomfortable. It was really important for us during that time to lean on each other. So we had monthly staff meetings where we would say hey I need help. This is not going well.

How can I better work with this family to meet their needs as we move through this new initiative to do more data logging? Okay, and that we have to celebrate. That is the hard, data logging is hard to. That we got to celebrate.

 Because we knew we were a celebration should be. We started celebrating with the Wall of fame. This is a big magnetic think that is on the wall. And if a kid achieve the goal, they got to be special.

They could be on the wall and at that picture, name, and something unique about them up there. Some people got on the week wall in week one. Some after four months and one hour of goal increase time. We celebrated small victories, we celebrated the wow, 90% full-time use.

This was cool, we saw the kids celebrating other kids. And families celebrating other families. And then we also have individualized some incentives. As we can't, we had a mom of a kid who was 15 months old. A cochlear implant user. It was really hard to keep his technology on him.

She is a young, single mom. We said hey, if we got to eight hours per day, because we are at four. What would be cool to you? Like an incentive to work for? She said an ultimate gift card.

We said noted, she said to-4 weeks they met the goal of eight hours. And she got her gift card. This is meeting the needs of each family where they are in order to get back to that language rich environment, where access to audible and intelligible speech for all of these babies. Okay it would be cool if we can stand up here and say eyes open and ears aren't implemented it back we no longer have where time. Discussions.

That is just not the case, but we will celebrate the small wins. From children birth-3 what cochlear implants, 70% show double where time after the limitation of eyes open ears on. And the majority of these kids were 12-24 months of age.

Which is a little bit like no man's land right? So we will celebrate the small successes. And then support, so, in working with families of children with hearing loss. We are not ever just focusing on ears and mouth. There is so much more to it. And that is where support comes in.

I want to camp on, our patient care therapist. She is a licensed professional counselor, and the brainchild of a risk taker who is at hearts for a hearing. In October of 2020, when she came on board, she has change the game for us. As providers she has changed again for families of children with hearing loss.

Now there are three tenants in mental health. Promotion, prevention, and intervention. When we think of counselors, we tend to think of intervention right? That is what is billable. But what we know about infant health his prevention and promotion. Although not billable, it can sometimes negate the need for intervention: So we took her and we took and put her in with every family pair

Who had a child or baby diagnosed with hearing loss for two sessions. And she did these questionnaires with them. I will not go in depth. Because we are running out of time. Basically what we look at parent-child interaction. We will look at belief in self advocacy and we looked at the possibility of depression. Especially postpartum with the mother.

Coupled with a semi structured interview for trends that we might see with these questionnaires.

Here is what we learned off of the back right within a month. Three of the first ten caregivers enrolled in eyes open ears on, were in need of mental health support. Mom needed counseling. She was showing possible signs of depression. We would not have known that guys if we had not incorporated support early on.

Okay let's do that let's go there. And then we learned, this was significant. A little bit later looking through the data. We learn that parent self-efficacy and parent-child interactions together were significant predictors of where time.

Each one by themselves no, those two together yes. That caused us to step back and go okay, new information. We have something significant what should we do?

We introduced phase two with our PCT and she is doing five, she is coaching the providers with five targeted parent-child interaction topics. That are very scripted, they have videos back to them on things like being with. And other things like the state of cognition and regulation. And we have a small cohort that has finished those lessons and we look forward to checking that data out. And seeing the difference that is made.

Okay, as we wrap up with doing great on time will have time for questions this is great. We are seeing consistent trends in improvement of average wait time as families progress in the eyes open ears on program. There are new to families alike, and that's not what we should expect 0 we should want. But we at hearts for hearing have approached this as no matter what the barrier we will do our best to support technology where time. And get the child to using technology fertile and use early and as young as possible. Okay, we have learned improving parent stress and self-efficacy contributes to better where time. We have learned that we have to hold the whole thing not just a child with hearing loss and their parents. If we are going to target improving where time.

And we have learned illicit providers can data log. How many of you are providers in the room? By that you are a speech pathologist early intervention. Raise your hand if you have a very data large? Raise your hand if that thought just makes you kind of nervous? It still makes me nervous. Okay, well we are going to continue. We will continue touching more families with data collection. Increasing sample size, continue with this phase number two of educational materials and a goal of reaching optimal where time for children before their fourth birthday.

Now it is on you. What can you do now to name the elephant in the room. Which is where time, and implement in your practice in your clinic, your classroom, to increase where time for children with hearing loss.

I would say it start data logging whatever that means for you. Okay, most of the manufacturers have an app, that gives you an estimated where time. What if, we look at the app, on the caregivers phone in every session.

We documented and have conversations around it. We normalize the fact that the where time matters, and optimizing our speech and language outcomes later on. I would say get creative.

How you did a lot come up where you data log, whether the kid helps you do it all of that. Treat each child and each family as unique. I know you will do. But when we approach problem-solving that way we will get further faster. And then collaborate.

The SLP team and hearts for hearing could not have done this without a team of pediatric cardiologist that believed in us more than we believe in ourselves. And that they are always available for the questions that you should know the answer to. And you just retune the don't. Because we are better and were in this together as a say in high school musical. All right, we have a couple minutes any questions? Yes?

That is a great question, in the beginning, it takes longer. But as you get used to it, you could probably do it in 3 minutes tops. We can get better right? Yes. We also somewhere.

That has affected protocol and that changes over time. In the beginning we were doing it with everyone, and we definitely continue doing I was a birth-18 months routinely. So much variability in there.

Once we do get a pattern of 4-8 weeks. Of consistent optimal full time use we will pull back. Because they are still data logging at all of that routine ideology appointments. And you can spot check at times too if you need to. Yes, ma'am.

The question is, the counselor that we hired patient care therapist came into sessions and completed those questionnaires within those two sessions yes. And she talked about the services that she has available to offer to families. Should they choose that from the beginning too.

Who would they be with? The short answer to that is be curious with them, not judgmental of them, and when we approach with curiosity, I think of it as I tried to get fit, I am on the treadmill, I am not telling you don't need to tell me I'm going fast enough I know that pic but if you're curious with me on the next thing I could try, and we all provide the option to tell the family got to download this week you can't do it, that's okay. It's

To try to recap this I'm struggling to hear you, I only got 60% of that. You said in clinical staffing, meeting, you as a provider encourage parents to use the cochlear app. No.

Wouldn't it be cool if all of the hearing technology showed us on the app. Let's contribute to that change. That would be great. I can tell you more I have data references to last question were about to get kicked out. Emily? Do you have a pediatric cardiologist that is your friend, start there. She asked about the tech how that is station. Let somebody more skilled and you figure that out. Okay thanks all.