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EHDI Annual Conference

Topical Session 1 & 2: Mineral A

March 18, 2024

9:40 AM– 11:55 AM (MT)

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>> Good morning everyone housekeeping before we get started, emergency exits for your knowledge one behind me and one behind you. All course evaluations are on the app this year. We can go ahead and get started with our team the path to effective DH H infusion.

>> All right, hello everyone. I will stay right here, my name is Emily Burke, I am deaf and hard of hearing infusion coordinator from hands and voices.

>> Hello everybody my name is Karen Hopkins. I am the director, yes this is a good one.

>> Yes access is important, again I am Karen Hopkins. And I am the Executive Director for the children's center for communication/the school for the deaf. I just moved from the state of Maine, so my identity as far as who I am is a bit up in the air. And today, you know, I am also the a coordinator specifically because I only have two weeks left. The EHDI coordinator for the state of Maine. I am representing Maine, and Massachusetts today. Also I am wearing the hat for the hand and voice president for HQ.

>> Hi everyone I am Emily's other half. The DH H co- coordinator infusion hand invoice's headquarters. We have some really exciting new research to share with you today. Also some strategy for effective deaf and hard of hearing infusion. Great, okay. Emily is speaking now. As you can see, this is our breezing Tatian deaf without deaf. thinking of the EHDI system all of you who we are serving who are the deaf and hard of hearing folks and children that we are working with. That is why I thought we we need to include deaf and hard of hearing from the cap immunity and all of those involved from every single level. So we can best serve the deaf and hard of hearing children that we work with.

From birth through adulthood. That is why I chose deaf without deaf presentation because without it is impossible. I want to take a look at the room I know faces I am happy some of my friends are here.

I want to see who was in the room. Who is deaf or hard of hearing themselves? Who are the parents in the room? Quite a few, great. Who else? EHDI leaders or folks will Volvo EHDI great.

>> Teachers how about teachers and educators?

>> Any teachers in the rooms?

>> Early intervention in the room?

>> First timers, great. Yes thank you so much for being here. Okay, the question is can we successfully serve children in the EHDI insisted with limited or no access to the experience in investment of deaf and hard of hearing speakers. We really do need are deaf and hard of hearing speakers engage in every level of the system.

And one thing that we are working on, changing kind of our perspective, of you know, there is been a push for inclusion, and what that ends up looking like, is one, maybe one deaf person at the table or won hard of hearing person at the table.

What we want to challenge today, is think about how we can create systems, where we have deaf and hard of hearing leaders representative. In a whole deaf and hard of hearing represented on every level of the EHDI system. In all of the .10 of contact for parents as they never get their journey pair

It is kind of a flip of thinking picks up today, we will invite you, to experience the richness, of the deaf and hard of hearing community that we bring to the table. And, we will invite you, to join us. Emily will share an analogy that will help you understand the concept.

>> Okay, so my husband is quite creative. He loves using analogies. They help me understand things well. Imagine a lake it is a calm beautiful a pair

It's like class, you look out upon it, I don't know if anybody has been to Aspen camp here in Colorado? It is a beautiful lake it is calm and serene.

But again this Lake is calm and we will say the lake is a deaf person. And you know, under that surface. There is fish. Gosh what else is in a lake? Animals, things that are alive. In this Lake that happened underneath the surface. Someone may ask me for a specific resource that I do not know? So I say hold on one moment, I will dive into this Lake, into the water, search through it with my goggles.

Looking for that resource. That's the same for the deaf community. There are deaf leaders that specialize in special areas. They are underneath the lake surface they are there. So I invite you all to jump in the lake with us. And find those resources.

>> Thank you Emily that is such a great visual on what we are trying to do. And I did want to just quickly mentioned, that Wyatt does representation matter? So, we know from diversity, equity, and inclusion work that we have going on and research that is going on. How important representation is pair

To our kids for them to develop a sense of identity. For families to have service providers that look like vampiric for kids to be able to see their future as well.

And I just want to share that, that the new blueprint for change from the maternal health Bureau. I will not read the whole quote you can go and read it.

Basically I want to say from top down there is starting to be recognition of the importance of representation. And it is also something that helps us create systems that are ineffective we can avoid full pause and tokenism. We can give families and children the kind of support that they really need.

While we present think about what does this look like in your state? What kind of representation do you already have? What is missing? Do you have deaf and hard of hearing guide mentors. Do have a deaf leaders at your EHDI advisory meetings? Do you have family -based organizations that include deaf and hard of hearing leaders and think about that what we are presenting today.

All of us are involved with hands and voices. So, when we talk about deaf and hard of hearing infusion, one strategy that we are trying to do is always a bring in the deaf and hard of hearing hopes -- folks in the field. Bring in different perspectives.

Us for myself, Elizabeth and myself, we have the only two people right now expected to represent the entire community, which is impossible. It would be like I am completely deaf, profoundly deaf, my story is very different from a hard of hearing story which is different from each individual story. So we are trying to recruit more deaf and hard of hearing advisory Council members. To represent the variety of deaf people who are involved in a community.

So we can support systems, students and children that we work with, so we are open for applications if anyone is interested. Right now we do have different committees as you can see up here.

>> I will add to what Emily is say, these are some of these strategies, that we are implementing at hands and voices, the advisory committee, we are using consultation approach, where we can advise on topics that are important to the community pair

We are collaborating with our DE IA partners this so much into Lapin over sexuality and between experiences of a underrepresented people of color and deaf and hard of hearing experience.

We are born leadership, hey, we have a deaf Board President for the first time. And we are working on resource development, that is going to demonstrate the perspective of the whole community.

>> I do want to add to that, we also do deaf and hard of hearing I was eight more mentoring, we have a mentoring program, that work with other leaders, who hopefully then can have those resources spread around the community.

So if you know any deaf and hard of hearing folks who could be involved in your state chapter, maybe be a part of a board of some sort? We do encourage you to get those folks involved, parents, professionals, any other deaf role models that could be a part of these systems.

>> That headquarters, the board there, has also taken it in would look at the hands and voices system. Also the members who serve on that board. We are committed to diversity, and representation, we are committed to inclusion. We invite you to see the change. And the represent a diverse board, we are looking forward to that.

>> Some additional strategies that you might consider to increase the deaf and hard of hearing infusion in your. You will definitely need to reach out to the deaf and hard of hearing community, so that deaf students who want to attend your events and take the lead in your state pick to ensure, DHH and adult and leaders are available pair

Someone has to take the initiative is basically what that means. Connect with peers states EHDI coordinator. There might be opportunities for agreements and funding streams, to create more leadership in the deaf and hard of hearing leadership.

We want you to look at every window of opportunity. We know we talk about one, three, six, and EHDI. What does that look like for education? Screening, transition to early intervention? Transition to early childhood special education and kindergarten?

Our deaf and hard of hearing leaders involved with your families at each of those points.

>> You will see a picture a graph on the bottom it is hard to see probably from where you are at. An audiologist, pediatrician, a deaf and hard of hearing intervention is pick all of this is happening at the moment the child is identified pair

They should be meeting these radical members of the team. Right at the onset. And then you have EHDI, and at this point it should be exposure to deaf adults. Next transition where they entered the educational arena. They need to be exposed to additional technology. To get ready to go to high school.

Another major transition, through all of these transitional times, we need to make sure deaf adults are there to support the family and the child.

>> I mentioned this earlier, it's not enough to say we want deaf and hard of hearing leaders involved. We have to actively pursue it. Thinking about formal partnerships with that deaf lead partnerships in the state. Do your EHDI have a formal partnerships. Do you invite deaf and hard of hearing to participate on councils and advisory boys and leadership positions?

Are you doing that in a way that is welcoming and accessible to the deaf and hard of hearing leaders? What about inviting leaders to your events, conferences, network opportunities, so people who are EHDI corneas. Maybe you brought with you someone from your program. Today did you bring a deaf and hard of hearing leader with you? These are questions, the hard questions but the questions that we ask ourselves to create change.

>> So many people say it is fine, it is fine, there is really no research connected to having those for deaf and hard of hearing including. While it is like how do you know? Therefore I decided, to conduct research. This is just one of my studies.

So I wanted to know how each family and what their experience was? How they feel about it? What their perspective was when they met someone who was deaf and hard of hearing adult.

May be, it impacted them, but it was really important for them, to have opportunity. So I sat down with 12 different families. With those parents. This is what I have found. So, from the 12 parents that I met with. Eleven of them, immediately said yes of course.

We need you know, because this is the life that I have and I want to empower my children to be strong, I want them to meet these deaf adults. And this was all over the state of Maine. And we have a program, for EDI deaf and hard of hearing adults and they can meet them early on in the system. And they were motivated to do so in that transition time.

The events, home visits, the system was set to create that inclusion, that full on, you know opportunity to have these deaf adults there picked it truly was in empowerment opportunity. What we found in the reach is that that was found they are. So really quickly, I am going to switch hats when it comes to language really quick.

>> I want the hearing individuals to hear my tone. And, I want the deaf individuals to see my sign.

>> These are quotes from Maine and I have many. These other ones that popped out to me, that really stood out. If I could have met deaf people earlier come up met more then one, get a broader understanding of the many ways that deaf and hard of hearing people exist in a world. It would make those first weeks easier.

We need to meet someone who was deaf and hard of hearing earlier. They are struggling to find a starting point early on. I feel if you can bring someone into meet them that is deaf, before they make their initial decision, that would be so helpful.

It was so heart warming to meet a tran seven Adele. There were days I could not figure out how I was going to be [Indiscernible]. My deaf mentor made it comfortable, to ask whatever question I needed. And to ask what is it like to be deaf? Is that of being connected to doctors, therapists, and being a patient. We are now in this community. And we are part of something amazing. It was then, I realize I could be the mother that I wanted to be.

>> Once I completed my research, I had to think about the very early, early on. Like what does the term early mean? Is it birth? Is it three months of age? Six months of age? 2-years-old? So a group of us got together and we did further research.

By just sending out a question. And we found that 65% of those asked, 65 of the parents, 165, 165 parents responded. And out of 129, of those parents, they were hearing. And they had deaf and hard of hearing children.

It did not matter if it was a child who was a baby, ages one, two, three it did not matter. The data collected. This happened in March of 2023-July 2023. That is when we sent out our questionnaire.

This research showed and I know it is hard to see so I will move this to the next one. It showed 85, 85% of hearing families asked whether or not once they look back asked, they were asked if they wanted to meet a deaf individual when the baby was between 0-9 months.

71% of hearing parents wished that they had met someone between the ages of 0-3 months, just an infant. Looking back, this is what they said, they wish they had that. Here is more research, if you are taking a look at the window of 2020. And we are talking about, current research, 2020-current families.

83% of those family survey, said that they really wish that they had met a deaf individual prior to the age of three months. So we were trying to figure out what does that mean? And we wanted to see, like the whole this series out in a whole. We saw earlier is better.

So looking back a lot of the parents.I wish I could have had this exposure for my child. We will be writing a case study, and we will post it and disseminated.

>> So, now that you are thinking of who are the parents in first contact with once they join the system? Typically those professionals are hearing. We obviously do have some deaf and hard of hearing professionals involved in these areas.

Guides, models, instructors, coordinators, audiologist, pediatricians, researchers, consultants, interpreters, and the list goes on. There are great and amazing deaf and hard of hearing professionals mixed among these professionals. And those are who they need to meet. We just need to figure out how to lose them and.

>> We are running out of time, I will not go what a smart goal is. There's things online to show you how to write a smart goal if you don't know already.

I would love if someone in the audience would be willing to share what is one goal that you have after this presentation, when you get home, what you going to do? What is your goal?

>> I am a parent of a deaf son so I guess one of my goals is to figure out actively connect our deaf and hard of hearing guys. I had a lot of deaf friends I had to force my way in. I had to knock on does and beg people to teach us ASL.

It takes a lot of work I don't want future parents to work as hard as I did to gain access into the deaf community. I want to start to harass my deaf friends more and tell them to be nice.

>> Thank you for that that's a good point that is something that we are working on it hands and voices. We will produce a new series for deaf leaders that maybe don't have that context of the EHDI system what it is and why it is important that they get engaged in a ball so we will create videos that are specific for deaf leaders on why they should be involved in that system. Is anyone else brave enough to share their goal?

>> Hi, also a parent of a deaf kid. Experience is different in the deaf community. Where I live it is welcoming and inclusive. I think what lacks is a system, to ensure that hearing parents understand they have the ability to connect pick

There is no real system in place for early connection and I agree early connection is incredibly powerful and I would like our state to have a system in place. So that is what I will be taking away, thank you.

>> Thank you.

>> Yes, that is why that is our hope. We hope with the research that we are to disseminate that the research shows earlier is better. And, your system is able to you know, that the system is able to take a look at the research.

>> Okay, last thing we want to invite you, while you are at EHDI, to share your goal on the aft, on social media. Use these hashtags DHH and EHDI in DHS and infusion. And hopefully we can start something. Okay and these are a couple of resources. You can always reach out to the three of us, part of our role at hands invoices to provide technical assistance to EHDI programs and family -based organizations. If you have questions come find us.

>> Okay if you want to read more, if you want to read more about our research, there is a poster out in the hall. You can look at that. Okay. Wonderful, thank you so much.

>> All right everybody in the interest of time, we will go ahead and get started, for safety reasons so everybody is aware, there is an emergency exit behind me and directly behind you. All CEU forms are found on the app as well. I will handed over to the presenters to give a nice talk on deaf and hard of hearing engagement and EHDI An early engagement systems.

>> All right, well good morning. Some of you did not even leave the room, that is kind of nice. Okay, so I think this presentation is a fantastic jumping point from the previous presentation. Obviously the title we will discuss deaf and hard of hearing engagement. At the professional level. In the EHDI system. So we have three deaf presenters and a hearing presenter all professor roles, and we will talk about why we have the individual who can hear on the panel today.

>> I am from California, and I am the co- coordinator of the EHDI system within the California turning over to Karen.

>> Hi this is Karen Hopkins, I am the main and Massachusetts excuse me coordinator for the EHDI system and for the state of Maine and Massachusetts children family Center for communications I wear multiple hats.

>> Hello everyone my name is Sherry Farina. I am co- EHDI coordinator. PI, happy to be here with you all.

>> Hello everyone, my name is Ryan Hutchison, I am the EHDI coordinator in the state of Texas pleasure to be here, thank you. So, you arty know who we are, so we don't need this. Before we leave today, the objective is you can't explain tran seven leadership and how it is integrated within the EHDI system. It is critical to have deaf adults at all.

The second objective you can identify different ways to include deaf and hard of hearing adults with in your state -based EHDI system. The third objective identifying a simple measure of steps that can implement change.

To ensure that you have deaf and hard of hearing professionals involved within your state system. There are only two states that have deaf EHDI coordinators, two. It is currently California, myself and Sherry. And then Karen. Who is the state of Maine. Karen is leaving that role in two weeks. So within two weeks, we are going from two.

>> Just be them Oh no.

>> So it is my hope, within our future, immediate future. That will not be the state of affairs our goal is to implement change and change the status quo. So, why is it is into go for us to be involved in the system? It is because this all relates back to the grant pair

We will apply for the Ursa grant isn't important for the educational systems and any debt professionals who are within the EHDI to apply as a PI. So what are other ways, that you can encourage deaf professionals to get involved at the leadership level in the EHDI system? It is critical. The reason is because we have the lived experience. Some of us are born deaf, we live alive deaf, and we will die deaf. We do know better than everybody else.

It's doesn't matter but audiologist the doctors we are us. We understand the experience. There are gaps within the system that we have to look at. We also have to recognize what deaf professionals bring to the table. They bring deaf cultural wealth and capital. What this includes is all of these elements, it includes familial elements, it includes aspirational elements. Educational, resistance even. Navigational. Linguistic, language that is incredibly critical.

What is not discussed often, is trauma knowledge capital. We have a lot of trauma, language deprivation, social isolation, we don't have enough exposure to DCCW. these individuals at the table will understand what not to do that increases the level of trauma, so they understand how to prevent it. At this time, I will turn it over to Sherry. We will take a look at what Sherry is doing at the state of California at this time.

>> All right thanks so, in California we did have the grant for many years. The Department of Health, at the health and human services and Department of education as well. And then, Julie was a PI at the time working for CDE. We did not apply for HERSA, there was a lot of changes happening higher up at those levels.

We felt like we wanted to make sure they were deaf people in the driver seat. So they asked me too apply, my first answer was nope, no. the reason was I did not feel comfortable with what I was seeing. And I later became upset with the department and I said okay yes. I better go ahead and apply.

I am proud to say, with a nonprofit organization we won the grant. Deaf run and community-based organization. And mentioned resistant. Working with state departments that were resistant to us.

They would then give us referrals, and we would refer them out to audiologist and such. Over time, I worked very hard to build those relationships. Because I don't believe we should be working in the silos. We should be collaborating with other mainstream programs, Deaf schools, sign in spoken what not.

All in one big space as won big family, because I cannot take all on all of that it requires a village. That concept has worked beautifully. Over the past four years, we have served and referred over 1000 babies and infants in California.

Who those local education agencies, school districts, deaf and hard of hearing hard of hearing programs. And regional centers you cannot forget the regional centers.

I know some laws don't apply to those regional centers. But if we have deaf babies we definitely send them there anyway. A new player that we have close worked with is the Department of developmental services. To bridge those gaps essentially. So there is a more comprehensive system at play. Our goal at the time with the 1-3-6 model. HERSA Does required the touch points of 1-3-6. And we also added other touch points at family mentor ship. At six months and at nine months.

We want those goals to be carried through, in California we just found out last week. We won the grant again. The next five years. With that I can say we have parent mentors, we have deaf coaches. We have for parent mentors who are try lingual.

One who is not. As for the deaf coaches we have subcontracts with seven agencies. And those area agencies hire their own deaf coaches to work with the family in the area. Always who you know California is a large state. We need resources spread amongst that area. So we have deaf mentors to work with families. It is been beautiful.

The name of the statewide program is named Lead K, Family Services. The reason is we want to keep the focus on language acquisition and language quality. The goal is to be kindergarten ready.

We have different contracts around California with different agencies that provide deaf coaching. They are responsible to coordinate those services in their specific area and region with their own deaf coaches that they subcontract with themselves.

That model, has worked beautifully. We also work with all of those family engagement activities as well. In the activities that we do, maybe we will do, one day, but seven different locations around California. Maybe from 10-2:00 p.m., all of those locations. We provide reading literacy events.

For infants-3-years-old. Every year, I would say we've had over 1000 families show up at these locations. Which has been wonderful. So it is really exciting to share all of the different ideas involved, so thank you so much for listening.

>> Thank you Sherry. Thank you. Thank you. Let me turn it over to Karen at this time.

>> Okay, all right, so I feel a little homesick I have to be honest, and I feel a little bit guilty, because I have these guys that are going to be taking the lead. And they are going to be amazing that's okay. So when it comes to the system in the state of Maine. We have worked for years.

It to clean up our language. Because we wanted to make sure we are parents at the table as well as deaf and hard of hearing folks at the table. Deaf and hard of hearing leaders. This I know is a very complicated graphic.

It shows the CDC or the state department of health, and how it, you know they used to have the HERSA grant for many years. There were changes made and it was too focused on the family, and to have deaf inclusion. We will like we do not added to this? And I am like, I don't mind you know, partnering with you guys. I would be happy and more than willing.

So, I have never written a grant up into that point. And I was kind of flying blind. I was able to get it. We were able to get the grant twice. And it really made some changes for us in the system. That we are able to have formal partnerships with the CDC.

The Department of Education was included. The schools for the deaf were as well. And then we had the role of the EHDI supervisors and coordinators. Everything was done there it was put into place. So for the deaf leaders, where they had the you know table advisory board. We had the deaf guys in the mentors and what have you.

Also when it comes to events just like what Sherry had mentioned, those events are so critical. To have DHH folks they had to be able and to be met. These are a plethora of examples. Our program is a formal partnership, we are able to be with parents early, we are able to pair with someone very early on.

As they transition from there, they go with another guide. This is all based in legal as well. This is based in law, and we have that set up in law. Even though I am leaving it will continue because of the law in place. Now when it came to the Council they provided feedback. Using the deaf individual on the advisory Council. So there is one very important thing to focus on.

We have the two programs, one is the formal deaf mentoring program. It is part C from the IFSP. Now with the EHDIdeaf parenting services, this takes place weekly. And this is for individual 0-3, and we just added the 0-5 program as well. Now the deaf guides they are part of the hands and voices program.

That partnership, we are able to partner together, so it is not a matter of just picking one or the other. We have been able to make this work with you know multiple different names. We go from 0-22.

It is wonderful, we can provide also a deaf camp for families, spoken language, IQ speech, signed I was, it is great it is all the same you know, Camp. And we are paid, at this camp was paid for by the grant. So there is no pressure, this is there for families.

All of the kids are able, and all of the families are able to get used to each other, so they can be like that is sign language, that is spoken modality. And, they are not you know, they don't have to just focus on only one and choose only one modality.

They can benefit from all of those things it gives them the opportunity to have exposure and socialization to all of the various language modalities. They really with their ISP, they can go ahead and meet all of those needs and services.

Yes and so, you know, is wonderful because they can see how their children transition. You know when they are, when their babies are diagnosed it might be overwhelming and this gives them the opportunity, and then they can see what happens from there in the future.

So, I know changes happen with transition. However, fortunately, before I left, I was able to provide the information for the next round. I was able to apply it. So that way, they will be able to incorporate that in the grant and whatever's left. And we have 25% is going to stay with the Department of Health. Or 75% will be kept in the deaf education in the deaf schools. So there you have it.

>> Thank you so much caring what I see is more and more parents of deaf children get access to this and they want to be part of what is going on, they want to see the schools for the deaf.

They recognize the value of DCCW, the next individual I will introduce is Ryan Hutchison. He is from Texas and he will talk about strategies as our ally in this work.

>> Hi everyone I am Ryan I am from Texas. I am also a coda I have to deaf parents. Coordinator for the state. It is really important that we realize, and recognize as EHDI coordinators what we know and what we don't know right?

I work for the public health agency getting a diagnosis that's our forte and strength. But as EHDI is started to involve deaf mentorship language access. We know that is not our expertise. Finding the right partners and deaf leaders help us.

We partner with the state wide outreach center for the Texas school of the deaf. They had the foundation of a deaf mentor program and supported statewide family supports. They know about they are connected, throughout the state come up with all of the regional schools. So they are ineffective provided for us to coordinate intervention right?

After we get the baby I diagnosis, it works with the leader who know the deaf community. Who are allies yes. It is important, as a hearing person, to recognize that we do need to engage deaf leadership and prioritize their engagement in the system. And to come collect family feedback. And we are still learning.

So again, if you are a coordinator work to involve the community allies and community deaf leadership and process and. And they are working with those families, and innate understanding, that you don't bring and recognize that privilege. So, thank you.

>> Thank you so much Ryan. I want everyone to know. That there was actually a poster presentation regarding this. Family feedback and we have found, that the majority of families wish they had deaf mentors and exposure before the child was three months old. The earlier the better.

There is actually a poster, and it's about that very topic, it is, the results of a study please check it out. As soon as you go this morning where they had the pleasure in every session. So it is actually on the left side as you enter the building look over that way. Any questions? Let's turn it over to the audience. Anybody? Yes go ahead.

>> Yes, I am curious about the data. Particularly because here at EHDI, we talk about data, a lot of emphasis on data. We talk about this deaf family feedback. And family feedback if there is any mention about deaf capital in the correlation of the family perspective with deaf capital. And we talk about the Hersa grant. Thank you for that question all such first content.

The research to the extent we were looking for feedback about what will happen in the past, and with the parents wish to happen, definately that was the focus there. There was a unanimous respond. They wanted deaf professionals involved before the age of three months. That right there, is a new finding. It is within the year.

So when you ask about, is sort of a lead into where we are going. So, just looking at that capital, it understanding the benefit and the why? That is the next step, that is where we are headed. Anyone else?

>> So I think it is amazing the different states have their own options. Over opportunities, but what do you suggest forte maybe at a national level? Having some type of standards to be set?

>> Sherry, it would be nice. If all of the states had more of a uniform approach. In their practice, absolutely. We are finding that we may be shifting in that direction, in the next cycle. But again, let's not forget obviously each state has their own set of politics at play. Their own bureaucracy.

Their own struggles, with their school system in particular. So some states have deaf children Bill of Rights about primary language some states do not. Some states have lead K legislation that has passed. About language some states do not pick there are 22 states that have passed that bill pair

We can do more, and I am hoping people maybe can see that big picture. And the importance of legislation. Where change can happen. If that bill passed in relation to those changes that we want to see. And that will impact how the system can actually shift.

>> Also I would like to include all of your questions when it comes to state part C. you need to ask your state and your EHDI coordinators. You need to ask questions asking where are our deaf leaders? And you can be like okay take a look at the laws and legislation.

Then they can provide more support for the process. In addition to that, think about the regulations and requirements of the past. It was never a mention of a deaf mentor this was recently at a pet we had just added the language in regards to milestones.

So we have to look at what eligibility requirements me now, and the intentional with the strategic plan to incorporate deaf leadership. The EHDI system, needs to have deaf individuals and the driver seat. It has to be deliberate in strategic.

It has to be within ten, as was mentioned, laws and legislation, and of course as Karen just mentioned, we have to question the system. With that said, I believe our time is up is that correct? Yes it is, at this time we need to)

Please, you can contact us. Apparently our contact information did not make it to the slideshow. Regardless, you will get a copy of the PowerPoint, hasn't been uploaded into the website. Please reach out thank you so much.

>> All right everyone housekeeping before we get started, there is an emergency exit behind me and immediately behind you. All CEU forms and course evaluations are on the app this year. And I will turn it over to Jessica to tell us how she is a perfect parent.

>> Can everyone hear me? Awesome, well I am not just a perfect parent, you are all perfect parents. Went hours son was first diagnosed, I kind of panicked, because my husband and I are hearing, all the generations back are hearing.

We were handed a baby and it was like a good luck go with God. What we do? What we do? We slowly figured out, is that we knew what we were doing. We have this idea in society a perfection and what it means.

Flawless, without a single floor to it. I realized that it is not really what perfection is. That is what we have been led to believe. And I went to an orchard one day.

I found, I was watching prices. This is before inflation was bad. And I saw a table at the back. And all of those apples were 50% off because they were damaged. And they looked like this. They were dimpled and dented.

That is kind of what we are, and especially parents who, who have seen stuff. We have, we seen some stuff. I felt a little bit damaged as well. And not really knowing what I needed to do or be?

The actual definition of perfection means lacking nothing, pole, complete. Those apples, were lacking nothing, they were whole, they were complete. I could use them for every single purpose that I would use pick

The pretty shiny one on the shelf the cost way more. You can pick it up and eat at the way it was. No matter what it had looked like. So we will talk about how we are all lacking nothing whole and complete as we go through the journey of raising the kids.

We will define what that is, we are persistent, have high expectations, use research, we fail, I am the champion of failure. We treat our kids as equals, we are caring, and we are tough, and we will talk about all of the different ways that we can demonstrate that as parents.

First of all knowing what our child needs and how to get it. When we first started out I did not know what my kid needed? Did he need sign language? Did any spoken language? Do we get cochlear implants do we not?

I did not know what we were going to do so we started asking questions. We started talking to people. The nice thing about people come up for the most part, they are really nice. It is an exception to run across someone who is not willing to help you.

Who is not kind or does not want to help you along the way. I picked the brains of a lot of parents. We live in a small town at the time, so the news of someone child in the community being deaf was big news. It spread like wildfire. Friends of friends called me and said do you know so-and-so? They have a daughter who is deaf, in their daughter's class. They started making connections for me without me having to try.

Because people are kind, they want to support and love one another. And knowing how to get what your child needs, is also really important. Knowing who to call. If you don't know to call? You can start really simply. Start with the Dr.

Start with the school. Just start asking around. People, we kinda find our people. It is not even that hard. Even if you lived in a rural area. In the age of things like this, it is even easier pair

We can find a Facebook group. We can find a Instagram account. Does all kinds of people out there willing to find one another, and you do not have to be geographically close. Having high expectations, watching parents keep those expectations high in the face of being told, your child, isn't going to do well.

I had a speech therapist tell me once, that we need to have your son's IQ tested. Because I think there is something cognitively going on with him. Because he was not speaking on the timetable that she had decided was appropriate. We were told not to sign.

We were told that maybe he has a language specific disorder. What we had realized is that we were not doing it right. She was on his own schedule and own timetable. And we have been told since then, that the language work that we did. It made a huge difference.

We never saw that SOP again, I will not go back to someone who has such a low expectations of my child. We can't always anticipate the expectations that the world will have of them, Nathan is 18 now. He is a senior in high school pair

Of course when you are a senior, you take the easy classes. So his classes are banned and strength training. We had, pretty low expectations when it came to band. What is this deaf kid who can't hear sound frequencies do in band? He'll make friends it'll be cute and sweet.

He will have these friends that he makes in band, and he decided that was not good enough for him. He had the band director tell them, you do well for someone in your situation. And that lit a fire underneath him. I don't want to do well for someone in my situation. I want to do well because I am doing well. He submitted auditions to for difference honor bands this year. Any got into three. Yes, I know, so exciting. He was so proud of his accomplishments.

He just said I want to see a fark go? He has no idea with the music actually sounds like? But he knows what it sounds like it for it not be in tune. And so, keeping those expectations Hi, even when others don't is really tough. Teaching them how to handle that when someone expects them and less of you.

He was in his strength training class. You know he's taking easy classes right now. He was lifting wrong. And the teacher came up to set a corrected him. And Nathan walked up to one of his friends and said why did not anyone tell me?

This whole class of jobs has been seeing me do this wrong all semester, why did anyone not tell me? And is when Carson said to them, well it is because you are deaf and they think you are dumb.

Nathan took that on the chin, he told me about it. In we did not know about Carson, Carson is a really nice kid. But he's a little socially awkward, so I don't think he realized, sometimes you can be a little bit too Blount in that situation. But Nathan has learned people are going to underestimate him and have lower expectations of them.

We have done our best to consistently keep those Hi, unless it is band and we got schooled we got schooled on that one. Starting from a young age, probably from the time he was ten. Our mantra it has been you will not be an adult living in our basement. That is not off the table. You will grow up and get a job you will be a fully functioning a gel and contribute to society.

He is working towards that goal right now. He did really well getting into college. National honor Society, honorable, he did that, he did all of that on his Own. You guys are here all about research EHDI is nothing if not research-based.

If you are not sure, and want to ask somebody, they will put you in the right direction. The number of times I have said to someone, you can laugh about my stupid question just wait until I cannot see you. Or sate you note this might be a stupid question, but we have a rule in our host is no such thing as a stupid question.

Because he does not know what is missed. It may seem silly the things that he asked, but we will always take the time to answer. And when you are starting at ground 0, like we were, and we knew nothing. There is no stupid question.

It is all in the pursuit of knowledge. We have been fortunate in my home state of Nebraska the deaf community there is very kind and welcoming. They recognize the effort that I put in to try to learn ASL. And it is not good, it is not pretty.

No one has ever laughed at me, which is so sweet and so just wonderful. We, have the sign program with hands and voices in Nebraska. And we try our best to provide good research and resources to our parents.

Too that end, we are in the final stages of finishing a resource document, that has compiled, all of these questions that parents have, and research or a link to a resource. So we can copy it and paste it right to an e-mail to a parent.

Whether that is what if the difference between I ever seen how do I prepare for an IAP meeting. How do I deal with family? How do you define family culture? The list goes on. I think the document is, I don't know how many pages?

It is long, it is long. But we have made it in a format that is easy to add or delete resources. We find her once or as length become obsolete. Because we want to get good, free resources, that are accessible to families into their hands.

Failure, I, I love what these two gentlemen say pick what you think about them personally what they have to say about failure, wonderful. Failure is an option here. If these are not failing you are not innovating enough.

That is from Elon musk. And when you don't know what you are doing, and you don't know what your child these, because the need is so unique. We just kept throwing things at the wall until something stops.

This is something Nathan has discussed as he hasn't gotten older. And as he is age. He has said, mom, I remember you being a try hard when you were little. You always trying new things. I said yeah, I did not know what I was doing? I was trying to figure out how did you learn. How did I need to discipline the child who literally does not have to listen to me and does not have to see me if I'm trying to sign?

He would flip his devices off, turn his back, and shut his eyes. How do you handle that? That was not in parenting classes or books that I read. Or as an adult getting ready to have children what do you do? Trying to figure out to navigate the process is tough. Took my we have had a lot of failures. We trying sign exact English that did not work. We tried total communication that did not work.

Learning ASL, and we really struggled with that. We finally landed on pigeon. Because we could not really understand the grammar structure and the syntax of ASL pick and we did try. But we landed on pigeon. So I assigned to him when he does not have to is device on.

He will voice to be back, we try to get him to use islands, but it is not for him. Ultimately he gets to decide what is the right decision for him. And that taught us as parents to let go. Like I think I know best pick up but we don't necessarily know best.

Failure is only a bad thing if you did not learn anything. I say this to my kids all of the time. They said I am scary when I am mad and worse one of disappointed. Because typically when I'm disappointed is because I've made the same mistake repeatedly and have not learned anything from it.

The other mistake is not okay, because you have learned nothing. You have learned nothing from this. So continue, continue to fail. Fail forward, as they say. And treating them as an equal against this is something that I have been guilty of as a parent. And my husband called me on it.

It was, kind of mad. Calling me on it. Because usually I like to think that I am right. But, we had chores for our kids. Our daughter is 18 months older than our sun. We center up to do chores somewhere.

We were living on a little farm at the time. Actually farmers laugh at us, three and have a can switch chickens is not a farm. But I thought it was. We had sheep, turkeys, and there was like a whole thing. They had the chores they had to go out and do.

One day, Jim pulls me aside, he says Lydia was doing his chores when she was Nathan's age? How come he is not doing his chores? Because he's little, and he is deaf. He's like no, no. He is perfectly capable of going out there and doing these things that she is doing.

At the same age. So that was a real, eye-opener for me. That I thought I was doing a good job as a parent and I was not being as equal with the kids as I thought I was. So, since that we've done a good job of keeping expectations the same. And he will Lydia was expected to have a job soon as she was able that was babysitting and detest link. So since Nathan was of age 13 at the time 22D hassled that was young. He got a job of detest selling and mowing lawns.

He continues to hold down a job. He is supposed to be at work today. They are teaching him how to drive a semi. Yes, he works power washing tractor-trailers. And they are teaching him how to pull the semi's just the cab into the truck bed. And I just, I just don't think too much about that. But he has not hit anything. And he has been accident free for a year now with his driver's license.

So we are good. So those other jobs he's expected to have chores around the house just like everybody else. We expect our kids, not to be the best at the things that they do. What to do their best. If they are doing their best, they are going to improve and they are going to do well.

We learned early on that success does not always mean coming in first. You know he got into those honor bears he was first he was not first year in any of them he was out last year. The fact that he did it that was success. And we are incredibly proud.

And then caring we have to be encouraging and truthful. My kids know when they are good at something and they know when they are not. We were never parents who gave them a false impression of their skills and talents. So, we are not an athletic people. At our house. We encourage athletics we encourage participation. But we are not going to go to state for anything I don't think ever. And that is fine.

He knows he is good at other things. He is very good at interpersonal skills. This kid to make relationships and friends like no one I have ever seen. The diversity of friendships that he has, that we set that expectation.

You are going to make friends you will have friends. Even Carson, who is so incredibly Blount, he was at our house on Saturday. In keeping our house open to that. Letting them know that they are not a mistake. And I have never once thought Nathan was a mistake. I thought I was the mistake.

That he deserved a better parent. He deserved to have a parent that was more informed. More well educated. And I came to realize that I needed to love him, more than I feared my shortcomings.

And, that is where that caring you can dig down deep and be brave. People, go into those meetings, and tell SOP where to go when she wants to dock your child's intelligence. I almost sent her a copy of the ACT cause. The standardized test scores because man I was mad.

Even 12 years later I am still burned that she would say that about him. Finding the strength and interest in pursuing them. When they have an interest in something that maybe they don't have a real affinity for. Finding something else I can replace it. So we have been good at standing back and watching our kids come up maybe this is not there thing but this is. Let's guide them, you know, in that direction. And caring enough, to make them mad. I think that has spent the top one. I know you are upset, I know this is something that you don't want to hear.

I am going to tell you anyway. The kids have learned now, everything that I do has a purpose, so if I asked them to do something. There is a reason picked they used to question me about that like why do I have to do this? And now they have learned okay mom has got a reason to do it. Just do it there is a reason.

Being tough, getting back up when things get rough. Some of us had really bad news. We went into the same meeting and we dropped the bomb. We were going to be homeschooling. Because we thought he needed more one-on-one attention.

Again, that was me, caring more than I feared. And we were told by the audiologist, do not do this. We are telling you this is a bad idea at this is the worst decision that you could possibly make. He does not lead less school he needs more school. He did does not lead to less socialization he needs more of it.

He does not leave less time with peers he needs more time with peers. And we said that we tried everything that you told us to do. We have a 6-year-old, who is nonverbal. Who has very little language. Not signing because you told us not to.

Who is not speaking intelligibly. And, that is more than this school district can provide. Will be called the school to set up services because we are in the process of relocating, we were told and I quote, we do not do deaf education here.

It took us 12 months of meetings and having advocates come in and phone calls to the deaf commission. Phone calls to the Nebraska Department of Education to get a deaf educator work with in one day a week for 45 minutes or so we asked for.

I said I can't do worse than this. We went back to the same group of audiologist, a different SOP, and a year later, and they told us. Whatever you are doing is working. In the SOP said when I found out when you were going to homeschool I thought this was going to be a, like the worst idea I have ever heard. And you did it and made it work. I take and eat my words.

That was the most satisfying thing in the world to know, that we had done what was necessary for him. By doing what others have told us should not be done. And couldn't, could not be done. And behold schooled him for five years and got him back into the school system.

We handed him a kid who was ready, who can be understood by his peers, who did very well academically. In school. Being of afraid of reality of the work ahead, I was told, when he was a baby. That you know, we will give him these cochlear implants and by the age of five who be all caught up. It is a miracle technology. And I thought great, I see you laughing. I see you laughing.

It was an absolute lie. Maybe it works for some families it was not a reality at all is not how it worked we struggled and struggled for language, and we taught every single word every single word had to be direct instruction we taught him figurative language, we taught him how to socialize, we went through if you never heard of hidden curriculum we went through that.

Every time we went through into a new situation, we would have to stop and think. Okay what is the potential issue here? What if, what if a battery fails? We have to have a backup. Back on communication. Which is why we continue to pursue sign language against the advice of people that are around us. And we worked.

We worked and worked. It was, progress for a really long time was measured in inches. Does anybody know the film Shawshank Redemption? Andy Dufresne, with his little rock camera. We are little bits at a time little bit at a time learn a new word a day. I would keep a list of words that he knew. Because he knew so few. That that was my motivation to keep going. Like we added another word today. It doesn't sound like it's supposed to sound as language and it has meaning. He added a new sign today and we put it on the list.

So we knew would you keep going, but it is hard to take Knox and get back out. I have seen kids be horribly me too my son. And you have to just take a minute, be mad, and keep going. Nathan has those moments too. Where there are times I just have to be on the receiving end of his upset and frustration.

We always tell him, you can have a minute, you can have a minute for this, but then let it go. So you are the perfect parent you really are. You are whole, complete, persistent, and you have high expectations.

You do your research, and if you are in Nebraska we can help you with that pick you are someone that fails you treat others as equals, you are caring and you are tough.

Thank you so much for your time. I appreciate you listening to me today. I did include resources on the back. These are some of the resources that are on the resource documents. And if you are interested in that, we would like to share it. So if you e-mail me and I will give you that. It is a living document. It will grow and it will change as we acquire the information. You have any questions or comments? Yes?

>> One of the things that I always wonder about with other parents. Those same experience right? Is when you are having sorry, when you are having this conversation. Because you have to have it every step of the way. So when you are having that conversation to providers, teachers, how do you get them to understand that they are also breaking the law without pulling your face back and screaming wildly? That's a best way to put it.

>> In what context?

>> Just under like access to language, trying to get the resources in the school system set up. I live in a Metro city I live in Memphis. However you would think it is a rural area where there are no services to exist.

>> We, we fought for an entire year. It was hours long we would be in an IEP meeting for 2-3 hours. Yeah, I mean, it is frustrating. And we kept making calls. I would make calls to the Nebraska Department of Education. The commission for the deaf and hard of hearing. They sent advocates to two of his IEP meetings. I read the law. Nebraska State education Law special education law. I read through it in the fine print pair

I finally I told the superintendent who was in the meetings. That you either provide direct services because I have proven that they are available with one phone call away. For when I file my formal complaint your name and your name alone will be on it. He said I'll make the call tomorrow. And we had services the next week.

It was literally one five-minute phone call. So it is so frustrating because I knew that was all it would take. That it was, we have a tradition of doing things this way. Your tradition is not law. This is the way we have always done that.

>> That's not a lot I have not seen that anyway?

Yes it is.

>> I just want to say thank you so much for sharing your story. You set a great example of persistence and not high expectations of you kid. Thank you for sharing your story.

>> That's a second person is going to make me cry today. I do my best to not cry. But yes. We are very, very proud of him.

>> Hi, I am to me. I just want to congratulate you. For being brave, and being courageous. I have a son who is college age, and I get emotional. College age I get emotional. It takes so much persistence, courage, stepping out of your comfort zone.

On top of that, here you are presenting at an annual conference. Where we can just sit here, and no, you know, you know we are not alone. But thank you, thank you for standing up. And sharing your life experience and journey. We appreciate you.

>> Thanks that means a lot. I told someone yesterday I've been imagining an asteroid hitting the hotel for last couple of days. Because I hit submit five months ago on this immediately regretted it. Who am I? But I think that is the point. I am not special., I was chosen to gifted with this child. I believe we are chosen to do this.

Not everyone gets to do this. It is something that we really do get to do. So, I want other parents to know we are way more capable than we think. And we can do more than we ever know. And I'm trying to set an example for my kids to push themselves and do more. So I'm glad the asteroid did not hit.

I hope that you go out here in just motivated, in knowing that, we are all very capable. Thank you.