>> Hello my name is Mary. I am the room moderator. This presentation is called Deaf and hard of hearing engagement in EHDI and early intervention systems. You have any questions I will be seated in the back. Okay. Thank you.

>> I'm trying to advance the slides here but I'm not able to do so. Is there someone who can help me with that? There we go.

>> We thought it was over there. But I think we are going to be in a different order. But let's do introductions hello I'm Julie and I come from California. I am one of two coordinators of the EHDI system. Started before I was a PI. Then I transitioned, Sherry is my co-coordinator, but we will get into that later but for the California Department of Education CDE. And I am a program assistant and now I am early language and education program consultant. At CORE which is an outreach for schools for the Deaf directly under CDE but I will go into that later. I'm very happy you are here today to learn more about how EHDI benefits from Deaf leadership. Take it away.

>> Hello good morning. Can everybody see me. I'm a little bit high challenge. I can try & a bit above my head. My name is Sherry Farina. I am the CEO of Norcal services for the Deaf and hard of hearing at the community-based nonprofit organization. We are the only nonprofit that runs the EHDI system in the United States. And we are outside of the big system. We work with obviously all components but we are not technically housed in there. Our program is called Leed K family service. Early start referrals. And the manager of that program is right here. Cheryl. Welcome to you.

>> Hello everyone my name is Karen Hopkins. I am from Maine. I'm the executive director of theMain center for thee Deaf and hard of hearing and I'm the person who wrote the EHDI grant for the Maine system. And also the EHDI coordinator for our state. All right. How many people in the audience today are Deaf or hard of hearing. Most of you? or almost all of you? that's great. So we are here to talk about two programs. The Maine program and the California program. The only two states that are run by Deaf people and we need more of our programs to be run by Deaf people can some of the co-presenters share, I thought so,

>> I tried to make Sherry do it, but anyhow I worked as a PI and I was the only one in the CDE system the California Department of Ed, and I wound up explaining to all of these higher ups, people who really didn did not know anything about Deaf babies, children with hearing loss and I wound up explaining all of this while other people ran the program. So I went to Sherry and I asked her to please apply to be the CEO of this nonprofit and CDE could partner with her as the leader. She could implement the EHDI service within the community and her first response to that was Ono. Oh no. Well I said why not. And she said because it is so much work for so little money, which is quite true. But what could I say?

So I began writingThe next grant because we obviously needed the money from CDE. At that point, Sherry came to my office. She came to my office to meet with my higher-ups. And that higher up had forgotten to get an interpreter for the meeting that day. And it was the second time in a row I believe that the interpreter had been forgotten. And she lost it. She was pissed. She said the grant, is it still available? I said you know it is. We've got a month left. And at that point for two weeks we stayed in front of the computer and that birthed the lead K family service as it is and we are now in the third year. We are starting our fourth year quite soon. Did you want to take it from there, Sherry?

>> No. No...

>> So the reason that I wrote our grant in Maine six years ago was because we were seeing some change in leadership. At the same time, HRSA decided to add family priorities and Deaf and hard of hearing engagement so the EHDI teams that I'm not really sure how to do that. Most of them were hearing. So they came to me and my response of course was thank you for asking. I was surprised to get that from my state. I was happy to help to write the grant. Now keep in mind I had never written large-scale grants before. I had gotten some small ones but I didn't know how to write a grant of this size. So I worked for two solid weeks, putting my ideas on paper, thinking about families, thinking about Deaf leaders and what would be most effective in the state of Maine.

Over the course of two days I show that off to some of my colleagues. Some of the people in the community to see what they thought was going to work.And what was not going to work. And it was really through this interaction with the community that I pretty much on my own was able to get this program up and running. You know, if you never start something you are never going to finish it. It's never going to happen. So I figured we might as well try and see what came of it and it did happen. I think it came from a place of being humble. To admit people from my state, hearing people, to admit they didn't know how to serve Deaf and hard of hearing people and that really is a benefit to the Deaf community. That is why we are here today to share some of the lessons learned as Deaf leaders in the EHDI system. Who is going to go next?

>> I can. This is what we do to make sure that Deaf and hard of hearing people are in the system. You have to take a leadership role and writing grants, partnerships, Deaf schools organizations, whatever state agencies that is what Sherry and I did. We partnered with the Deaf school as well because we as Deaf leaders did what, we do what is called Deaf community capital wealth, cultural wealth. Sorry. So we know that cultural wealth is the capital that we have to offer. So we knew that that could benefit Deaf babies in the long run which is what we could bring to the table.

>> Okay so I can see more about that. So there are seven critical DCCWs... sorry, make that eight DCCWs. Obviously language breed language benefits us. It's a natural language. Next education best practices teaching one another. Aspirational, role models, Deaf role models, coaching, networking. Bringing in Deaf adults to make children and families feel operational. Resistance. If we see orders in the system we know how to address that and advocate for ourselves and our needs. Parents and children are learning those behaviors from us. They are learning how to navigate the system and how to oppose oppression.

Last night we saw Deaf space as a P we were networking and getting to know one another for this is happening in different pockets all across the states.

Navigational capital. How we live every day in a world that is designed for hearing, so we know how to get a latte from Starbucks as well as get a college degree. How to get an advanced degree. We know how to raise our children. We know how to have a family and all of these skills are important. All of them are informed by our trauma, our experience, our language deprivation, our social isolation. Our fighting for identity, our struggles. And all of that can be passed generationally. We can break the cycle. We have the power.

>> I think that slide was just explained.

>> In a nutshell. Sure.

>> So, you see all of these badges from, and this is Karen's badge. Recognizing all of the areas that Julie just explained, the different areas of skill. The badges just grow and grow. She is a state EHDI coordinator, she is a parent. She is a part of the consortium, she can sign. She is a presenter, she is part of [indiscernible] so there are many things that you have many areas of expertise and sometimes we don't realize what we can bring to the table and I think that's what Julie's point really speaks to. So hearing allies are critical. In this fight. In this work.

>> The system operates in silos. So when it comes to grantmaking you know there is a part of education is a standalone. The Department of Health care services, developmental disabilities, everybody is working, DSS, whatever everybody is working in a silo. So, by writing a grant that really required collaboration we are not operating in silos anymore, we are working to get up and we refer to each other. We have representatives. We are all at the table. So when the referral comes into the educational agency, they understand the whole picture. And our parent mentors are at the table as well. Deaf coach, a coordinator who they can contact when they're ready for the information that is also shared. So what you see here, the lead K family services program and what our grant is covering is the one, three, six. I think everybody is similar with one, three, six, the goals of EHDI I don't have to rehash that, but we have added another goal for six and another goal for nine, and it's all about connecting with parent family mentors and Deaf coach enrollment. The reality is that many parents are overwhelmed with too much information. And identification. And often, for Deaf coaches are not really brought into the picture until the child is one or two. And really we should be by their side from the very beginning. But it just depends on how fast the local educational administration or agency accepts our services and put that into the pipeline. That is really key.

So here on this slide you can see some of the organizations that we partner with to make sure the children and their families get basically every part of us. Everything is covered. So we work with four different state departments. Parent organizations. Hands and voices in California. And we are also working with the Deaf schools in California. Our hearing allies or partners as well for the options schools. and California education for the Deaf and the Association for the Deaf in California so there are a lot of community partners as well.

So when we do family engagement activitiesWe are all there. All of these organizations you see, logos on the slide are there. We hosted a huge family engagement activity on Saturday. Seven local agencies in California, sorry seven places in California simultaneously. It was an all day 10 AM to 2 PM event. It was the same day, the same time in seven locations throughout the state. And it was for families of newborn or slightly older Deaf and hard of hearing children so they showed up to whatever their location was closest to them. It is not really statewide or nationwide. It's really a local impact because parents want resources in their local community. They want to see and know who are the points of contact and who are maybe the audiologists or what school might be nearby or their private schools or public school options. In public LEA reps are there. The Deaf school sent reps, the DSS had a table, booth there so basically it is all community resources at the regional centers were also involved.

And obviously the heart of our work is storytelling. Teaching parents how to read stories to their babies. Developing literacy skills for birth to five. So they are kindergarten ready. That is the heart of our program.

And that is also included in our Deaf coaching programs. It is an opportunity to meet Deaf coaches informally at these events and understand what things are about. Parents do not automatically understand what a Deaf mentor doesn't sign up for the program. especially from different cultural backgrounds they may not have experience. We have a large Latino population. And the Deaf word in Spanish, sorda, is not viewed in a positive light, it has negative connotations and that applies to other cultural backgrounds as well.

So this is just a chance for parents very informally to meet each other. We had activities for the kids.Last year we had almost 1000 families come to this event.

So, clearly quite successful.

So I would encourage you to copy the model in your states. Your family engagement activities. Maybe they can happen in one day. In one place. We had to do it in several different places but it clearly had an impact in the families in our state and everybody being in the table, everybody involved is very beneficial people leave with a positive feeling and they left also with free books. We had a swag bag for every kid.

Can I add...? now you understand why we are exhausted. We did all day events and then we came out here. And then all the walking we have to do here adds to the exhaustion.

> So ourDeaf coach model works this way. We passed a law in 2015 called SB 210. That law requires teachers to administer language milestones, to assess that. There is an advisory committee, and ad hoc committee that wrote of the information. After collecting information from all sorts of areas and it became, regardless of modality, regardless of English or ASL being used, this assessment is used. It's a universal application for this law. So we are not trying to segregate or see disparities. Whether people are using ASL or oral modalities. We are just looking at language acquisition. That is key. So it really doesn't matter what language a child is acquiring. They need to be acquiring language.

Either one language or multilingual families or assign as well as spoken English. So we have a parent profile pamphlet and every teacher is required to give to new parents, newly identified parents when they start their services. So the parents understand from the get-go what acquiring language is and that for Deaf babies it doesn't happen the way it happens for hearing babies who have access to sound and incidental learning. You had to give input to be able to receive any output eventually.

So the importance of language milestones. If a child is not meeting this language milestones there is an opportunity there. For the team at the IEP for example, for the team and parents to talk about the importance of learning language. Regardless of other disabilities they may have. How do they learn. Maybe they learn in a different way. And we have to address that and it is important to document all of that from the beginning. And work on the strategies. So that is what the law requires.

So our Deaf coach model, they go through training, a training curriculum that we got via another grant actually. So they go through the training. Obviously we do fingerprinting, background checks etc. Because we're not going to send them to work with families just as you would do in your states for anybody working with children. Their expertise is valued. And they bring that to the table when they meet with educators. So the teacher will share what language milestone is being worked on. And the Deaf coach then has the information and can develop activities for that specific goal.

And it sort of goes there. They meet with families whether it is weekly or couple times a month what is written into the IFSP. We subcontract with seven agencies. For Deaf coach coordinating and as agencies hire their own Deaf coaches in their areas so we are not doing all of that interviewing. We are working with these other agencies but we are of course making sure there is consistency throughout the program.

I don't know that we have so much time to go on.So perhaps if you have questions I'm happy to answer them but I will hand it off to Karen.

>> The image that you are seeing here is a diagram of the Maine system it looks complicated but it is not that complicated we have the CDC and HRSA grants. We have the main department for the commission for the Deaf and hard of hearing and we have than the general state system. All of which are in partnership to develop connections to work together, to serve our children.

I am the kind of glue in the middleThat holds everything together, that dotted line at the top connecting the federal partners to the state partners. I think that is really important that I as a Deaf person and connecting hearing people at the federal level in hearing people at the state level for the purpose of supporting our Deaf and hard of hearing children because I'm a visible Deaf person in the state of Maine and I can encourage people to work together. I think it is really important that we commit to going to meetings and bringing Deaf members of our communities and parents from our communities in triads to present about the things that we are doing in any venue that we go. In this way we can make sure that each of those stakeholders remains really visible. And we can continue to earn respect for Deaf people and families and model the type of respect that we have within our program.

We developed a website together. That was a fascinating process to incorporate different perspectives into developing this website. We have hospitals, audiologists, early interventionists and so on. The timeline of the EHDI service portfolio that are all represented here in this website. And you can see that each page has a translation into American sign language. Again for the visibility of that language in the Deaf communities so that if anyone uses ASL they can come to this website and get information in that language.

What is also important in the design of that webpage is that each page has a different Deaf person. We want to make sure that we represent the different ways of being Deaf which is a core tenet of the EHDI program. We want to explain hospital process, early intervention, interacting with medical staff, and we hope that all of those providers will use this website interface with parents. This is something very new so we have not seen a lot of uptake quite yet but we are working to get the word out.

We have a lot of Deaf leadership in the state of Maine that have been engaged in this program, which is really great. Through Deaf mentors, that program has been very strong. Guided by your side, two hands and voices, through our early intervention processes and meeting with families early on in identification. We established a formal agreement for providing these services to families. For part C families. We are required to meet in person. We try to meet early with the team of four or five providers. To address some of the issues, the questions that a family might have early on. With a newborn.

Families can refuse to have that meeting. But not many do.

Previously we asked families if they wanted to meet a Deaf person when we were framing this meeting. And a lot of families didn't know why they would want to do that. Instead we have now said oh, I'm going to be coming to this meeting would you like to meet my Deaf friend or just my friend? I'm going to bring somebody. So this has really changed the framing of this person who might not be familiar to them and who has helped with uptake. We have some committees that are advisory to the process. We have feedback group. That involves both Deaf adults and families to tell us what is and is not working very well. And as Sherry mentioned, the events that we have put on have been very powerful. The natural interaction between people who might not otherwise have the chance to meet each other for families and children to meet Deaf adults, for them to mingle and just have fun in a casual environment really works. We have seen the results of that. We have seen people with different language modalities, spoken language cueing, ASL get together and to learn from each other at these events.

We involve both types of programs, Deaf mentors and guided by your side into the EHDI model. We have a certification process. There is an acculturation of mutual respect. And this all happens through training. We invite Deaf adults to become part of the program. We pay them because we recognize their time is very valuable. And we prioritize them within our system. So this is similar to some of the other comments that have been made. Seeing as though we only have two minutes left, is that right?okay. Time has gone by I suppose we should wrap up.

>> I could address the first question. Not only Deaf professionals within EHDI but Deaf leaders. So you know, the phrase out of sight out of mind and that truly applies here. Taking a leadership role in your communities so that you can be seen. Make yourself a permanent seat at the table. Instead of asking permission, take charge. And you will be amazed at how, people got used to us being everywhere all the time. At first it was unsettling. And not just one of us, but we were a pair. Two Deaf ladies and it worked pretty hearing stakeholders began learning from us. They began seeing themselves as partners with us and things got better. They began checking in with us. They stopped making assumptions. We became more and more the go to when decisions were being made at the state level particularly with SB 210 that was mentioned. The language milestones. We were empowering people with knowledge that families were having these Deaf babies and they needed this type of leadership in the state. From 0 to 5, so that they were literacy ready at age 5. So emphasizing English and ASL equally at least one being a foundational language, not a methodology. Although methodology is used for spoken English. There are methodologies. But the languages are ASL and English. Right? And as Deaf leaders we were able to represent that.

>> Absolutely. It is important that you know that SB 210 was our lead K bill. So I'm sure by this point many of you have heard lead K as a term you've heard legislation happen in other states now. Let's see those hands. Fantastic. So that bill became basically the model for this. So lead K, do you remember what it stands for question does anybody know. Language equality, people, acquisition for Deaf kids so they are can garden ready. That is the K part. So we got a HRSA grant and it was called lead K family services. That is with the program is and as I said we work with many partners across the state and allies. Many of you are experts in your fields, but you perhaps do not know that there are other experts in other places. So being able to speak out, being able to figure out who should be at the table and how Deaf and hard of hearing adults in your communities can be involved so you as a Deaf and hard of hearing person in your state if nothing is happening take the lead and made it be your terms and your turf.

>> I think our time is out.

>> Can I just say one last thing about strategies? Your Deaf organizations, your Deaf schools apply for EHDI grants within your state. They cannot August, September. I am working with CSD currently with a grant writing workshop to both of us Sherry and I together so please keep an eye out. Okay.

>> Thanks everyone.

>> Great.

>> Thanks for coming.