>> Hi everyone. My name is Liz Watson. I'm the room moderator for you guys, so if you have any questions, just find me, I'll be in the back. I do want to point out the fire exits. One back there, over there and off to my left.

I'm happy to introduce you guys to these ladies. I will actually not be introducing them. They will be introducing themselves. This is developing a coordinated statewide system of earliest interactions for families. If you have any questions about the room, just let me know. Thanks.

>> Oh, boy, this is not going to work. Too short!

Can you guys see me? Yeah? Okay. Glasses will help. All right.

I'm going to shut the door so I can see a little better.

Okay. Good afternoon, everybody!

Thank you for coming!

It's so nice to see such a great group of people that are interested in this topic.

So we are going to talk today about how you can think about developing a coordinated statewide system of earliest interactions for families in your state or area.

Hmmm ...

We thought we would give you a quick overview of what we are going to talk about today just to kind of frame the afternoon for you. Will we are going to be together for a few hours. We are going to do some talking. We are going to break you up into some groups and you'll do some activities so hopefully you're not sitting all afternoon after lunch. We are going to talk about family-centered in general, overview, what does that mean. Family engagement and empowerment. Statewide coordinated systems. We are going to give you some practical strategies for identifying and including your stakeholders in your state. And we are going to talk about collaborative reflective practices.

So a little bit about who we are and why we're here and then we want to know who you are and why you're here and what states are represented today.

If you can take just a minute and get this SLIDO app on your phone with the QR code, we are going to use it a few times this afternoon so if you wouldn't mind, it would be great to have you involved.

Is there anybody that does not have a phone? Hi!

Like old home week here, I get so excited to see everybody.

Is there anybody that does not have a phone with them?

>> I didn't bring mine.

>> Do you want one?

>> Sure.

>> I do believe that you can have multiple answers, so if somebody was next to somebody else, I think you can have multiple answers for some of them so it should be okay.

>> Okay. Everybody have it?

Thumbs up!

Okay. Great!

Great great!

Let's start with Claire.

>> Adjust this a little bit. Good afternoon everyone!

My name is Claire Jeffers. I am here as -- I'm a mom to a three-year old. My son was born profoundly Deaf and our family uses both ASL and spoken language to communicate. I am also -- I work as a writer and a public relations professional.

For the Maine educational Center for The Deaf and hard of hearing, Governor -- in Portland, Maine, and I'm also an ASL student at the University of Southern Maine.

Thanks for having me today.

>> Hi everybody. I am Amy Spencer, early intervention and family services coordinator at the Maine educational Center for The Deaf and hard of hearing. I do serve on the Maine newborn hearing program board and the Maine interagency coordinating council, which really does help with some of this coordination of a statewide system. And I'm an active member on the HRSA team that we'll talk more about, the earliest interactions Maine and I initiated in and continuously evolving exploring language and opportunities process for Maine. I do live in Southern Maine and I love exploring with my little family who I do miss dearly. That's me.

>> I'm Ken Hopkins and I'm the Executive Director of the Maine educational Center for Deaf and hard of hearing in Southern Maine and also principal investigator of Maine's HRSA grant. Many different hats are on my head all the time. I'm author of Maine' s Memorandum of Understanding for Part C, I'm a Deaf adult, mother of three. My youngest is also hard of hearing. I'm a Doctoral student and researching the process that you're going to learn about today, so we'll be interested to get more information from you. And my focus is really empowerment and how can we empower families. And I'm on a lot of different boards and committees and membership committees and just super involved in everything and anything going on. Our disclosures.

So we wanted want to know who is here today. In your app, if you can say what your role is, are you a parent, are you a HRSA grant writer, are you a superintendent of the School of for the Deaf, who are you and what state are you from? Those are our two questions.

We are going to go back and get the QR code up again. There you go.

For anyone that just joined, the QR code for the app, we are going to do some interactive activities, so if you want to get that on your phone, that would be great.

see, we have a lot from Arizona and Colorado!

West Virginia, DC, South Dakota, Connecticut, all over the place!

Fabulous!

Think about who your neighbors are, maybe.

Okay. Second question.

The second question is: What's your roll in EHDI? Audiologist?

It's helpful to see who's in the room.

We can try to make it match you as much as we can. Lots of EHDI coordinators!

My team, my colleagues are here.

Audiologists.

Okay. Thank you. Thank you for sharing and giving us a few minutes of who you are.

A few more coming.

When it's not your computer.

Today's objectives, which I think you probably read if you're in the room. You probably took a peek to see what our goals are today.

And we are going to start by talking about developing a foundation and shared understanding. If there's nothing else that I've learned in my 30 years in this field is you and I probably don't have the same definition of a word or a thought or a concept. So one thing that I love to do is develop shared understanding. Before you can go on, before you can talk about anything, is our understanding the same? So thinking about family-centered early intervention, I'm curious what that means to you and what it means to me. And if we're thinking the same thing. So think for a moment on what words stand out to you when you think of family-centered early intervention, and we are going to use the acronym FCEI.

You can put that in your app and we'll take a look and see what people think.

Family's big. It's important. Support.

Family-centered. Partnership. Family first. Information. Collaboration. Parent-driven. Language acquisition. Flexibility, yes. Engaged. Partners.

Family choice. Respect. Providing support. Integrative, that's a good word. I would say I agree!

Anybody disagree with any of those words and feel that we don't have a shared understanding?

Amy, Claire, do you agree?

Okay. Let's move on to the next one.

So thinking about empowerment and family empowerment, what words pop out to you when you first think of that word?

Encouraging, knowledge, a lot of people think knowledge is important, informed, education, choices and opportunities, advocacy. Great words!

Listening first.

Unbiased education. Team.

What do you think? Does everybody agree? Is there anybody that wants to challenge this definition?

Agree? Now, coordinated systems, because we're talking today about developing a coordinated system, what words pop out to you when you think about a coordinated system?

Try one more. If not, we'll just call out for some ideas.

Okay. The who has some ideas for coordinated system? What does that mean to you?

Here we have collaboration is the big word. Communication.

Seamless. Equity. Partnerships. Unity. Equitable. Expertise. Communication. Collaboration is the big word. I would agree!

Anybody disagree with collaboration is the big word for coordinated systems? You can't do it without collaborations, right? Okay. So think for a minute about coordinated systems. And and an example of that in your state and is a statewide organization of EHDI and a family-centered intervention,s is it possible in your state? If you can turn to the person next to you for one minute and have a very brief conversation about what that would look like in your state, if you can think of an example.

Okay. Maybe take another minute.

Anybody want to share? I would love to hear from somebody. Amy's going to come around with a mic. What do you think? What's an example of a coordinated thing that's happening in your state?

>> I have been around forever and, yeah, Wendy held up her hand and handed me the mic so I just wanted to point that out to everybody. Coordinated systems, I have been doing this for 25, 28 years, and I think some some areas we've done a good job and now it's falling apart. COVID had a role in that as far as screening because early childhood screening we were doing a lot of it and COVID happened and nobody was doing any screening anymore and it hasn't started up again. In some ways we have to restart that system and as we restart that system, there's new players and some of the new players don't understand all the coordination of referrals and who does the next step and how to get families to the next step, what the financial assistance is available, how do you access that assistance. So we have the opportunity to improve that coordinated system, but at the same time we had a coordinated system that fell apart and we are rebuilding it and hopefully rebuilding it better.

>> I love that you said reset and start again. That's what you have to do sometimes, right, when things aren't working? That's great. Thank you for sharing. Somebody else.

One more?

>> Hi, my name is Kelsey, I'm on the Kansas Commission for Deaf and hard of hearing, and I'm also an EHDI stakeholder and parent of Deaf children. As far as the state of Kansas our EHDI committee has a great relationship with the Kansas School for the Deaf and their outreach program is wonderful and the Commission as well is working together with everyone to improve our services that we're offering throughout the state.

>> I do love Kansas' system. It's a great outreach collaboration, yes. Thank you.

Okay. So we are going to talk a little bit about our EHDI system in Maine and kind of use that as an example to kind of give some ideas and suggestions that may or may not be helpful in your state, but before we get into this, I would love to know what's the biggest issue in your state with collaboration and why did you come here today. I'm guessing there's something you want to know, something that you're struggling with in your state, in your community. So if anybody wants to share, if you have a burning question, to make sure that we try to capture that for you.

Hands up.

>> We're in Colorado and our system is a little bit -- I'm going to use the word broken -- in that our State Department holds all of our referrals for newborn hearing screening and very limited people in our state actually have access to that information, including our EHDI program, so they don't have access to it, which makes it really, really hard for all of the players to make a cohesive, supportive environment for families when they come in and families are getting missed. So we are making progress, but trying to figure out how to make that as simple as possible without completely rebuilding the whole wheel.

>> I'm in Kentucky, so welcome, I know Cincinnati is Ohio, but we're close. Welcome, everybody. Our biggest issue, I feel like, is everybody works in different silos, so we have our detection people over here and our intervention people over here, and a lot of times we don't know what's going on. And what happens is the kids are falling between the cracks and it's kind of like what you said, it's families that are missing out on the services that they need.

>> Hi, I'm from Washington State. One of our big issues is the I, the intervention and the information that families get initially.

>> Okay.

>> I'm from Illinois and one of our problems is politics kind of getting involved there so we are not sharing information the way we should, because there's different groups with different, I don't know, motivations and goals and they are not really sharing information and getting that resource to families.

>> Hi, I'm Chelsea, I'm from Connecticut. I can relate to everyone that has spoken so far, especially to the effect of the silos. But also, I feel like there's no collaboration, like we all have goals and it should be about the families and these children, and everyone has an idea about how that is best moved forward, but working together is very hard.

And I think having more open communication as well as better communication and not thinking about it just from the each organization. So working with other programs is really hard and getting everyone to be on the same team. I guess we are not all on the same team, even though we are, if that makes sense. I hope everyone understands that.

>> Hi, I'm from South Dakota. We are not mandated in our state, but it's on our advisory committee to vote on it in April, so I'm really excited about this.

But we don't have data sharing agreements between DOH, DOE, DSSS, so it's really -- and I'm new to this role, just a year, so it's difficult for me to get information to and from Department of Education to make sure these kids are being seen. It's really just a big barrier for me.

>> Hello. My name's Wendy, and I'm from Arizona. I think my biggest issue is that I feel sort of like the same thing that Courtney was talking about. I just feel like some agencies are more focused on their episode agenda and what's right for their silo, and not putting the child and the family first. I work in a pediatric hospital and it's really hard sometimes to advise these parents because I don't know what all the pieces are. And I've tried to figure out all the pieces. Asklilah, I ask herb all the time what all the pieces are. Will it's very, very challenging because it's not a very organized state in some areas, so I'm so excited about this presentation, because I really want to have a really well coordinated system so we can help the families. Without that, I feel like we don't really have the infrastructure to make sure we are consistently doing the best job for everyone.

>> That's so great. I don't know if we have magic, but hopefully we have some suggestions. And none of your thoughts or comments were surprising to me. They all were where we were and some where we still are. It's an evolution, right? I love this quote, because it kind of fits with what you said a little while ago about reset. Without continual growth and progress such words as improvement, achievement and success have no meaning.

We are going to talk a lot about that and how our system has evolved over the past 25 years and where we're going and where we think we may be going, but who knows where we're going. Amy and I were chatting about that a few weeks ago thinking this is kind of going pretty good, but we thought 10 years ago it was going pretty good and then we got more feedback, more research, more discussion, and it's evolved to where it is today. So I'm excited to see where we'll be in 10 more years. Who knows? History of our EHDI program.

So screening started in 2000. And in 2000 there was a new law. The new law said if you screen, then you have to refer. Oddly enough, there's no law saying you have to screen. But to date none of the hospitals or birthing facilities get that. Yay!

They think that the law says that they have to screen, so we'll just run with that until there's a problem and when there's a problem, we'll write a new law. That's basic foundation. Everybody in Maine, all the hospitals and birthing facilities are screening really well, and referring. Following up, right? So when we think about follow-up, that's an issue for almost every state. Everybody has an issue with follow-up, that's where things start to follow through. In the past our physicians and audiologists would give direct referrals to specific groups.

They would give a referral to the School for the D eaf. They would give a referral to the oral program. They would give a referral to the children with autism. Who was in their connection, that's where the referrals went. Sometimes physicians would say do you want to talk or do you want to sign? This was with a brand new family who just had an identification of deafness for their baby. They don't know. And of course they're probably going to say talk, right, because they haven't gone through any process. So what we had was families being siloed, the agencies were siloed, the physicians were siloed and everything was happening in its own corner and it wasn't working. I was going to home visits and just feeling so sad after I left every visit because these families had no process. They had no connection to anything other than where they were sent. They didn't have a choice.

And again, no process.

So I just started thinking about what does this mean for families. I was brought in at the time later, when somebody said maybe you should talk to this family about those options. Okay. Go in and talk about options. What our state wanted at that time was a checklist where I was supposed to go in and hand this family a piece of paper that said: Sign language, spoken language. Sometimes cued speech was on there years later. That's what we did. We handed them this paper, what did you want to do? But it killed me every time I did that, and it had to happen on the first visit per the State Department of E ducation. We were under DOE, we still are. I remember struggling and one time I went to a home visit and I opened the door and there was a father sitting there and he stood up and walked out and said she's yours.

I saw nobody in the kitchen. I went out and I held open the door and I said where is she, who is she. My wife. She's in the living room. Okay. Go in the living room, see a baby in a car seat, no mom.

I'm looking around, where's Mom, where's alma mater. Mom, finally I see in the corner in the dark Mom sobbing uncontrollabley, there's a Mom, a baby, Dad's gone and I'm supposed to do the checklist. No way. No way. Checklist went away. Sat down. Waited. Waited. Waited some more. Long story short, I was there a very long time. That mother had never held her baby from the day she found out there was a hearing difference.

When we went through the visit, we focused a lot on touch, visual, I was just commenting on what I noticed with that baby and what that Mom, and I saw the baby's looking. He kind of smiled a little bit. See this, see that, oh, his eyes lit up when you touched him. She got closer, closer, closer, finally she held the baby. We talked. The baby had a mild unilateral hearing loss.

Trauma, right? Trauma.

The baby was not Deaf and she still thought she could not do this, quote. I can't mother this baby. And you want me to fill out a checklist? No. That home visit was a turning point for me in my career, in my passion. It kind of fired me up. I said no way, I'm not doing this ever again. And so the children were being identified and we were going to these houses handing them these papers, but we weren't ready as a system. Now we had all these referrals coming in but referrals were going everywhere and families were in so much trauma because we were getting them identified earlier and earlier and earlier, but we weren't ready.

So we started working on a Memorandum of Understanding with our Part C agency. And again, at that time families were referred to one agency or another, services were provided based on who got to the family first. So if I was the one they called, I at least talked about a couple of options. If somebody else got involved first, all they did was sign with the family. Somebody else got involved, all they talked about was hearing aids and listening and spoken language or cued speech or whatever it was they were talking about, but there was no system. Services often ran parallel to each other. Part C would go in and do assessments and start services. I would go in. Somebody else would go in. There were so many people bombarding these families from different agencies. It was totally a professionally-driven model. Which doubled the burden on families, tripled sometimes. And it was a therapy model instead of family-centered.

Now, back then our agency was just starting this early intervention concept. We were not on the IFSP, so we kind of did our own thing, which in some ways was good, because that piece of paper, the checklist, I put aside.

I got in trouble a few times, but it didn't matter to me. I said somebody else is going to do this checklist; I need to connect with these families. And families were getting very, very mixed messages. Listening in spoken language agency might be saying you should always just talk, get a cochlear implant, signing is bad. Some of the ASL Deaf community members were saying don't get an inmate implant for your child, the audiologist was saying one thing and the doctor another. That's pretty common in our field for the families to find mixed messages but, again, inside I was dying. We started working on this MOU. Basically I just kept showing up at the the state agency. They didn't really know me then. It was many, many years ago. I kept showing up asking questions. Why are we doing this? Who is coordinating this for families? It's a mess!

And I talked to anybody that would listen. I showed up at Department of Ed. I showed up at Department of Health. I showed up at legislative meetings and wherever I thought I should be, I showed up. I brought it. I brought "it", meaning papers of quotes from families.

Then I started thinking I'm one person, but I need families with me. So I started bringing families who spoke for themselves. I didn't need to speak for them. At that point I was not a mother of a hard of hearing child, so I couldn't speak to this at all. So I started bringing families, and I just started showing up everywhere.

We had kind of a hard history with department off ed and the School for the Deaf and the spoken language industry, which was almost a competition which felt so wrong to me. These are families and everybody's fighting and pulling and pushing over this one family. Sometimes I felt it was a numbers game or money game or I need these families to increase my numbers. That's how it was feeling to me.

We had a change in leadership. Our Executive Director changed. Department of Ed Part C director changed, and that was my window. I said okay, now I get somebody new, somebody with no history. So we met right off, as soon as I could get an appointment with them. That's key. Watch for any windows of opportunity. Somebody changes, there's turnover, you bump into somebody in the mall, talk talk talk talk talk.

So we met a lot. A lot.

And we focused on commonalities.

We had more commonalities than we had differences. And we found a shared perspective. We understood the her role, we understood my role, we talked about the role for the School for the Deaf, the audiologist, doctor, everybody had a purpose. And everybody was so needed. But the competition was not.

So we started developing a joint process. And a vision together.

And this was our purpose that we figured out we wanted to agree on. To develop one family-centered early intervention program for families who have d/Deaf/Hard-of-Hearing children in Maine. Sounds pretty simple, but it's not as simple as you think, because visions were so different. So we often had to agree to disagree. But what we focused on was the law, the statutes. What was the law for Part C? What were our statutes? We were state funded. What was the vision or strategic plan of this agency? What was everybody's goals and how do we pick out shared things? That took some work, right, because we had to get all that data, but it was so worth it.

We saw an increase in identification, an increase in collaboration, and overall, an increase in child and family positive outcomes. This process took five years.

Five years!

So this is what we are talking about today is not quick. You're not going to go home next week and start and have it done in a week. It's like baby steps. I think we're still doing baby steps. We will never be done. Amy's going to talk to you in a little while about a process in early intervention that she really spearheaded. What's next? How is it going to change again? That's fascinating and it's fun!

If you go into this work with an ever changing mindset, you're going to have fun with it and you'll enjoy. We were feeling pretty good. Our EHDI system was set up -- our early intervention was set up that we were going to be going in to families' homes and we were the primary point of contact with Part C. We were going to be doing our process.

Now, it used to be called six visit process, some of you have seen that. It was kind of working. We had to come up with a six, a number six, because again, they wanted a checklist. And a checklist is one.

And then I told the story of that mother that was crying. I told a a story of another mother and another mother and I said I need time. We need time to connect with the families before we start bombarding bombarding them with options and choices and hearing technology and ASL and all this stuff. So they agreed and they let us do six. So we had to have all that done by six visits. And then they would move forward.

Six isn't a magic number. And Amy's going to talk more about that in a little while. That was working pretty well, but it was still not enough. The EHDI system was still disjointed. We were doing our thing that was kind of working better, but then we had our EHDI program over here that had the CDC grant and the HRSA grant. So again, there was a change in leadership and the window was opened, and HRSA was changing their priorities.

They wanted to focus on family engagement and Deaf adult engagement. So at that point our EHDI system said we don't know how to do that. We've never done that before. We focus on data. We focus on screening. We focus on education. But Kim, you do that!

You know how to do that!

Your staff do that!

You have Deaf adults in your system, why don't you write it? I'd never written a federal grant before, but when I read it, I said you're right, this is what we do, it should be here. We talked ail talked a lot about who should be doing what and it made sense. I locked myself in a room for two weeks and typed it up and we were awarded. I had no idea what I was doing with a federal grant, I had never done that before. Lots of learning and lots of need for me to learn the HRSA system and for the CDC grant to partner with me on who was doing what. So again, role definition was really important.

The first section of that grant was hard. We didn't have a collaboration. I was doing the HRSA grant and running a statewide agency for early intervention and education. They were doing the data. Again, this isn't working.

So we decided to share resources and share data and funding responsibilities and just kept meeting and meeting and meeting and meeting.

And then we made a formal HRSA team. With the team, it started with the CDC director, myself. So the CDC grant and the HRSA grant is where we started. Then we added a parent, who was also our quality improvement specialist. We added the audiology consultant, a parent consultant, and that was our team for a while. Then we knew we needed more, so we added an intervention coordinator and Part C. So that's our team today. We meet monthly. But again, this is year six for us and we just did that last year.

One more. Who did I forget?

>> FBO.

>> The family-based organization, right. We have five parents on our HRSA grant team. That's a lot, but that's how it should be. We had parents and d/Deaf/Hard-of-Hearing adults that are running EHDI in Maine.

We made our focus family engagement, Deaf role models, early intervention, developing resources, and started thinking: Who do we need to pull in to the table to make this work? At that time as well, again, the priorities were changing, so we looked at funding and we figured out that by separating these two grants in the way we did, we could actually do more, because we were focused on those areas and the grant funded a little bit of my salary, a little bit of our audiology consultant, the parent consultant, quality improvement specialist, communication specialist, audiology consultant and our FBO. The CDC were focusing on data, database, screening, but when we started to come together more, we figured out we both could kind of do both. We needed all the perspectives at the table. And it just grew from there.

And then we formally added Part C, which really kind of was the missing link to pulling it all together.

And the collaboration totally allows us to do more than if it's all together because most EHDI programs are paying the salary of an EHDI coordinator and they're paying the database. That sucks up so much money and there's not much left for family engagement, for developing resources, lots and lots of things we're able to do because the money is split. Not everybody can do that nor should they, but thinking about ways you can fund pots of money and other people to collaborate with to pull in when you create a team, if you look at your Part C, you look at your Department of Health, your Department of E, School for the Deaf and spoken and -- language agencies, they all have money. If you're pulling everybody together you're going to share the work and the resources. Again, it's not easy and takes a lot of time.

This is our current system, our EHDI system. We have the CDC and HRSA on one side and MC D/HH, which is our educational agency and we are the state deaf education agency in Maine, so we oversee everything from birth to 22, intervention, School for the Deaf, site sight-based programs around the state and outreach. That was a different focus for most states and HRSA. MNHP is our Maine newborn hearing program, it's most states call EHDI. We had EHDI and we had early intervention. We merged them together and built a community of support that was serving children in one, three, six.

So when we think about the evolution of our partnership, we got together a lot. We had a lot of meetings. What really helped was looking at the two work plans and figuring out who was responsible for what. And we identified the gaps. We looked at home births, midwife training, rural areas, those were big gaps for Maine. Maine is a very rural state and that's one of our biggest focuses right now. The CDC, Department of Health, there was one person working in that agency. She couldn't do it all alone!

So reaching out to us, we were able to offer more support, the quality improvement specialist, the parents, the family-based organization, to make it whole some. There were technology needs and we really needed to focus on our Part C collaboration and bringi ng them to the table so we had one unified group.

Thinking about our referral process, we spent a lot of time on this over the years. As I said before, in the beginning it was disjointed. Doctors would just refer wherever. Then we made Part C the point of contact, the formal point of contact. In that we were right there with them, because we had staff at every other nine sites around the state, our staff were fully embedded with Part C. But those referrals had to come from screening and that wasn't happening very good.

So when we added the parent consultant, she gives a referral to the EHDI program, and to CDF, our Part C agency. Two referrals go out and that instantly connects to us and our early intervention team who's there at the sites. Then we have triangles where if there's an issue with follow-up, one of those agencies is following up with each other, because we're connected now. So we know a baby started here, the family, and it didn't get to the next step or didn't get to the next step. So by building this unified group and sharing data and sharing the database and having Amy as our early intervention coordinator actually typing in and looking, yes, this baby had early intervention, or yes this baby was seen by an audiologist or yes yes yes, everybody is looking at the same database and filling in the gap.

Before we had to get the signed release and nobody was able to get into that database, but it made all the difference when we came to the point after building a lot of trust, that they let us into the database and it was one system.

We also give a referral directly to Hands & Voices for Guide By Your Side and parent-to-parent support and Deaf/hard of hearing engagement. Amy?

>> I just wanted to add to that, because that was a real big turning point that I feel like for that process. When I finally had access to the data system, that Maine hearing board program had and could troubleshoot things. Like if a consultant came to me and said this child popped up, I could look it up and see what's happening and make sure that they're connected to the right resources.

And I can kind of triangulate that with Maine Hands & Voices, is there a d/Deaf/Hard-of-Hearing guide going with the parent guide. So when I send in an interventionist and meet the family, they know the background of where the family is at in their process of their follow-up audiology appointments, where they're in the process of meeting another parent and that sort of thing. It really has been a game changer in not missing kids and not -- and for having parents to repeat the things already going on for them to a bunch of different providers if we're sharing information. I just wanted to add that.

>> Okay. So MNHP in Maine is the EHDI program. We have HRSA, MB -- our education agency and CDS which is Part C. What we focused on was closing the loop through ongoing communication and shared data systems. And then Memorandum of Understanding that we developed with Part C. But remember these things took a long long time to build and to develop trust with.

What we have really had to focus on was aligning our philosophy. And we had really different philosophies. But when we looked up the mission of MC D/HH, the Maine educational Center for The d/Deaf/Hard-of-Hearing and we looked at connecti ng our strategic plan to both the EHDI work plan and the HRSA work plan, we found there were more similarities than differences. I encourage you to get other agencies' strategic plans, work plans, their legal entities if they have to follow, what are their rules, and show them how you can actually help them. That was a huge, huge help to us when we said, look, we're doing the same thing. Why are two people spending state money on the same thing? I'll do that or do you want to do it? And because we had built trust, we trusted each other to do what the other person was doing when we were double doing it again.

Now Amy.

>> So as you can imagine, this was a big shift for the early intervention team in general going from us doing our own thing and then being really embedded into the early intervention Part C team in Maine. We do have early interventionists assigned to each of our nine sites, as Karen had mentioned. So we attend weekly team meetings with each of those sites. We hear about all of the kids going through the Part C program.

We are act as a consultant to any team that -- any child or team that has a child that has suspected hearing differences. We kind of consult about anything language access-related. We sit at the table and we can kind of overhear, oh, there's some communication concerns. Oh, have they had a follow-up audiological assessment? We are really there doing that and we're really tracking those kids who have follow-up audio assessments and following up with their providers to make sure those are happening and we get the information if there's a hearing difference. We do serve as the primary service provider. We have a primary service provider model in Maine. We serve in that role for families that have Deaf and hard of hearing children. We implement the exploring language and communication opportunities process.

That's really the end goal is to lead to language and communication planning for families. And I'll talk more about that.

Any child that has suspected hearing differences, we are on the team, or if they're d/Deaf/Hard-of-Hearing or have additional disabilities, but maybe their primary service provider is PT, physical therapists, occupational therapists, but we are actively on the team and on the IFSP for any of those kids if hearing difference is involved.

And really this open the door a lot for developing more shared understanding around the needs of children and families who are d/Deaf/Hard-of-Hearing and it really kind of helped us share with early intervention what are our goals and why do we have them.

It really helped us build those relationships with other team members across the state so they understood who is MC D/HH, what do they do, why do we want them on our team. So we've done a lot of education with child development services teams, a lot of lunch and learn times, and sometimes it's some of the same information year-to-year because there is so much turnover in early intervention programs that we think it's been really helpful just to stay on top of ensuring that they understand our process, understand why we're there at the table and what our role can be to support their team.

We also have this wonderful team to support us.

That's a real big positive is that our team can utilize the child development services team as well and pull them on board, oh, this child's not crawling yet, that's really not my background, I'm not sure what to do with this, and being able to come to the table and say, oh, can I get a consult from OT and be able to pull them on really easily because we're at team meetings weekly.

So the ELCO process is exploring language and communication opportunities. So you'll see that acronym throughout this a lot. And really it was developed as a process for empowering families by exploring all of the language and communication opportunities.

The ELCO professional guide is available at our earliest interactions website under professional resources, I believe. Then you'll see it listed under early intervention. So you're welcome to access that.

>> For the first time!

>> For the first time today, you guys are the first -- this is version four though, but this is the first time it's been accessible.

Take a look at that if you want have access and you can pull it up. You're welcome to do that too.

>> Will we have access to this PowerPoint or no?

>> Yes, I think they should be putting it on the EHDI website. We didn't get it uploaded until today, in full disclosure, so that's why it wasn't there. If not, our contact information will be at the end and you can contact us and we'll send it to you.

So the why of ELCO. Why this process? Really, we're really in support of family empowerment to make evidence informed decisions. We know that parent/c hild interactions highly predict language outcome so there's a huge focus in this process on parent child interactions. Language outcomes are really dependent upon family involvement, so if the families aren't knowledgeable and understand what all their opportunities are and they are not really on board with what's happening, then it's not going to be as successful and we know that through research.

Family culture and values are different from family-to-family. Family priorities are different. We also wanted to make sure that the information all families throughout the state were receiving similar information. We have a lot of different providers. So is everybody sharing the same information with families in a similar way? I mean, we know that it's so important that families have that really consistent and comprehensive information.

And we really wanted -- we have a focus really on that critical language period and the importance of access. And I think that's -- we've shifted the way that we're talking about children's hearing differences and their audiological assessments. The conversation is more about access and then exposure to language and how can we get that for our children.

So this one says crucial to ELCO. You can't see that. The crucial part to ELCO is that it is not a script. It is a guide. It's written like it could be a script. You could certainly read it to a family, but I don't think it would be very engaging. But the idea behind it really was to have certain topics that you're going to touch upon for each of the approaches or for the overview. You're going to make sure that you mention those things so that, as part of a conversation, they're giving very similar information across the state and from family-to-family, but it might not be in exactly the same way for each family because things pop up. Conversations go one way or the other way, but the guide itself can really act as a way for you, as a professional, to reflect back, oh, did I touch upon all that? Oh, next time I want to take a note to make sure I mention that about that approach.

Also we have providers that are specialists in cueing. If they talk all about cueing and only talk a little bit about ASL because they're kind of passionate about cueing, are the families getting the same experience? So really kind of, for those providers, it's the other way; it's like honing them in a little bit, like okay, come back to this information about cueing and make sure that we're sharing equal information about each approach in the beginning particularly.

So this pinball machine is here because I sort of equate walking into a home, pulling the ball back, letting it go and seeing where it goes. We sort of have to follow wherever it goes. We have to respond to those things. And we don't know where it's going to go. But do we want to hit all of the points and all the buttons and the bells and whistles around this pinball machine? Yeah, we do, eventually we want to hit all of those.

I think really importantly we want to be explicit of our role. That our role is as an informer and guide and not as someone that's going to tell the families what to do. But we are there, questions, want information, resources. And then really supporting the families as the explorer and expert on their family system, their child, what will work for them day-to-day.

And really encouraging that exploration and any change that is needed over time.

So the how of ELCO, really meeting families where they are. So not going in with your own agenda, but really walking in, checking in, seeing where families are. And yes, in my mind, as an interventionist, I know the things that I want to communicate with the family, but in that moment, I need to be responsive to what they're asking. And then can I move towards something that I think is maybe will feed and help them through this journey? Yeah, absolutely. Developing those trusting partnerships is integral to be able to have this process be successful.

Fostering that baby/parent relationship as a foundation, similarly, we can do this throughout our entire time as early interventionists with families, really talking about, like Karen was saying, noticing the things that are really working. Noticing, oh, you responded to him right away, that must make him know that how he communicated that was really successful!

You know? Just little things like that. Oh, he's really looking at you, as you're walking around the room, just fostering that attachment between parent and child.

We really need proficient early intervention specialists for d/Deaf/Hard-of-Hearing children and I know we all have a shortage. We're looking -- we have two positions open. We had three and we just hired somebody that's starting this summer, but that's great, but also we know we need more specialists. So kind of supporting those development of more programs to support training, early intervention specialists for d/Deaf/Hard-of-Hearing children. The other thing, continuity of resources, that was a big reason why the ELCO process was put in place too was because we do have a resource list and we try to share the same resources with families so everybody is getting similar information.

And of course everybody is Googling and researchi ng, but giving really solid, foundational resources that we know are accurate is really important.

And then parent-to-parent support, you'll see that as I go through the ELCO process, that parent-to-parent support and Deaf/hard of hearing adults are within any approach we're using with any -- and then ongoing assessment.

We'll touch upon that too.

>> Thanks, Amy. So I'm Claire, as I introduced myself earlier. I'm a mom of a Deaf son. We thought it was important to put a real photo of the early days up here for you guys to see.

As you can see, my son is -- I think he was almost three months in the photo, so that was March 2020 is that photo that you're looking at, March 13, 2020. We all know what was happening in the world at that time. We didn't disclaim this earlier but I think a really important and exciting disclaimer is that Amy Spencer was my early intervention provider.

As we were sitting here, I knew that I had first met Amy in my home sometime in early March. My son was identified as Deaf the first time that we found out was February 14, 2020. So he was 7 weeks old.

And our pediatrician at the time, I remember, happened to go on vacation the next week, so we had this weird week delay. As a Mom, I was like no one's available. Then the next week or a week or 10 days after is when we met Amy and a couple other members of the team.

And I was really curious what actual day that was, because I knew it was early March. Turns out it was March 4, 2020, which was yesterday. So as I think everyone in this room can understand the evolution of kind of seeing myself here today, being with Amy and Karen, it's a really amazing symbol for me of just how far we've come and the success that we've had and how amazing this program has really helped our family.

I just wanted to acknowledge that, that it was March 4, 2020.

And Amy and I had a really awesome day yesterday, March 4, 2023, walking around Cincinnati for the first time, both of us discovering the city together, now as friends, not only as colleagues. I just wanted to acknowledge that.

So anyway, I could ramble on forever, but I thought that was kind of a nice little side note.

We both know I can talk a lot, so please tell me when to stop.

Our story started out very similarly to what many of us have heard in the past. My husband and I are both, grew up hearing. My husband actually more recent history was identified as hard of hearing, but for all intents and purposes, we're two hearing individuals. Both of us had never met a profoundly Deaf person before our first child, our son, first and only kid. Our experience of kind of the first identification, the audiologist was very similar to a lot of stories that I have either heard about or read. It was certainly shock. It was the fear of failing. It was the fear of can I do this.

Tears came to my eyes when Karen recalled the story of the mom whose baby was unilaterally mildly -- had a mild hearing difference. And everyone' s different. It doesn't really matter. Everyone can have a different experience. You don't have to have a profoundly Deaf child. It can be any spectrum of hearing difference that can really put you into a tail spin of how do I do this, can I do this, am I capable, am I prepared, am I going to have enough time, am I going to have enough energy, because I don't have enough sleep, as you can see in this photo. I mean, it's an okay photo, but I'm being a little vulnerable sharing this photo with you. I am tired, I am not showered, that is 100% a PJ shirt.

So we were just exhausted, as any new parent would be. The first time Amy came to my home, it was the first and only time, because the next time was post shutdown. So most of my relationship with this program was for basically the first 18 to 20 months of my son's life was over Zoom. That was my interaction with this program.

And even still had a really positive, successful result, which I think says a lot to how this program is run.

So the first and only time -- the first time that Amy came into my house, I was breastfeeding on the couch with my bopy and half naked and not showered and just 10 to 14 days from this first identification. And Amy was sitting to the right of me and there was a member of the CDS team sitting on the floor with a clipboard. And my baby was nursing.

And I really just felt very discom Bobylated. I didn't know where to land my thought. I didn't really know what questions to ask. I was still processing this is kind of -- this is our new reality. We have a lot to catch up on, we have a lot of information to go through. I wasn't even thinking about decisions.

So my maternity -- I was lucky enough to have a maternity leave that I had three months maternity leave from the job that I was in at the time, and that actually ended -- my actual first day back at work was March 16, 2020. That was like the -- when I was still pregnant, that was going to be my first day back at work. We all know what Monday, March 16, 2020 was. That was actually the first day that many offices around the world just went remote.

So I actually never went back to my office. That was the first day back at work and I started working remotely from home.

So we have our own, unique, specific experience, as every family does. Ours just happened to land right at the beginning of COVID. And so we had our own unique challenges on top of being new parents and on top of having this early identification. That was just kind of all swimming around together at once. But I think it's important to acknowledge that that was our specific situation and doesn't matter what time you're talking about, time of year, decade, what's going on in the world, every family's going to have their specific unique experience of what's going on with them.

So that was ours.

Develop trusting partnerships with the early intervention team. For us, it was Amy, of course, and a Deaf mentor within the same program who was available, both available, on Zoom and our Deaf mentor, Melinda, was our ASL tutor. So that's something that we elected from very early on that we were starting to learn ASL over Zoom with our Deaf mentor.

And I think some of the key components of what really worked for us, because of how this program is set up, is that we really felt like even though we certainly could see Amy come in with a binder or Amy come in with papers and she had certainly some paperwork that she brought with her each time, it didn't really feel like she brought an agenda.

And it felt professional and it felt planned and it felt coordinated, but it also felt like we were just meeting with Amy as a human being.

So one of the most important questions, and I hope I'm not skipping slides here, but I think every single meeting, and remember, this was over Zoom, so the screen would pop up and our faces would pop up. We would just be looking into a screen and I would probably be nursing a baby and Amy would be on the other side. We were all going through this crazy time that we were all experiencing with the world being what it was.

We were just looking at each other like, okay, we're doing this. You know, the first question was always: How are you guys doing? How has the week been? We haven't talked in a week or so. How are you doing? How are you sleeping? What's new with my my MILO. Maybe I had emailed her some questions in the interim week that we knew we were probably going to go over. The meetings felt a little bit more organic. They just unfolded with where we were in that literal moment.

And while I certainly can't remember the meeting where we talked about -- I do remember pieces of this, but I don't remember Amy necessarily say this is the meeting when. I remember the binder and I remember looking at things and I remember different steps and asking a lot of questions.

And I really just felt like Amy's role, even at the time I wasn't thinking this, but in hindsight Amy' s role was just providing information, answering questions if we had them, and not giving any -- there was no bias. There was no sway whatsoever. It was just here are all the things that we could potentially do together and it's okay if you change your mind.

So that was basically the sentiment that I got. And I think even just the fact that I remember that, being a sleep-deprived parent and I can now recall that just by memory, that was just a really important piece of how it made me feel. Anything else I'm missing from this?

>> So I thought those two were really important coming from a parent perspective versus my perspective or Karen's perspective, just hearing how's that working for a parent.

So I'm going to talk a little bit probably a little quickly, through the ELCO process. This is part of the ELCO process. This is earliest interactions, we talked about that a little bit, just building that foundation of interacting. We talked a lot about the serve and return and that type of information and how important that is for foundations of language, regardless of visual language, spoken language, it doesn't really matter.

Proficient providers, we do have all of our team identify ourselves as family-centered early interventionists and we are early intervention specialists for d/Deaf/Hard-of-Hearing children.

That's sort of our role and that's how we label ourselves, I guess, but we are teachers of the Deaf, speech-language pathologists, we do have an OT on our team who's fluent in ASL, we have ASL specialists, cued speech, family trainers, special educators. We have a really diverse team so we feel pretty lucky about that. We need more of them, but we feel good about the diversity of the team we have right now. Continuity of resources was another how of how we're doing this, this ELCO. And like I said, this document will, hopefully, support people in using more -- have a more continuity of resources across their states and our state itself.

There is also a list of resources that's ever evolving. Like I said, this is version four so this will also be ever evolving. Things change. Research changes. We're looking for feedback from families, from the Deaf community, from staff, from our Part C organization. So it will not be a static document, but we're lucky to have internet and be able to put things on there and change things as-needed. And this is another way that we're trying to have continuity of resources is through our earliest interactions website. We are building it, so it is not complete, but it is getting better and better by the day.

And we're hoping this will be the landing spot for audiologists, pediatricians, other professionals working with d/Deaf/Hard-of-Hearing children, families, everybody. So if everybody is accessing resources and getting information about events from a similar place, I think that would be really helpful for continuity for families.

This is our professional approach for the ELCO process. It's a cyclical approach but it has stages. The first stage being the overview of language and communication opportunities. That looks fairly similar family family-to-family except oftentimes I will say hey, we are going to like just talk about this overview of communication and language opportunities. The pink side is more of the spoken language side and the blue side is visual language. Where do you want to start? I can't start in the middle because I need to talk about the sides first but I can start on one side or the other. So really just putting it to them. And some families are like, I don't know, you pick. That's also fine, but if they're really curious about American Sign Language, I'm going to start there.

And then after we do go over that overview, the overview has a guide. Touch these key points for each of the approaches.

And then we really follow -- it's really family driven. So the family says I'm really interested in exploring cued speech or ASL a little bit more. Can we discuss that more in depth? Maybe they don't say it in those words. Then we do. So we'll kind of explore the different components that are necessary to be in place for each of those approaches.

You'll see here, this one's representing American Sign Language. And around it, the bubbles really represent the things that need to be in place in order for this to be a successful approach.

Each one will kind of talk about that there needs to be a specialist and early intervention on board for that approach, whether that's an ASL family trainer or whether that's a cued speech family trainer, speech-language pathologist, pathologist. d/Deaf/Hard-of-Hearing role models, you'll see around each of these webs as well as parent-to-parent support.

We know that families need to develop strategies and skills for that approach and use them throughout daily routines. So this sort of, you'll see, I think I put all the approaches in here, but we are not go over all of them. We're just giving an example. We'll explore a little bit more in depth and then maybe they will I'll say parent-to-parent, have you already met a parent, that sort of conversation happens? Oh, yeah, I kind of want to meet a parent that's using cued speech. Okay, I'll find a parent that's using cued speech and pull them in for a meeting. Oh, I really want to know more about manually coded English systems, so I might pull someone from my team who has had a lot of experience with that and pull them in. That's the time when I'm not the one saying manually coded English systems are great for this reason or not great for this reason, but I'm saying that professional has come in and says that's worked for this family or that family.

That professional can come in and say that. And then d/Deaf/Hard-of-Hearing role model visits, some families have Deaf guides and then they also want to meet a person that grew up using cochlear implants and now they're an adult so I'll find that person in the community. Really the ultimate goal is family empowerment and -- and that's developing the language and communication plan. It's in a cycle, because we are not going to stop there. We are going to write a language and communication plan and then we are going to review it every six months.

We are going to make sure that we look at that overview again. Any questions? Do you want to talk about anything else? Oh, yeah, I met this family that's using American Sign Language; I'm kind of curious about that. Then we go through the whole cycle again. And I put this slide in here because, yes, this is part of the process is understanding the impact of your child's hearing difference, but it is not our focus as far as like this is the only thing we do. It gets integrated into everything else, into all of our conversations, and yeah, we have to back up to how we hear so they're understanding what's this test we're doing as the audiologist and how does my child's hearing difference impact their access to language in certain environments and what is this piece of paper I got or didn't get and can you help me get it, all of those things.

And this is also something we start with. It's just really talking about that, no matter what your type of language, whether spoken or visual, as long as they have access to language, they are going to develop these skills that you're ultimately wanting them to develop, communication, knowledge, thinking, social skills, those types of things.

And I kind of talked about this. I did talk about this.

So part of this process of exploring with families a little bit more in depth, we are really following their questions and their interests and like where they want to explore. We also talk a lot about benefits and limitations of that approach. So once we get into oh, you're seeming really interested in the bilingual bimodal approach; what would that look like for your family? What do you think the benefits would be for your family and MILO? What do you think the limitations might be? Learning another language, that might be a challenge, but I think we can do it. That type of conversation.

Another big thing with shared resources and sharing events and play groups and things like that, that's a big role of ours, just making sure that families are informed to make connections. Meeting people in that actual community and out and about and making your own parent-to-parent dates, that's also just more natural too and kind of finding the people that you resonate with and kind of providing those opportunities to find those people.

So I talked really fast and I'm really sorry, but I was trying to catch us up a little. Did I do a good job? All right, great.

So benefits and limitations, we thought we would take a little break because everybody's been sitting a long time. Whatever you like to do on your break, go to the bathroom, stretch, whatever. And then we thought we could probably group at tables. We are going to hand out language and communication approaches to each of the tables and we are going to have you sort of think about the benefits and limitations of that approach.

And maybe jolt some jot some things down and write it on the paper. Try to assume a variety of perspectives, because we know each family is going to be different on how beneficial that approach is going to be. The thing that's going to impact it the least is probably their hearing levels, I've found, and more so family priorities, values, culture, situations, things like that.

So take a break and we'll have a language approach, a web on each of the tables, and you guys can have a discussion about that and we will come back in how many minutes? What time is it? 10 minutes? We'll come back in 10 minutes.

[Break time]

learnings

Early intervention early intervention

.

>> If we want to come back and just get started on the benefits and limitations, we'll have a couple minutes to do that.

>> All right, everybody. In the interest of time, it sounds like we're having really good conversations. I'm going to wait for the interpreter, I'm sorry. All right. In the interest of time, we are going to wrap up a little bit and just have a quick discussion about sort of anything that you saw as variables that would really impact one family to make a different decision than another family for your approach. If anybody wants to make comments, we are going to do it like that because we're -- there's other important things. Hold on.

>> Hi!

I'm from Kansas and I'm a professional but also a parent of two Deaf children. And the -- I really like the linear model of having English and ASL on a perspective and all of the in between because my children, who are Deaf and hard of hearing are now 7 and 8 but five or six years ago I felt like we had to be pro ASL users before we could use visual communication with our children and I could see how that could dissuade families to use sign language for their children. The idea can be so overwhelming but I really like the approach of meeting them where they're at and say you might be interested in it and we can go there if you want to explore that. I wonder how, if in the future, if more parents were offered that option, if that would benefit their child's language development but than if they're forced to enter one or another.

>> Absolutely. And the Boston University research is I think going to be helpful. Has everybody -- does everybody know the research that says even if families are developing alongside their child, that the language outcomes are still improved in the long run as they're learning American Sign Language. I feel like being able to share that with families who are thinking about it or feeling nervous about it would help support them in that process. Thank you for your comment. Anybody else want to share anything?

>> I'm Ashley Rens low from Colorado. We have cued speech and speech and language and I think one of the biggest limitations that we talked about is probably the access to providers who are skilled, who can support that family all the way through. I know in Colorado, we do have some people but not enough to support the families every single week in the way they would want. That's one of the, I think, biggest limitations that we've come across.

>> Yep, absolutely. We have the same experience in Maine.

>> I hope I'm understanding the question correctly. One of the challenges I came across with a family, this was one experience, but this mother was a CODA so she had had Deaf parents and she was very resistant to sign language because she felt from her personal experience she felt it limited the professional and educational opportunities for her family. That was a different conversation than I usually have because she had prior knowledge that was related to one very small example of opportunities for Deaf adults.

>> Yep, absolutely. And I think that gives you that opportunity in your mind as a professional to be like, okay, so what experiences can I offer this family that maybe will shift their perspective to think about things in a little bit different way, too, because you've met Deaf adults that use ASL that maybe didn't have the experience that her parents had, but validating the fact that, yeah, that sounded difficult for your parents. That would be a different navigation, you're right.

>> Anybody else?

>> We had ASL. Benefits that we did were just it being fully accessible, the fact that it's a complete language and you don't have surgery, which is always a benefit. Some of the struggles and limitations that we came up with were mostly based off of almost accessibility in like rural areas. So things like friendships for the children, finding education, childcare that have ASL involved in that, friendships.

Then we also talked about -- we just used the term d/Deaf/Hard-of-Hearing Plus but the kids that maybe have other limitations like cerebral palsy, cognitive impairments, blindness, those are other challenges to add to the table.

>> Absolutely. And we did actually just recently add a multi-sensory communication web to our approaches because that pops up all the time, and we have a lot of families using multiple approaches in different ways, object communication, all of those things, and we didn't want to leave that off the table either. So we added a supplement for that in the professional guide as well. Thank you, guys!

Do you want to add? One more, yeah. Do you want to wait for the mic?

>> You had mentioned play groups, which I think are so imperative, but in my state, I'm from Connecticut, according to our birth to three, play groups are not a natural environment. So I guess my question is, if we have to -- I think that play groups are essential, because you're making the assumption that parents have the capabilities on their own to go out and seek friendships or other parents or other families that are d/Deaf/Hard-of-Hearing or have similar situations in their own family. So having that challenge, I guess, my question is, did you have to face that when you were creating your model in that natural environment and what that means and how to bypass it or integrate it into the changes that are necessary?

>> We have the same challenge in Maine. Part C does not identify our play groups as an IFSP service, so we have them available outside of the IFSP and we do try to get funding to decrease travel barriers, so we can offer gas cards to families. We try to have events on Saturdays to try to get more families to be able to be involved, working parents.

It is a big challenge for sure. There are some states that play groups can be on their IFSP and I would love to know how to make that happen, because I agree with you. And transportation is a big issue. And we do try to provide some options around the state. We can't necessarily provide options everywhere. We have limited staff and limited people, but we do acknowledge that as being something we want to focus on. So if we had a group of families in one area that were interested, we would certainly make a play group happen for them or encourage them to do so on their own, too. All right.

I'm going to move on. I'm just flicking through these. Maine Hands & Voices, Guide By Your Side, they're a family-based organization we work with. This is our website and our HRSA grant. Ultimately, we're working towards that family empowerment to make some thoughtful decisions about where we are going to start. This is what that is, where we are going to start. It's not necessarily the final what we are going to do forever. We don't know what we are going to do forever because things might change over time. This language and communication plan just goes through that families feel comfortable, like they have enough information about each of these approaches and we have them check those boxes to say, yep, I know what manually encoded English systems are, I know ha this is and I feel comfortable right now and I don't want any more information. Advantages and limitations, like we did. And here's where they will say this is where our personal journey is at this moment. So we're looking at maybe a bilingual, bimodal approach. Then we have a little checkbox system of do you know what Guide By Your Side is, Hands & Voices, do you know about family events and play groups, because we want to make sure we didn't miss something and that's something imperative for families.

Where your child and your family are going to connect with other d/Deaf/Hard-of-Hearing children and families, and listing a few of those options so they feel like they have some options.

And then we do ongoing assessment on all children every six months per our kindergarten readiness legislation and we work with the Odyssey team out of Colorado. We use those assessments and list those here because we want to use those as part of our reflection of our language and communication plan. If things are going well on those assessments, great!

If things are not going well and we're using a certain approach, like what's the missing link? That's where the webs can be really handy and reflective too is not only as a way to think about and understand that approach, but also to know, okay, we're using the listening and spoken language approach but really the gap's getting bigger, not smaller, what's going on here? We're looking at all the bubbles, you have a provider, learning some of the strategies, oh, you haven't been able to get the hearing aids on him at childcare at all and he's there 40 hours a week. That could be where the challenge is. Are we really going to hone in on that challenge and focus on that or are we going to switch the approach to a more visual language approach because he doesn't have auditory access? It can be used in both ways.

Yes.

>> Sorry.

>> That's okay.

>> Sorry.

Just clarify for me, this is Ashley, that guides, your IFSP, and you review it every six months and utilize that to come up with the strategies and outcomes for each family.

>> Yes. So the assessments are great because a lot of the families will have family-based outcomes about understanding developmental milestones, because I didn't expect I was going to have to hone in on this so much.

Like going through the sky high with families, these are the assessments that we use. The sky high is one that is not on Odyssey, but it remains kindergarten readiness legislation, goes from birth to six, so we can use it throughout, until they go to kindergarten. So we can use that as a way to look, like six months from now, what do I expect my kid to be doing. He's here now. In six months, let's look, maybe this, this and this should be happening. So it can be helpful in a lot of different ways.

And then in summary, we really want to ensure that children have -- families have knowledge and resources and all the information. They especially have parent-to-parent and d/Deaf/Hard-of-Hearing role models, that we're really focusing on those family and caregiver interactions, because we know that's so important. And then the benefits and limitations are not static. They are dynamic. Every family, it's going to be different what their benefits and limitations are. They might have culture and values that we might not hold in our own family. And then ongoing assessment is essential, so we're making sure we're making changes in the language and communication plan as-needed to encourage language development.

We are going to watch a quick video.

>> While Amy is getting it up, we are going to show you a video that I don't think it's on our website yet, right? It's going to be. This is a video that accompanies ELCO and it walks through the process a little bit but it tells each family's story related to their journey. This was created as part of our statewide coordinated intervention system. We pulled in specialists from listening and spoken language specialists, cued language specialists and ASL specialists, so people that didn't work for us, but were part of our greater system and contracted in.

It also involved lots of parents from different entities and different agencies, so this video is an example of something that you could do with your state is to pull everybody together to make something. And you're highlighting each specialist, so they feel good, they feel good to be asked, they feel good to be the expert. But families are the ones that are really highlighted.

>> I'm just going to add to that that ELCO, although I have been sort of like the lead on it, we've pulled in so many different people at so many different times that sometimes Karen and I would be like what are we asking, what are we doing, because we're just trying to process with our d/Deaf/Hard-of-Hearing role models, like does this feel good to you as a d/Deaf/Hard-of-Hearing person? Does this information feel good to you? And similarly, oh, this cued speech family trainer has this really great way of communicating this to families. So we've pulled everybody in in developing this guide as well. This is just advice from families and it just talks about that empowerment, that journey, through the process.

(Video playing)

>> Oh, it went.

>> Or maybe not.

>> Panic.

>> It is a big deal. It's a huge deal. And you're probably going to lose a ton of sleep and you're going to stress and you're going to worry. But you would anyway, hearing or Deaf.

>> Afraid to change -- still learn and still going to grow. It's just getting your mind used to them growing and learning in a different way than you had planned. Plans changed and that's it. And no matter which road you choose or which path you take, everything really will be okay, as long as you give your child love and attention. That's all they need.

>> My best advice would be to remember that it's a very fluid process. You're always going to learn more. You're always going to see different approaches. I think you just have to do what's best for your family, do what you think is best for your child, don't worry about any sort of judgment. You're going to be supported. It's a pretty good community that we have here, people with hearing loss, and you're going to be supported.

>> Whatever works for your family, you just go with it. This is what's worked for us, this is what's helped her succeed. I'm not afraid to change it if something happens. We did have to change it. We went from 100% verbal communicators to also adding in cued speech when needed.

If we get to the point that we have to change it again, we will.

>> It's a new world when you find out that your kid's Deaf.

>> Anything, any disability or anything, it's scary, but it's language. It's not something that they're missing technically. They're missing their hearing but their hearing's through their eyes, so the biggest thing that they told us was, especially from picking what to do, like from hearing aid, cochlear or ASL, your child will be different than anyone else.

>> Don't be overwhelmed at first, which is really easy to do. Just understand that there are a lot of people there to help you and that you can make the process fun.

>> Making it fun is key to learning sign language, we think.

>> I think for other families that are trying to determine what's best for them, it makes sense to go with what you're naturally doing or find the resources to give you those options and to find the way that best fits into your daily life so it doesn't seem like extra. I think there's a way to make it work for your family that it can fit into place as it already belonged. I think there are days that it will change, but I think long-term we're sticking with kind of the same thing but we're letting our child, Lucas, drive that approach.

>> It's okay to not know which one is the best for your family and what route to go down. Sometimes you go down the path of we're going to try learninga learning sign language and if that doesn't work, it's okay. It's okay to change your paths and kind of figure out what's going to work best for not just your child but for the family.

If we felt that Haley needed more support, we were open to it. Being open to all of the options that are out there and trying to explore those options are also really key.

>> Listening to your kids is huge. As parents we kind of get set in our ways, like when I started, I'm like you're going to speak, you're going to sign. Cued speech was not even close to being in the realm of anything I thought he would do. He started doing it and spoke up and it was like this is working for me. If I wouldn't have taken a step back and listened to him and been like let's talk about this, he wouldn't be where he is right now. So it's important to listen to your kid. If they want something, stop and talk about it. Maybe you don't have to say yes, maybe it's not the right thing, but being open to the different options for your child is really important.

>> Everybody's journey is going to be unique. What makes sense for one family may not make sense for another family. So I think really sort of think about what's most important to you and how to achieve that.

>> Make it fun. Ask questions. Accept help when it's offered to you.

Learn about Deaf Culture and I think most importantly, you just be your child's advocate. The most well-intentioned person still isn't going to know what's best for your child and your family. So be your child's voice and be their advocate.

>> Just make them strong. Make them strong and let them know that if you are not there to be their advocate, they have got to be their own advocate. And my daughter has no problem saying anything to anybody. She has no problem telling people I'm sorry, I can't hear you, can you speak up. She has no problem with that. Because I told her from a young age, you are only going to hurt yourself if you don't speak up.

>> Not set limits or assume that something's not possible. To stick with the highest hopes and dreams you have for your child and do everything you can to believe that it's possible.

>> Any advice to everybody, do what's best for your family.

>> And always ask. Ask questions. You never stop asking.

>> Avery got her hearing aids at three months old. We would be out in public and strangers, people come up to you and they say things and they ask questions. I figured out early on that how I approach this, your first instincts is to be like, you know, what, how dare you come up to me. But I think I figured you out early on how I approach this and how I answer people is how she's going to perceive her challenges. So I always handle it very positive. I always speak about it positively. I always take it as a form of it's my chance to educate people on d/Deaf/Hard-of-Hearing children. You want your child to be comfortable in their deafness, are and confident with it.

So we just recommend getting as many opinions as possible and making sure it's a combination of hearing people and Deaf people, just to make sure you're covering all the bases.

>> Definitely. I really was fortunate to call upon my experiences as a Deaf child, working as a teacher of the Deaf myself, and it really helped for me to know all of the different options. And I do know that what works for your child is what makes the right choice and it doesn't matter what you choose; it's just important that it's a good choice for your child.

>> Okay. So you can see some pretty empowered parents, right? The other thing that stands out to me every time I watch that video is the concept of journey. You heard again and again, if it doesn't work, I'm going to try something different. If we go down that road and it doesn't work, we are going to watch my kid and they are going to tell me something different. That's a really, really big message in our ELCO process is you're going to try it. If it doesn't work, you change. So there's no real choice. It's a beginning step, really.

And you saw that in that video. They're very malleable, very flexible, very empowered and very confident. So I think that's so awesome. Those are the words of families.

Okay. Now a little bit of strategies for you for identifying your stakeholders, your partners. If you're interested in going back and either tackling a brand new system or starting where you are and trying to make it better, maybe this will help.

So think about your state and in your mind, who are your stakeholders? Who would you say are your stakeholders? Then you're going to think about how can I build a relationship and a trusting relationship with them? You're going to do that very first activity that we did with reassured understanding.

So this is Maine's or really in general stakeholders. Your families, that's your number one stakeholder.

None of us would be in this room without families of Deaf children. Family-based organization, every state should have one. Your early intervention program. Your EHDI or newborn screening program. HRSA. CDC's not on here. It is with, again, Maine is split. CDC and HRSA. That's why it's set that way. The Deaf community, huge stakeholder!

Again, wouldn't be here without the Deaf community and Deaf children. Schools for the Deaf. Agencies specializing in d/Deaf/Hard-of-Hearing. Audiologists, hospitals, clinics, legislators, get to know them.

This is how they used to be. We had all these stakeholders, but we were all working in parallel ways. Many were overlapping. Many were siloed, like we talked about at the beginning of this afternoon. Many of you said silo, silo, silo. So our goal was to do this. This is what we have been working a lot on is how do you combine and how do you overlap appropriately and when do you overlap appropriately and when do you not? And when and how can you pull in who you need every step of the way to move your system from point A to where you want to be?

So we talked about shared understanding. The other thing that's been really helpful is really being aware and conscious of communication, transparency and respect. In our organization this year, we have been spending the whole year defining those three words. You always hear administration doesn't communicate. Administration isn't transparent. So and so doesn't respect me. I hear that!

In every organization you hear that. In state systems, you hear that. That agency didn't tell me what they're doing. That agency is hiding something and they pop up with a new activity. Or that agency doesn't respect ASL. That agency doesn't respect spoken language, whatever, you know that. Working on that and figuring out, again, shared definition of what do those words mean. It was fascinating when we started to work on that in our organization, because some of the words were similar in definition and some were different as to what communication means. And a lot of our staff couldn't define it. We want you to communicate more.

Okay, great. How? You want more emails? You want more staff messages? You want weekly meetings? What do you want? It didn't come out that way. It was just simple words.

Openness. Communication. All these words again and again, and again, but it wasn't clearly defined and we're still not there yet. We have been working the whole year and I'm hopeful by June to have the shared definitions so I can do what my staff want me to do, but it's hard. That same thought works with systems work. It also works with families. When you're in their homes working with shared understanding, you may have a totally different definition of "whatever" from the family. Think about that and keep that in mind in all of your meetings.

Collective resource and process development, we mentioned that video. That moved mountains in our state. Developing that together, pulling people in. Sometimes you can find funding to pay people. So if you're the one that wants to be leading a charge, do you have funding? Is it funding from the School for the Deaf? Is it funding from HRSA? Can you partner with CDC? Say do you have any money at all to help me do this? Maybe they don't, but they may be able to write it in the next work plan. Again, get buddy buddy with your people and know your system, know who has money and try to make it work. When we pulled people together working on various projects, the video, resources, audiologists together, what other ones have we done, the tip sheets, I think they're here. These ones. We developed the kindergarten readiness process that was in legislation. That had all the stakeholders, like many states have done, but we took it another step with that kindergarten readiness, a manual, a book with assessments and the milestones was developed with that full team.

So the hope is that -- may use it with the family. And the audiologist may say here's a resource for you and it's the same one. How many times in your state have families told you I've gotten 10 different copies of something about ASL? Or I've gotten ASL and then I've gotten Lis el's information and it conflicted? When you create something together, it's going to be one document that's a coordinated resource.

We have an audiology workgroup that is led by our state's audiology consultant that works for MADCHH and she pulled every audiologist in the state that did pediatrics together and they meet frequently and they have been developing one resource for ABIs, for hearing aids, for cochlear implants, for what have you. We have many tip sheets, but they were developed together, collectively, so the hope is if you're born in Southern Maine or Northern Maine or the East or the West, you're all going to get that same document because the audiologists have buy-in. If we were to develop something in our program, which we could have, and gave it to audiologists and said here you go, this is a new resource, it probably would sit on a shelf because they don't have buy-in. They weren't part of it.

MOU was written with many, many perspectives brought to the table. Amy and our team are working on tip sheets for early intervention, pulling in the outsiders again. The ELCO development that you've seen, the resources today, the website is all done with different perspectives. The video and our hearing screening process with Part C and part B in the state.

I'm going to go back. I jumped.

Maybe.

You find it, Claire.

Yes. So one thing that we -- we had been criticized for not sharing information and coming up with something new and nobody was involved and nobody knew about it until we had done it. And it was fine, because that's our job. We're the statewide Deaf education agency funded by Department of Ed so we were just doing our job. But in retrospect, we really weren't collaborating on things. We were living in a tunnel, doing our job. When we opened up and started sharing more, hey, we're thinking about developing a video, do you want to be involved, that opened up so many windows of opportunity for collaboration.

So thinking about supported by family-centered intervention primary service provider model, when we started bringing in those specialists and bringing in d/Deaf/Hard-of-Hearing adults to families' homes as part of their Part C system that everybody had, that everybody was offered, that built trust for the Deaf community and it built trust with parents, parent-to-parent support. In your system, whether you're at the audiology visit or in a home visit, what can you do to pull more people in so that everybody's buying into your model?

And one thing that we had to work on this, was recognizing everybody's strengths. Again, you get in your tunnel and you're doing good work and you feel good about it, but there's people over here that sometimes you disagree with. We really worked hard on identifying their purpose, what was strong about them, what skills they had, and pulled them in when we needed that specific skill. We had many of those skills on our own team, but by pulling the outside provider in, again, moved mountains.

And perspectives. We talk all the time about what's your perspective on that? What do you think? I have a thought and I think I know what I think I want to do with this whatever, but what do you think and what are you thinking and you thinking? Those meetings we have with the HRSA team, we're asking, Amy, what do you think, Part C, what do you think, and it's made our system collaborative and malleable and flexible.

And we talked about several people today time. It takes a long time to build a system. It takes patience. It takes collaboration. And it takes trust building. It's not going to be quick. We will never ever ever be done, as long as I'm in this seat, and probably you too, Amy. It took us a while to realize that, because when we were working on ELCO and Amy finished her project and, okay, I'm going to print it, somebody else said, oh wait, here's an idea. Then I think we took 10 steps back and said this thing is never going to be done.

Like she said, it's on the fourth edition already and we've never put it out. Nobody's seen this other than us and our families. So a family was like I guess we should show it because it's never going to be done and I think we really believe it never should be done because research is going to change our work, family perspectives is going to change our work. The video, there were several things when I watched the whole video that said, well, maybe we should change this or maybe we should change that. Every day something changes.

This is who we are. I would like to thank who we are, and many colors, many differences, many similarities, all connected, it's never perfect. It's never going to be perfect, but our hope is that everybody feels like they have a piece in this massive puzzle.

So what is everybody thinking at different parts of the baby's life? When you think about your stakeholders, everybody has a perspective when a baby' s born. Think for a moment, brand new baby in the hospital born, had hearing screening, referred on hearing screening, went to the audiologist, identified as a profoundly Deaf baby.

What's your thought? What's your thinking? Probably, if we were to go around this room, we would probably have at least 10 or 15 different thoughts. Because you all come from different perspectives and you all have different experiences.

So this is our little brainstorm as to what we were thinking maybe. So a new baby, the families are probably thinking they're shocked, they're overwhelmed, they're feeling incapable, they're scared.

A little bit later, they're over extended and they're fatigued, but they're diving into information. Four to six months the biggest learning curve with language, information and next steps. So they're moving along. They're feeling a little bit motivated with slightly more direction, even in doubt, indecision and questions remain. Thus after talking with many families, as Claire for help with that slide, it's probably what we think is probably in a lot of families' minds in the first few months. The Deaf community is thinking where is language for that baby? Give that baby language access. How can we get involved? We want to meet these families.

Part C is thinking, okay, we're the primary point of contact, we have got to get in with that baby. It's an established condition, let's go. Let's get the referral, let's write the IFSP. We are going to use our PSP model, follow our MOU, let's go, let's do it.

Then we have a screening program, our EHDI program. They're thinking was this baby screened by one month? Did the data get in the system? Was there audiology follow-up happening? Was identification by three months? Data data data. And they're also thinking about what might have gone wrong? Did the baby get what they needed? Was the script at the hospital was that right? Did the family get the screening at night, during the day, all the things in the EHDI coordinator's mind and they're thinking about how is that family doing.

Our program, Amy was thinking they're focused on parent/child attachment. We try to slee slow it down a little bit. We're curious if the baby was screened by one month. Did the baby audiology -- we want to begin the early process and ELCO with the families and we're always always always following their lead. We never jump ahead.

As much as we know.

Did we offer parent-to-parent support yet? Has this family met a d/Deaf/Hard-of-Hearing adult? And just ensuring understanding every step of the way. And the importance of language access and acquisition.

So I missed a couple. Our family-based organization, they're thinking this is a parent that needs another parent. We should be the first one is to meet these families. We need to connect with them. Has the family met a d/Deaf/Hard-of-Hearing adult yet? And they want to make sure that this family knows about their events, their programs, their services, and that there's parents out there that they can connect with. Other d/Deaf/Hard-of-Hearing agencies are thinking similar things sometimes, but they want to make sure that families know about their services and that they're available for consultation when we need the specialization. And they're wondering what do the families need, are we meeting their needs? We see that a lot. And the legislators, what are they thinking about about the new little Deaf baby? Are they following the law and following the new legislation that happened last year in Maine, are they doing that, this Deaf baby? Are the families aware of services? Good. Okay. You got the funding you need? Good, yeah, check, I'm going back to committee. That's what they think.

We went through and did all the way up for a while. We are not going to go through all of these. I'm sure you have in your mind different thoughts. When this is posted, if you want to glance at it for what we were thinking, it was a fun process, especially the legislators. I had fun thinking about them. 36 months.

So creating a better system. I can't stress enough the impact of you, one person, and the difference that you can make. I'm going to be talking tomorrow afternoon in the plenary and some of the slides you'll say I saw that yesterday. There's only a few that are the same but this is one because it's important. 1% can make such a difference. You have to be the one to begin the conversation. Nobody else is going to do it for you. If you have passion and you have drive and you feel it's important, whatever "i t" is, do it!

Go for it!

What have you got to lose? Nothing!

Be open to change and evolution. That was a huge learning curve over the years for me and our team. Good, we're done, check? No, we're not. You have to be open to always be willing to change the system and listen to other perspectives.

What about your family-based organizations? Do you know who they are in your state? Reach out to them!

Have dinner!

See if you can go to one of their board meetings and just listen. What about the Deaf community? Have you ever talked to a Deaf person in your state? For show of hands, how many of you have, in your very own state, talked to a Deaf person? That's pretty good!

If you haven't, please consider that a challenge for you in the next month. Where are they? Where is the Deaf community? See if you can find them. That will make a better system. Think about what support you offer, the opportunities. Are you providing services in home? Are you providing services through teletherapy, telehealth? Is whatever your group, your agency, your service, are you visible in the community? Do people know what you do? Maybe. Maybe not.

How can you make them know what you do? You can hire Claire like I did to be our PR person. No, you can't, because she's good. She's staying in Maine. But think about that. And are you including parents? When we contract, I'm always looking for those stakeholders. Something like PI, data, accounting, DI specialist, what else do we have? All the contractors that we bring in, I always look for either a Deaf person or a parent first. If I can't find a Deaf person or a parent, okay, I have got to hire a hearing person sometimes, but if you can start with somebody with lived experience, it's going to make your program so much stronger. Think about that in your state. Patience, persistence, just don't stop. Keep going.

Okay. What time is it? How we doing? Okay. On your table -- no, not yet. Amy and Claire are going to come around with some markers and some paper. And I challenge you to think about your stakeholders in your state.

So you're going to draw your circles or squares or triangles, whatever you want to put them in and see who they are. You could do like we did, that slide back, just make circles with different colors. Think about your strengths of your personal and professional connection to them. If it's really strong connection, draw a line. Put you right in the middle of all these circles. Draw a line that's solid, like I got this person, we're a team, we're solid.

If it's somebody you've never talked to, don't have any line at all. If it's somebody that you've met with periodically, you have been on boards together, you might have seen them at a meeting, you feel kind of connected, make a dotted line. Take a few minutes and do this and just think as you're doing it, how could I improve my connection to each of these stakeholders.

If you feel can strongly about it, start with you.

How did you do? Do you have a web? Do you have people? Do you have agencies? No? Yes? You're not done? That's okay. That's okay. You don't have to be done. You could do it on the airplane on the way home. Make an action plan.

So when you're thinking about these stakeholders, how many of you, when you wrote a certain one, your inside went ugh, I don't know if I want to write this one yet? No? Maybe? Yes? There's always one. There's always somebody that just makes you feel a little uneasy. So what works, what might not work, and what are your personal/professional blocks to collaboration and inclusion? The first thing you have got to do is get past that feeling and it's hard. It's hard. We've all done it. I don't have magic for that, I don't have magic for anything other than communication and shared understanding and other things that we've talked about. But those people who make you feel funny and you have different philosophies and different feelings are some of the most important people that need to be on that web, because without them you're not going to create a statewide system, it's impossible. Because they are going to work against you. So you want to bring them as close to you as possible so you can move forward. What do you think might work in your state and what would be a huge, huge barrier? Maybe one or two people sharing?

Anybody?

Let's start with thinking about what might work in your state as you're thinking of opening this process or continuing the process you're on. Anything that stands out? I see a hand.

>> Hi, my name is Erin and I'm from Kansas. I actually feel like we have very similarly a lot of the pieces are sitting there and ready to go, but I just was reflecting on perhaps I need to do a better job of sharing what our vision looks like to some of these stakeholders and making sure that they really understand and buy-in.

I think we have -- I have people in those organizations that I think buy-in and understand, but maybe not necessarily the top-down yet. So just thinking about how I need to strengthen some of these relationships and then -- yeah. But I feel like we've got something sort of similar, but there's some things that you guys said today that helped me know, okay, there's some things I need to strengthen or add to what we're already doing.

>> What state did you say you were from?

>> Kansas.

>> Are you presenting at EHDI?

>> Yeah, Tuesday, on our language assessment.

>> I like it when there's things that are similar, because we can learn from each other because we don't know. We're just moving forward. But there's something in every group that everybody can learn something from. Great!

Thank you.

Anybody else?

What's your block? What is it?

Where are you saying this can't work because of ... Baha what?

>> For me professionally -- I'm Kelsey from Kansas. Me professionally, one of my bigger blocks is relationships with legislators, just because it's intimidating. And I've watched their sessions and see how they talk about the Deaf community and the Deaf population and it makes me mad because they don't recognize them as people first, so trying to educate them and also school districts and just about Deaf Culture and the importance of valuing the persons, it's ugh.

>> You're a parent, you said, right?

>> I'm a parent and also on the Kansas commission for Deaf and hard of hearing. Even in a professional role I'm still intimidated by these legislators.

>> Yeah. Invite them for coffee.

>> Okay.

All of 'em? At once?

>> Seriously, seriously!

I've done that many times except I don't drink coffee, I drink diet Coke. I've done that so many times with somebody that I just kind of wanted to get in their head. I'm coming to our state capital, will you meet me for coffee? If you say I'll buy you coffee, sure, they will give you five minutes. They want your vote so they are going to listen to you. Even better if you know who's in their constituencies, what town they're trying to win votes, bring a Mom or Dad or Deaf Thibidault that Deaf adult.

>> I am hearing and they're more likely to meet me versus him because he would have to have an interpreter, which stinks. He told me he wants to utilize me to build the relationships with them on behalf of the Deaf population.

>> So you have the first cup of coffee and then you say, can we meet again for coffee? And then you bring that Deaf adult with you, because you already got 'em and you'll win them over because you're a mom.

>> I'll make that my goal. Thank you.

>> How are we doing? We almost there? We're almost there. One thing we said in the abstract is one of the goals for today was to give you a couple of tools. Self-reflection for when you feel those moments that this isn't going to work or it's going to work or you're in a rut, think about just for yourself, I'm going to read through these. What makes you feel energized and drained? What makes you want to laugh or cry? What makes you feel empowered or weak? What makes you uncomfortable, short temperd or easily frustrated? What makes you shutdown or put a wall up? Awareness of what you are bringing to the table is critical. What are your limits personally or fill philosophically? These are gold mines, because if you read through these before you go to one of those meetings that are really hard, it will help you process before you walk in that door.

Because if you are going to meet with that legislator and you're nervous and you're scared, rightf ully so, okay, what makes me feel energized? My kid!

My child!

That's why I need to meet with him and change the system!

What makes me feel drained? The fact that I need to go see this legislator that isn't going to talk to me so how do I get by this? Just little tools, little tips to help you kind of get through that moment of feeling I don't know if I can do this. And the last one is really important. You may have limits, everybody has limits, that I am never ever going to ... what? To get this accomplished.

Or I have no limits. I'm going to just make this happen and it's going to happen. What about your own personal philosophy? We all have a bias. We do. What we do with that bias is what makes it work or not. We have a bias. We all do. When people say they are totally unbiased, it's really not true. You have a bias, but you have to figure out what do you do with that bias when you're talking with families, when you're talking to people that have a different philosophy. So philosophically, do you believe in one family-centered coordinated early intervention process? Maybe you don't. I don't know. I think you probably do because you're in this room, but you are going to encounter people that don't. So what do you do with that? How do you bring them over to your side?

And self-awareness, again, I like this picture. I found it on the web a long time ago and I pull it up every once in a while. Being aware of myself, before I go into a meeting or before I even go to a home visit, what can I do versus what can we do? Because you're only one person. But it takes one person to start it. But one person isn't going to get you anywhere. You need a team, you need coordinators, you need people, you need friends, you need those legislators, it's more than you, but you can start.

So what you just did in your mind was a quick reflection of personal check in. It's a good tool. Take inventory before you go in, before you're talking to somebody that you may not be comfortable with and before you handle any kind of situation.

It's important to do this with your team. I talked about our HRSA team, our HRSA CDC team, the earliest interactions team, we reflect all the time. We have regular monthly meetings. We have an annual retreat, which is not A typical, I'm sure you all do this. But we're always revisiting our philosophy, our perspective, our shared vision that we created together. And we also go back to best practice, because if you want to get something accomplished, the best way to win over people that disagree is to show them best practice documents. JCIH. The FCI principles, those documents that people have worked really hard in creating, have them in your pocket, ready to pull out, and show them where they fit in their work plan, in their strategic plan.

And then identifying and allying responses with everybody else's plan, where does it fit? I can't stress this enough. We talked about the families. We talked about this in the beginning. You're going to hear it again tomorrow. It's a journey. Everything we do is a journey. There's never one choice. There's never that first checkbox that I talked about that I wanted to put on the shelf. It should never be that way with families. The first thing you should say to them after you say hello is, okay, we are going to go on a journey together. Let's do it. And then define what is a journey. Do we have the same understanding of what it is?

So when you think about a journey, you can create a system that's malleable and open to change. But you can't do that if you're not thinking it's a journey. It's impossible. And it starts with you, of course. And we have a few more minutes. On your paper, flip it over or grab another piece or whatever. Step one, two, three. What are the first, second and third things you want to do today when you walk out of this room, tomorrow on your flight back, next week when you're back in your office? What are a couple steps that you're going to take with you from this discussion today?

Okay. I would love to hear somebody's step one.

I'm keeping you busy.

>> We don't have a Governor governing board but we have an advisory committee and we have a cross-section of our stakeholder community but there are gaps. So the first thing I'm going to do is what I have been thinking about in the back of my brain is reaching out to some of the community members that could help fill those gaps. And I've let other things kind of take priority, but this conversation today has really brought that to the top, so I appreciate the nudge.

>> That's great.

There was another hand up.

>> I have got to bring it up to our stakeholder group in the morning, so not wasting any time.

>> There you go!

Anybody else?

>> I just thought that I would define what I think everybody's roles are. And then when I get back, have them define what their roles are and see if we are in agreement or totally misunderstanding each other.

>> Shared understanding, right?

>> I'm going to go have a drink and idea share with colleagues and stakeholders and friends that are here.

>> I'll come with you, Ashley.

Anybody else?

Okay. Great. One more? Yeah!

>> So I recently got approved to work on a project where we'll be recreating family leadership modules for our family leaders in early intervention throughout the state and as well as for families and videos for families. We'll be doing this in collaboration with our parent training and information center, so I'm really excited about that. I literally just got approved for it on Friday.

>> Yay!

That's fabulous!

Congratulations!

>> My first thing on the list is to include our early hearing detection intervention program with us. I want to make sure that they're involved in the production of all of our material.

>> That's so great. So great.

That made me think of something Amy told me to remember to say. One thing that we've done over the years, especially since we have the HRSA grant, was look at our stakeholders and see who was the hardest person in our stakeholder list and we paid for them to come to EHDI or I paid for them to go to Hands & Voices. I looked at what conference or what thing was I doing that I could bring them with me and talk to them the whole time. We brought our Part C person right in the middle of the five years of the MOU and it totally changed him. He was a different person after that meeting, after an EHDI meeting, but I kind of scripted one for him to go to. I said since I'm paying, will you go to this one and this one and this one? And I went with him. I said oh, did you notice this and did you notice that? One year we brought I think it was 11 d/Deaf/Hard-of-Hearing adults from Maine, because that was really important to me that year. It was when we were really starting to make sure that d/Deaf/Hard-of-Hearing adults were in our system and I wanted to make sure that they had a family-centered early intervention. We found money somehow, that was a lot, but we had extra money. You don't usually have extra money. You can have extra money for one person, maybe, somewhere. That works. That's really helpful.

And sometimes you can count. We figured out a way. EHDI had money for parents, right? You have to bring parents to EHDI. So one of our new early interventionists happens to be a parent of a Deaf child, so we were able to bring her in the parent role, which she is, but double whammy, so thinking about how can you get -- she's not a hard person. But some people who are hard people, you want to bring them with you. Keep 'em close. Keep 'em close. We are done, I think, right? That's it. So that's our contact info. Feel free to reach out to any one of us if you want that Mom perspective, Claire will, I'm sure, be happy to share. Amy, the brainchild behind ELCO. Me, I don't know, whatever you want to ask me. We're happy to share. We're happy to talk with you and learn from you, because we're all just one person, right? So thank you all for coming. Anybody need to add anything? Want to add anything? Okay. Thank you thank you thank you.