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EHDI – Florence

Creating a Statewide Family Centered Early Intervention System

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[Live captioner is standing by].

>> [Speakers off mic]. [Captioner cannot hear the speakers].

>> So... we're here to talk about something we've been working very hard in, on in Maine over the last four, five years. And we're, we're very excited about it, we think it's going very well and... we're very excited to share it with you.

>> [Speaker off mic]. Okay... is that better? Thank you... just the premise of having goals and always striving for improvement. Nothing is finished, everything's a draft in my mind and we just have to keep improving.

>> So... what we're talking about today is how the agency I run, Child Development Services has worked with the Maine Education Center for the Deaf and Hard of Hearing. Child Development Services is overseen by the Maine division.

We have, so... we're the lead agency for both those programs, and... we have nine sites across the state. We go all the way from New Hampshire border at the south to Canadian border at the north and anywhere in between. I know a couple people in here are from Maine. Anybody else ever been to Maine? It's a big state and there are some parts of the state that they just have names like township number 25 and maybe three people live there, if that.

So... it can get pretty remote. On average in Maine, we serve 1100 infants and toddlers every year. To put that in perspective, Maine only has a population of about 1.5 million, so... it's one of the smaller states, but we serve about 1100 infants and toddlers.

We implement Dr. McWilliams plan. He's a good friend of mine. We implemented with Fidelity across state. And... as part of that model, each team has a full cadre of teachers and therapists who ‑‑ each site has OTs, PTs, speech therapists, teachers, social workers, so... regional teams.

We started out with Dathan and Melissa's early childhood coaching. It's a blending of two models, primarily routines‑based early intervention.

One of the things to add, have any of you heard of Dr. McWilliams? We're in discussion about looking at data for deaf and hard of hearing children with this model. Dr. McWilliams is very curious about this. It's fascinating and we're anxious to explore it further.

The agency I work for, the Maine Education Center for the Deaf and Hard of Hearing. We serve children's through grade 12 ‑‑ actually, through 21 years of age. We provide lots of educational programming, School for the Deaf programming, outreach programming, early intervention ‑‑ the whole gamut and the program that you're going to hear most about today is early childhood and family services. ECFS for the acronym. That program [ ] supports families who have children birth to age 5. And we provide information, early intervention ‑‑ support... family resources, we provide support in daycares, preschools, homes, wherever these children are, is where we go.

We also have a focus on transition support. Into part B when the child turns 3 and into kindergarten. We have a lot of services that happen at that age.

This is our ECFS team. We have a whole team of Deaf Educators. Early childhood Deaf Educators, teachers of the deaf that are ASL‑trained, deaf mentors, this is trained SLPs, special educators, cued language providers and educational audiologists, we made it our mission to have as many people and as many perspectives at the table under our umbrella in one place.

And we have a deaf hearing team ‑‑ that's really important to me and really important to our agency. We don't have any group in our agency that has only hearing staff. Parent‑Infant Program, our outreach program, our School for the Deaf, our pre‑school ‑‑ all of our programs have deaf hearing teams.

>> So... we realized that there were two systems going on serving the birth to 3 population. There was ‑‑ so... when you hear us ‑‑ we refer to MECDHH or ECFS, that's Karen's group and ECFS is mine. MECDHH was running parallel and we weren't running together. We decided to create one whole team that works together, coordinates, collaborates and felt we needed a Memorandum of Understanding between my agency, the part C lead agency and Karen's agency ‑‑ the lead agency for deaf and hard of hearing.

The purpose of it was to develop one family‑centered early intervention program for families who have deaf or hard of hearing children. One team.

>> Karen: And prior to this MOU, we weren't playing so nicely. We had families referred to one agency or the other ‑‑ I just realized we're on opposite end of the room. That's funny to me, because that's how it used to be. We were separate, but we probably should move closer, because that's how we are now. We technically, can't do that. It struck me as we were talking about post or private MOU and this feeling of disconnect. We do a lot of work together. That's better ‑‑ yeah.

So... anyway, families prior to disagreement were referred to CDS or MECDHH. We didn't always say the same thing. We said different things and CDS didn't understand the Deaf Education part. It was tricky and complicated. Services ran parallel ‑‑ families had to tell their stories time and time again. Then the therapists went and told it again. We said, this is not okay. We started getting a lot of feedback from families that they were feeling pulled between agencies, our agencies, ASL specialists, spoken language specialists, all the different agencies and everybody was pulling back and forth.

We really worked to make this smoother and one system...

>> Oftentimes... oftentimes... the advice or strategies that we're giving families would conflict. We've been doing primary provider model with part C for awhile. The reason behind that ‑‑ the way early mention used to be, PT on Monday, OT on Tuesday, speech therapist on Wednesday, Thursday, another doctor, and Friday another et cetera. Nobody was talking to one another. We were kind of doing that with this. It was burdening to families. They had multiple providers who weren't communicating. They had to tell their story again and again... just wasn't coordinating and... it wasn't productive on our end and it was, I think counter productive with families and also confusing them.

>> Karen: The other thing that both agencies started realizing is state‑funded agencies, they were billing the state twice for the same thing, so... fiscally, it wasn't responsible at all. When we started talking that way to the upper ups, they really started listening. Money was the least of our worries. It's all how you play the game and get what you need.

I love this slide, this is what we've been doing and what we will continue to do forevermore. We had to agree to take these steps together.

>> Roy: So... in developing the MOU, we had to think about where we were coming from. We were two separate agencies working in conflict ‑‑ definitely not collaborating. There were changes in leadership at my agency... which helped facilitate some of this. We had some initial meetings, we brought in a facilitator to kind of walk everybody through about how this could look. We identified issues that we might be having, we agree to disagree on some things and then we really focus on what, what do we share? The missions of both agencies ‑‑ how are they similar? Where do they overlap and was he greed to focus on that and we needed to understand our roles as well.

>> Karen: We decided to make one referral source. So... everybody in the state would refer to part C. That was really hard for our team ‑‑ really hard for me to trust him with my families and my babies that I've always taken and okay... I gotcha. Going to turn them over to him. Very scary.

Now... now... but... that was a big leap of faith and it was really tough for my team to trust him and all of his providers because we know, right? We know the deaf kids. We know Deaf Education, they don't. We put that aside after much talk and deliberation, for the best interest of children and families and we said "we have to try, we have to give it our best effort and just try." Because they are the education referral source and they are part C and they are the ones that are legally responsible, it made sense.

So... letting go of that and a lot of trust in the process is where we were. Our goal was to create one early intervention team for the whole state of Maine and one seamless point of entry. It's really hard to do.

What we ‑‑ infants and toddlers, birth to 3, deaf and hard of hearing kids. That's what we're talking about. There were nine of them around the state of Maine, assigned one of my staff.

So... early on in the presentation, we talked about the, the model of RBEI and having the whole team. Now we added a Deaf Educator that had been trained to be open‑minded and responses to families and listen and all those things we want early interventionists to be.

We put them on our team, weekly teaming sessions, they took part in the eligibility evaluations. They were part of the development of the IFSP and the goal was to support families. And one of the ways we did that was adding my staff as primary service provider. And like I said before, it was separate. We kind of had our own service provision, they had separate PSPs that were working with families that didn't know about deaf children. So... let's merge and let's have my staff be that person, initially, and I'll talk more about what that looks like in a minute.

We wanted one team. And working together, we wanted our staff to be able to review audiological information, join service coordinators at that very first visit with families. What was happening before, his staff was going ‑‑ hello ‑‑ actually, that's kind of nice. I can lip read you, but that's okay.

So... the welcome visit, we did a lot of conversation about that. There was a lot of push and pull. You have to be there and no, I have to be there because it's the deaf kids and I know about the deaf kids and I want my staff to answer those questions. And he said but it's our job. Let's do it together.

So... now, our staff, often go in together. So... the staff can do their job ‑‑ and the not so fun stuff. My staff can be the ones that are ready to answer the questions.

What we were finding, his staff was going in, doing paperwork, doing the initial part C stuff and the parents had questions that didn't get answered.

So... later, later, later, they got their questions answered, but they need to know what's going to happen next.

The other thing we did was CDS added checks for their staff. We needed to do checks for our staff to make sure they're following the process the same way. Initially, they weren't. My staff was doing their same old thing while sitting on their team ‑‑  
 >> Roy: If you're familiar with the model. RBDI, there's a very formal fidelity checklist. And so... you have various components of RBDI. You get evaluated and observed. Evidence‑based practice, if you're implementing with Fidelity, so... it was important to us that all ‑‑ everybody providing services was doing it with Fidelity of the model. Those Fidelity checks applied to Karen's staff as well.

The interesting thing ‑‑ the videos I used in some of the trainings for RBDI are almost exclusively Karen's staff now. They're doing it better than a lot of my staff at this point ‑‑  
 >> Karen: Part of the reason is I have a smaller team. Those in early intervention know that coaching is a big part of deaf intervention. My staff was already trained in coaching. In his staff, it was new to them ‑‑ they were more therapy‑based. We were able to support that process.

So... having my staff attend routine based interviews has been a magical piece, being the provider interviewing those families, being able to sway it and follow the families through the journey, understanding that perspective. It's been magical.

So... each child, each family, is referred to part C. Is given one of my staff, early on, to be the primary service provider. Every child in the state starts their journey with one of the early interventionists who is trained on being open, honest and biassed ‑‑ all that.

We have six visits, give or take. Six is an average that over 20 years of doing this, we said it takes six visits. An average of six visits. We talk about all the things we should be talking about with families. Early communication, attachment and bonding. Do we talk about that enough? I don't think we do.

Looking at those earliest interactions with families, making sure touch is happening, making sure eye contact is happening ‑‑ that they're actually holding their babies. I see that a lot. They leave the audiologist, they go back home, have this diagnosis and all of a sudden, that disconnect happens between mom and baby. I had one family that I showed up at their home and it was evening, knock on the door, dad shows up, ran out, said... you deal with her.

Okay... peaked in, didn't see anybody, couldn't find mom, couldn't find baby. Hello? I'm deaf, couldn't hear her talking. I guess I'm just going to walk in the kitchen. Walked in the kitchen, looked around... living room... no lights on. Finally see mom huddled in the corner in tears, sobbing, don't see the baby. Where's the baby? Looking around... talking to mom... baby's over here in her car seat. Mom hadn't held her baby once since she left the audiology office. This was three weeks later. The baby had mild unilateral hearing loss. That disconnect. We have to start with that. We have to start with attachment and bonding and getting those families kind of be okay, the mom and dad at first. Everything else comes after that.

We start with understanding, okay... you have this information from your audiologist, what does it mean? The baby has hearing loss, moderate, mild, what are we talking about? What's the data we have? We explore all the communication approaches. And my staff are trained to explain all of them.

It's very hard, if you were watching my staff, to know their background, to know their personal bias, their personal belief system ‑‑ watching them. Five years ago, it was very obvious to see oh... that one really likes ASL. That one really prefers cued speech. That one prefers this thing in spoken language or what have you. It's really tricky.

This person... what do you think her training is in? Every single family said something wrong. I said... okay, we're doing something right, they're not showing their bias, that's good. Technology is exciting, hearing aids, cochlear implants. They leave the audiologist and they're not sure. I had one father tell me, I don't know ‑‑ they said something about food. Food. Speech banana ‑‑ okay... got it. That's what the dad took away from that visit. Understanding the impact of convective losses, we get referrals for that. Outcomes, we do a lot of visionary work. Vision for tomorrow, vision for six months, vision for five years from now and we write a plan ‑‑ the communication plan, their plan, and one of the magical parts we do in Maine is parents write that plan in their handwriting. Talk about empowerment, that's new. We just added that in the past few years.

When your mom and dad say I want this in spoken language, cued speech, whatever it is ‑‑ it's ownership. They own it. It's not my plan. We used to go in and interview and write and check the box, they want this, they want that, then all of a sudden, I had a wake‑up call one day. This isn't my plan, it's your plan.

So...

>> Roy: We got the MOU written. And... there were things we needed to do after it was written. One was to make sure that Karen's staff had all the necessary training for routines‑based early intervention. That they understood the model we were using and developing the inventory, our eligibility eval tool with Fidelity.

And we started sitting down together, at a regional level, at a state level, and having conversations, you know... as Karen says, coffee chats. So... Karen made a trip to all of our sites and met all the part C teams and explains how this was happening and I talked with my part C teams as well.

And... you know... explained the MOU and they were hearing the same message from you know... both people. And... everybody was on board. More or less.

>> Karen: More or less. What my charge was for my staff was to go make friends. The first year, that was all they really had to do. At first they said "we gotta jump in and do this." When you see somebody at the photocopier, pretend you have to photocopy something. You have to say hi to them. You have to talk. Do that. Have coffee chats. Say "what are you doing for lunch?" Sit down and have lunch. Get to know them as people, because they are kind of the enemy before. They didn't give deaf kids what we knew they needed. Be nice to people, who are these people? That was the first charge.

Okay... yeah... so... again... it was very slow to start, but we did it on purpose that way. Because... one thing we've learned ‑‑ if you hurry and do things too fast, it doesn't work well. We spend a lot of times figuring out roles. Who is saying what? The staff figuring out roles and they step on each other's toes sometimes. But that was okay. We went in with a trial and error model and everybody knew that and we had full disclosure at the state‑level meetings. In homes ‑‑ we'd say, this is new, we're trying it, let us know what you think. Figuring out strengths, what do I need? What does he need? What does my staff need? What are we good at? What are they good at? We started seeing that in each other. Hmm! He knows a lot about this routine‑based stuff. He's really good at data. She knows about these deaf babies and we started talking about that together and our staff started talking about that and they started recognizing strength in each other and using each other for that. I need to call you because you really understand whatever. And I started hearing that most. The CDS staff started accessing my staff more and more. They'd have a 2‑year‑old, for example, that wasn't responding well to speech therapy. They would bring my staff, maybe it's a hearing loss, has anybody checked the hearing? We were finding so many kids in this model because... they all knew each other and because my staff were there ‑‑ it was an instant thought. They saw you ‑‑ haven't checked the hearing, maybe I should do that. So... that was really cool.

>> Roy: So... I mentioned that we ‑‑ when we first moved to a primary provider model in Maine, we started out with [indiscernible] poaching. (?) What occurs in the weekly teaming session is all the part C team is there and now it included Karen's team. We had primary coaching opportunities. Somebody might say, working with this family, this is my challenge and the team discusses it and comes up with some strategies that they might try. They ask questions and... eventually part of that might be maybe it's good if I go out with you on the next visit.

Admittedly, the first month or two, the parent staff was sitting in those meetings ‑‑ it was a little uncomfortable and awkward because nobody knew how this was supposed to function and what we saw was, you know... somebody would bring up an issue, you know... a challenge they were having with family and Karen's team started to chime in and participate in that conversation.

Over the course of a couple months, we started to see the value of everybody. And everybody brings a certain skillset to that team. A certain expertise.

So... once we got comfortable with it, the conversation really started flowing and we saw the value in all team members, including Karen's staff.

So... I just want to give a very brief overview of routines‑based early intervention. Dr. McWilliams was at Vanderbilt and Siskin Institute in Tennessee. At intake, we have a conversation about the people that are involved in the family's life. Family, friends... neighbors, social groups they might be part of ‑‑ their work friends, as well as the professionals that are involved too. Part of that is just really understanding who all is involved, but the other thing is... we really want to go to those people on that ecomap as our first approach. These are people already existing in the family's ecosystem, they should be the ones to provide support, if possible. Rather than inserting a new stranger into the mix and duplicating something ‑‑ why disrupt that ecosystem more than necessary? The first part is to see who is in the family's life. The next is ‑‑ we conduct a child and family needs assessment that identifies the families concerns and priorities. We do that through the routines‑based interview, a long, structured conversation that goes 45 minutes to an hour and a half. It walks the family from the time they get out of bed to the time they go to sleep. We really dig in deep in all the routines to find out what's going well, what's not, is this a challenge, something you're concerned about? Something you want to work on.

At the end of that ‑‑ the family has identified all their concerns and priorities. They could be child‑level outcomes or family‑level outcomes. It could be about the child using words to express their wants and needs or it could be that the family needs advocate housing, reliable transportation. Any of those. And those concerns and priorities go directly into the outcomes. Whatever they said in that interview is what they were concerned about and becomes the outcomes.

Then our services in the home is to build care‑giver capacities. We want them to learn the strategies and integrate those strategies into daily routines. So... they can work on things during mealtime. They can work on things during diaper change, during bathing at the playground. The child isn't just getting one hour of therapy a week or intervention ‑‑ that's taking place seven days a week, all day long because the parent knows it's branches.

We do that in the natural environment. We know children this age have a hard time learning generalized skills across settings and people. We want to empower the care‑giver and acknowledge their role as the primary change agent in the child's development.

>> Karen: So... after that all happens ‑‑ the interview happens ‑‑ we start the six‑visit classes I mentioned. Six visits gives the family time, gives the early interventionist time to get through all the initial things you need to talk about.

The reason we made this process is the hurry‑up kind of thing that happens in our field. We have to hurry, we have to hurry, we have to get these kids amplified, we have to get them language. We do, but six visits, it can take a few weeks or months to calm things down and do it at the family's pace.

By having these six visits, that gives my staff a little bit of freedom to breathe and a little bit of acknowledgement that we do need to follow the family's process and not their agenda.

So... early on in this process, as I said before ‑‑ we're focusing on early interaction ‑‑ for me, I don't care if they talk at all about the deafness in that first visit. I want them to focus on this. Communicating, being face‑to‑face... following the child's lead. Helping families look at that baby, why are they crying? What are they looking at? What are they reacting to? Touch... interaction through the daily activities that Roy mentioned, the routines‑based, cuddling, tickling, putting the [indiscernible] away. You see a lot of moms nursing their babies. We can't do this.

Early on... we touch on the communication approaches. And again, if families want to hurry through them, we hurry through them, but we don't have to.

The next four to six visits is where we really get into the meat of it, we're explaining, we're demonstrating, we're comparing, we're contrasting, we're talking with the family about their priorities.

Again... how do you see a child communicating in your family? In your neighborhood? That's cool. We explained the roles of the various professionals that they may or may not come in contact with, if they start with one approach or the other approach ‑‑ we talk about different agencies that are involved based on one approach or the other. And we utilize those part C coaching opportunities to bring in different people.

We also are explaining what's happening add logically with these children. We're explaining the hearing technology ‑‑ again, we're bringing, we're touching, we're feeling, we're going on visits with them, with the audiologists, we're providing child‑specific resources to the families and we're reviewing outcomes and making sure we're staying on track with what the family wants to be doing.

At this stage, we're also supporting all the other outcomes the family has. For example... some families might want date night. In the middle of all this craziness ‑‑ they kind of miss their husband or wife. We're helping them talk about that. Haven't had that date night yet. We're on sixth visit, how are you doing? Let's call grandma. Maybe they need help with sleep.

>> Roy: I just want to say, you might think ‑‑ how does this provider know all ‑‑ you know... this is a deaf and hard of hearing kind of expert here ‑‑ how do they know about sleep or date night? There's that team every week. So... if the parent brings up sleep issues and Karen's staff is thinking, I don't know about sleep. They go back to that team and say, I have an issue to talk about. A family is having trouble ‑‑ their child isn't sleeping. Their whole team can discuss it and Karen's person can go back out to the home the following week and talk about sleep or bring somebody from that team who really knows about sleep on the next visit.

>> Karen: The benefit of that ‑‑ one of the benefits, is that every single provider is not going in separately. They're not thinking, let's go to the sleep specialist, now the PT, oh, sensory stuff at 15 months old ‑‑ here's an OT appointment. We bring them in. They get comfortable with us, we're their guide ‑‑ we're bringing in all the outside professionals that work with specific communication approaches.

For example... we're bringing in spoken language specialists. We're bringing in the cued speech specialists. Sometimes they come in together ‑‑ sometimes they come in separate, but none of them are going alone. The magic in that is before, as you know in our very politically‑charged field, the one agency would go in and talk about "I'm the best, this is my agency, this is my approach, you should do this." The other one went in "if you don't do this, your child won't make success" and so forth.

Because they were alone with the families, they would bring in the troops, they would bring in the troops and they would bring in the troops. And these families were trying to mediate all this. So... we had a lot of conversation about that and said "how do we stop it?" Families were coming to us, very concerned.

>> Roy: I was very naive about the politics in Deaf Education when I entered into this. My philosophy was the parent always chooses, we don't tell them what they should choose and... you know... they need to ‑‑ parents have ‑‑ our obligation is to give them complete information, so they can make informed decisions. And... they have the right to make what we might think is the wrong decision. That's their right and we respect that.

So... it was very important to me and Karen and I had a lot of discussion about this. We are not pushing a family any direction on anything ‑‑ it's their choice ‑‑ we'll give them that information, make them make the choice.

>> Karen: Family feedback has been a complete 360. Before this process, my phone was ringing off the hook, his phone was ringing off the hook. I haven't had one parent complain in the past three years. About that agency, this agency, that person or this person, nothing. Nothing. As children grow and go on, maybe get involved in different things, maybe... but early on ‑‑ not happening. This is the other thing that's a work in progress. Not perfect, we created communication language webs because... we wanted to make sure that as much as possible... each of my staff, when they were doing communication approaches, were being unbiassed and were saying the same things. Kind of a script. And scripts are fake, you want somebody to just go in and know it, but if it's not your field, if it's not your passion, how do you do that?

So... as a team and getting support from all those other agencies ‑‑ we're creating webs that focus on each different approach, American Sign Language, cued language, auditory, verbal, bilingual, bimodal. In each of these things, it says what is needed for success. If you're going to start with that approach, for example... listening and spoken language ‑‑ you have to wear your gear. You have to put the cochlear implant on that baby. As much as possible. You have to work with spoken language specialist ‑‑ you have to. Same thing ‑‑ American Sign Language, where's the deaf community? If you're choosing ASL... you have to have balance in your life. You have to have models. You have to be working with an ASL specialist. If you want the outcomes you want for your child. Cued language. Have you learned cued speech? Are you using it throughout the day? With this... right off the bat... six visits, we're explaining all this to the families. Knowing that, in some ways, it's going to go in and go out. That's okay. We're going to come back and back and back to this every six months. And more or less if we need to with assessments.

We developed a script and it starts with what's important to the family. Why would families choose one approach over the other? What families have told us in Maine. What's involved in each of the approaches and so forth. That's still being reviewed, but we use them as a pilot right now. It's working pretty good. We're doing a lot of practice. We don't want to be reading a script. This is on one side and on the other is a script. It's getting better, but it's been fun to kind of watch the team kind of figure out what's needed and watch families process that when we go back and we're not seeing an outcome with spoken language or whatever. We'd pull that out and say "remember, we talked about the hearing aid? It has to be on the baby's head, remember?" Because we're talking about it all the time, families are owning it again.

The other piece with communication and language opportunities is bringing in the specialists, they're able to really talk in depth. If I have a family that wants to learn more about American Sign Language, I'm going to bring a deaf adult, an ASL specialist, that's fluent in ASL to talk about that with me. Same with cued speech specialist, what have you. The concept of informed choice ‑‑ I love this quote ‑‑ reflects the fundamental belief that families make comprehensive, meaningful, relevant and evidence‑based information, from professionals, in order to make decisions that are most‑appropriate for their child. Right?

I think we all would agree with that. Is it always easy? No... but that's helpful. And I can't stress the next two bullets more... the role of deaf and hard of hearing adults in this process is so critical. You have to involve them ‑‑ you have to. They're the ones that lived this. They know. They know what it's like to grow up using one approach or the other ‑‑ to change approaches, to try and change to something different. They know what it's like to live in a household, if you're using ASL to communicate in spoken language. They've been in their shoes, they've been in the parents shoes. Connect them early on ‑‑ in this process, we built them into the first six visits.

You can see, there's a lot crammed in, but there's a lot of time within six visits to make that happen. Every parent has the opportunity to meet deaf and hard of hearing adults and other parents within the first six visits.

I mentioned that. The communication plan. Our communication plan really looks at language at the home and making sure that families really analyze that and understanding that if you want to communicate in American Sign Language, that's a whole other language, it's grammar, syntax, all of that. The language and communication opportunities that the baby has within the home. Who's communicating with them? So on and so forth.

So... we're working with the family, the family has written their communication plan, they started their approach, after the six visits... and after the communication plan is written... it may not be my staff that stays with the family. The primary service provider is the one that best matches that family's communication approach.

If it's listening and spoken language, it'd be a listening and spoken language specialist. If ASL, then ASL specialists. If bimodal ‑‑ then it's both. That took a lot of work. They go in together... they go in separately. They have to go once a month together. We worked a lot on that. Listening and spoken language specialists, deaf specialists, ASL specialists, doing a home visit together.

Wow... it took a lot of work, but it's been really fun. Watching our deaf adults learn to interact with the specialists has been magical. Having the family see the different perspectives can work together ‑‑ it's okay. We're looking at those families.

So... we have a new provider in there ‑‑ or not. It's the one that started with that family is listening and spoken language‑trained, or cued speech ‑‑ they stay. If not, that changes. But... what we kept with my staff going back every six months, regardless. That neutral balance, unbiassed person, comes back in to check on things. How's it going? How's the outcome? Remember those bubbles. What'd you pick? Are you in the deaf community? All those things.

They do assessments every six months, they're looking at the data. And bringing information back to the team. Progress monitoring has been huge for this project. We're trying to not let children go too far before we're talking about it. Years ago... in Maine and I think the whole world... families would start on a process, listening and spoken language, cued speech, ASL, what have you and nobody ever looked back. Nobody really commented that this baby isn't really talking at 3 or this baby and the family isn't signing at 3. If a baby is not making progress after six months, we're just going to take note of it, we're going to chat with the family. Are you with the deaf community? What are you doing?

Sometimes we go a little bit deeper. 18 months, we'll start talking. 24 months, we'll pull up those communication options again, we'll look wholistically, what's going on? Doing more assessments? We won't let it go.

All families have the opportunity to meet deaf and hard of hearing adults. In Maine, we have the formal deaf mentor program and the Deaf/Hard of Hearing guide program at Hands & Voices. The programs are separate and both highly valued. The deaf mentor program is part of the IFSP. It's written out as family training. The deaf guide program is part of those early visits ‑‑ any time a family wants to chat with a deaf adult, we can bring them in ‑‑ any time. The parent to parent support, we do a lot in Maine with getting families together. Our Hands & Voices chapter is very vibrant. What we've found is, by having natural interaction at events... families are so much more comfortable with deaf adults. We make sure that we have deaf adults from a variety perspective at every single event.

So... it's not scary, they're just there and... they're watching the deaf adults interacting with the deaf kids ‑‑ whether they're talking or signing or cueing, what have you and they're like "I want to try that, that looks cool. Maybe I can learn a sign or two." Or "that person has a cochlear implant, I want my baby to meet that person. It's just natural. You don't have to have an appointment or visit ‑‑ it happens on the playground.

>> Roy: So... we got into the, the pilot year and we had to think about how has this gone and has this worked? And... you know... what do we need to change? What do we need to tweak a little bit? With implementation science, you look at how implementation has been and look at the data and determine what you need to tweak a little bit.

Yes... absolutely. So... true with families... true with this collaboration and then... that.  
[laughter]  
 >> Roy: This was originally 25 minutes ‑‑ can you imagine? The highlight year, we had our challenges interpreting the MOU, our responsibilities, what we do require is some role release, which can be challenging for some people. It means that you're not necessarily the expert anymore or you need to impart some of your professional knowledge to somebody else and trust they can take that strategy to the family and release some of that special knowledge to the family and trust they can implement it with their child.

We, we got a lot of buy‑in and as we got further into the year, it was truly one team. So... these families didn't say "the person from MECDHH is coming today." They said the person from early intervention team or CDS. They didn't realize we were two different agencies working together.

There was concerns about the timeline because in part C we have 45 minutes to get to the IFSP ‑‑  
 >> 45 minutes?   
 >> Roy: 45 days! Yeah... it's a very tight timeline. I think that Karen's team has those poles they had in firehouses. They hear there's a deaf baby and they jump on it ‑‑ they gotta be out there immediately and we work our way through it. These parents need ‑‑ they can't wait 45 days in some cases. We worked our way through that.

So... you know, the recognition of you know... just the information, that early support we've been talking about all year long.

And what we had really ‑‑ in the long run ‑‑ created this community of practice and this whole team ‑‑ in the center here ‑‑ the CDS team that now includes Karen's people.

On the outside, we have the cued language, family trainers, ASL family trainers, we have all of those folks around us that are supporting that child's early intervention team.

>> Karen: And the other thing we did, we made it in Maine as the only way to work with deaf and hard of hearing children is to go through them, unless you do a medical model. If they work with part C, they had to contract with MECDHH and become part of this team. We talk and figure out what we need to figure out. It's been really ground breaking. We don't anymore say that. Families don't know anymore ‑‑ they just know with early intervention ‑‑ there's been a lot of reflection ‑‑ a thought of thought ‑‑ a lot of changing and really, the staff are happy. But... most importantly, the children are happy and how the one system has been the magic ‑‑ where continuing to work on our communication approaches and I think that's always going to be. Things change ‑‑ we'll always be looking at that. We're working on a part B communication plan right now and the process within that and we're formalizing those webs I showed you.

I don't know how much time we have left ‑‑ but we'll give you a few tips. Number one, accept that in your state if you try something like this ‑‑ it's trial and error. It won't be perfect right off and may not be for a few years. We're still fixing things. Start small, find somebody that you can connect with. Facilitators help ‑‑ facilitators are needed. Sometimes it's hard to have these conversations. Bring all perspectives to the table ‑‑ you can't do this with one or the other or the other... you have to have everybody at the same table.

Be open to change ‑‑ be open to give a little bit on something that you might not want to give a little bit. Set up regional focus groups that help so much. Really... going to each area and looking at that community, the culture of that community... in Maine, as I'm sure, all of your states ‑‑ if you go way up north, the culture is very different than it is in the southern part of the state and the west and the east ‑‑ really looking at what each part of Maine looks like and who are the professionals in those areas. This will not happen in one time. It will probably not happen in five times.

Set short‑term goals... this means we'll try this and have your long‑term goals. Always make sure you have a parent at these meetings. Can't do it without that perspective. And deaf and hard of hearing adults, you have to have those perspectives. To do it without that, not going to work.

Start with what's already in place in your state, kind of figure out your state. What do I have that's working? What do I have that's not working? Where's part C? Part C is the door. They're the ones that get the money. They have to do this, legally. Where are your early intervention providers? Where are your ASL specialists? Bring them in. Can we make this happen? They'll be intrigued, when they find out one door means that they have a seat at that table. Everybody has a seat at this table. Not one ‑‑ not the other ‑‑ it's balanced. Find your experts and identify your champions. Who's out there for you? Who's going to support this? Find your open‑minded team and build a team that will be that first point of contact for families.

Those people have to be open‑minded. They have to be in the parent's corner. They have to be able to have the straight face test and more than the straight face test, the body language test. The eye test.

Early on, when we started this, I was chatting with a mom who's here, that was our first mother we did this with. I was questioning her last night, I hadn't seen her in awhile. She said "you guys have gotten better." I said "what do you mean?" She said the first visit, the provider did a great job, said the script, said all the words, but her body language. When she was explaining one or the other... it was different. Her eyes were looking away. She didn't have eye contact. I knew what she wanted me to do, even though the words were right. I talked to parents that said that too. We started role playing, bringing in other parents that were further along in the system. You have to practice ‑‑ now look at it there.

Practice within your state ‑‑ pull people together. Can you explain ASL? Have a deaf person watch you. Was that right? Was it accurate? Can you explain this thing in spoken language? Are you doing it the right way? Training in your state ‑‑ if you want to do something like this, you have to cross‑train. Have to cross‑train. Understand whatever is happening in your state in part C, figure out what their philosophy is. I'm going to pull the kid out, have them at a center ‑‑ that's not what they do in Maine. We had to learn that model and embrace it. Opportunities, buy into that. There's no one way. We've seen deaf adults through this whole conference. Not one of us are communicating the same way. We flip, we flop, we do the same things. That hard of hearing perspective ‑‑ bring them into the table, bring them into the meetings. The medical perspective ‑‑ if you don't explain your model, the doctors, it's going to back fire. The same with the audiologists.

We were talking about that this morning. We have a couple audiologists that don't understand our model. We had a mom go to the audiologist and say "I didn't get a speech therapist" after one visit. If the audiologist had said "tell them you want to jump through the six visits." There's a six‑visit thing they need to get through ‑‑ they'll get there. We had to figure it out, our staff said I gotta do the six visits and some parents were saying "I know what I want, I don't want to listen to everything else." We had them sign off on the six visits. They, themselves decided they don't want to learn about it. We don't have to force this model on anybody.

Without learning ‑‑ you know how there's a difference in working with adults and babies ‑‑ we did a lot of training on that. Cultural sensitivity ‑‑ do your early interventionists get the deaf culture perspective? If they don't... make sure you train them on that. Do they understand the audiological perspective? What about home visiting? Do your staff know how to go into homes? Look at all these things in your state. Have we trained early interventionists and all these things. We brainstormed ‑‑ what do we need training on? These are the things that came up the most.

Focused on support of families. Look in your state... where are these people? Where's the parent to parent support? Do you have a Hands & Voices chapter? Where are they? Where's the deaf adults? Internet ‑‑ what's happening? Are people really getting on the internet? Yeah... how can we support that? The community ‑‑ the rules, the southern, the northern, the eastern, we have a whole Amish community. What does this model mean for that? They don't want technology ‑‑ they don't want their baby screened. How can we work with them? Understanding their state and how whatever model they're going create fits with the people they have and the professionals. That's the heart of this. You have to get them on board.

We're doing planned studies ‑‑ little, little steps of change. We started that first thing ‑‑ we're going do this in a couple months, we got this ‑‑ no... we had to do little steps of change. How did it go? Let's plan it, let's do it, let's study it and act. We have done this over and over again.

So... we did a home visit... how did it go? Did it work or not work? This is a really good process to follow. You have to stick to it ‑‑ if you don't have that and you don't have somebody to do it with and you're both in the same mindset that you'll stick to this until you get it, it won't happen.

This is my favorite quote ‑‑ I use it all the time. This is from a parent. Parents say what we really want, really need as parents, and opportunities to contact other families with deaf children, helping make you regular contact with adults who are deaf and hard of hearing, information that is accurate, honest, unbiassed and fair, and then the emotional support to make your decision.

Any questions? Yes?

>> How did you train the staff? Did you bring in services or figure it out over time?

>> Roy: I'm nationally certified trainer in routines‑based early intervention ‑‑ as are our staff. We provided the trainings. Karen's staff joined our staff, so... some new staff of ours was getting initial trainings, in refresher trainings, et cetera. We were able to do that in‑house.

>> Karen: Yes... is this on? We did ‑‑ we brought a lot of people in. I like grants, and... we're finding grant money to bring in somebody that knows this thing in spoken language. Somebody that gets whatever ‑‑ we found that we can do a lot of this, by having somebody else say it. They can see the exact same thing you say, but having somebody else say it and you follow‑up, really helps a lot. We tried to highlight the staff and people in the state trained one way or the other. We could highlight local resources and bring in others as well.

>> So... what happens if either of you leave? How is this whole relationship institutionalized?

>> Roy: We've had somewhat of the same concern. You know... I think I ‑‑ I have faith that this has become business as usual, for our teams. They really know this and they appreciate and value it.

So... there might be some of that historical knowledge that would go away, but... I think that our ‑‑ both of our staff's would be very vested in making sure this continued as it was and continued to improve.

>> So... we have ‑‑ the Memorandum of Understanding, it's a two‑year document. For two years, two years, two years, we have it. But we've had that fear. But... in the document, itself, it highlights who is doing what for each thing. If anybody wants ‑‑ I'd be happy to send it to you.

It is kind of scary. I think that we both agree, like Roy said, that people are buying in.

>> I have a couple questions about coordination, what about deaf plus babies? Is someone from your group ‑‑ the PSP in those cases? If not, how do you coordinate care for those? And also... as far as coordination ‑‑ it kind of sounded like you were all in the same building. I imagine that you're, like... not everybody from part C is in one place, right? You probably have regional things and... in your dealing with all kinds of babies, not just babies that are deaf and hard of hearing, so... how do you coordinate those teaming meetings across the state?   
 >> We determine the primary service provider based on the family's concerns and priorities. So... if most of the outcomes are about deaf and hard of hearing... then, what makes sense for one of Karen's people to be PSP. Let's say the child has autism. It might make sense for one of my staff to be the PSP, but in those situations, we'd definitely be bringing in Karen's people to provide consult, joint visits and see them regularly. We can make sure everything's being addressed, but we're basing the primary provider on what the family's most‑concerned about.

And... we have a ‑‑ so... all of our regional programs have an early intervention program manager who we meet with on a monthly basis.

So... it's ‑‑ we're very lucky and we can really communicate, message, train, be very organized, all on the same page. Unlike some states ‑‑ we don't have a vendor model where we give a lump sum of money to a vendor to provide early intervention ‑‑ the sites are ours. They are CDS sites. We have more control than other states might have ‑‑  
 >> Karen: We do have a specialized specialist that is a deaf‑blind specialist ‑‑ my team as well. There's a lot of state‑wide work. We use teleservices a lot.

>> We're going to take like two more questions ‑‑ our time is up.

>> I think mine is a longer than two‑minute one, we can talk after, but I was wondering the funding flow ‑‑ how does the money work out for the differences? Maybe it's a short answer ‑‑ I don't know. We rely on federal part C grant and state appropriation. We provide money to Karen's team. So...

>> We made everything fit. It used to be two separate line items. Now we get additional part C for each child. We went through and made every single thing fit part C. We made sure it fit and we also ‑‑ the HRSA grant is how we brought in parents and deaf and hard of hearing adults. We merged the two ‑‑ the HRSA grant and part C. Great... thank you.

>> Thank you.

[Presentation concluded at 11:44 a.m. ET].

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