>> Okay, let's see if we have captioning before we get started. Good afternoon, because we have just such a short time, we are going to go. Sounds like you can say your name and where you are from and then it's time to go so we are going to go I name is Shelley Bergeron, I am from the statewide outreach center in Austin at the Texas school for the deaf but I work in outreach where we work with families all around the state, with students and professionals. Although I personally do have two sons who are deaf, both are adopted, I got them both at four and 15 so I didn't go through this whole system I am familiar with the system. Our objective today, I'm not going to talk about them, but my goal for today is that you actually will get something that you can bring out and use at home in your state.

Just so you are aware, you don't need to know all of this but compared to your states, this is kind of the overview of Texas. We have just a few school districts, a few schools. We have 53 regional day programs for the deaf and those are all independently run and managed by their local boards who determine what mode of communication they use and how they work those out. We have one Texas school for the deaf which was a bye-bye program and then we have three charter schools [ INDISCERNIBLE ] then we have 42 early childhood intervention agencies. They are state monitored, but each also are more independently run as well. So we have a lot going on in Texas. This is just a quick overview of our numbers for 2020 and then our most recent numbers from 2021, and the good news is we will never be without a job. This is also just a quick overview of kind of how things look in Texas and how we work things. We have our partner, the Texas EHDI program. We are the state average center which is a wrestler a C and we have SSA's on there which are family advocates and they help us for babies who have not passed their hearing screening but have not yet gone to identification, they are reaching out to those families making at least 600 through 1000 contacts every month reaching out to those families to try to get them to the next step, which is ideally to get them to identification, but they are working really hard with all of these families around Texas. There's only three of them, and two of them speak Spanish and they are all parents of children who are deaf or hard of hearing and have been through the ECI system. These are our stakeholders. This is not an exhaustive list. Families I think are the top and that includes parent too parent support even though it is not listed separately and then all of these other stakeholders not in any order. Of course there's more but this is mostly an idea for you guys to think about who are your stakeholders and if you have any that maybe you haven't thought about. Okay, so this is where I want to go. We are going to look at the problems and briefly talk about the problems and then we want to talk about what we can do about it and what have we been doing. Okay we all know we have lots of barriers. Consent is an issue in Texas. Both consent to provide information to our teddy system, provide information to SOC, as well as between our part C and Teddy. Of course, loss of follow-up, loss of documentation. As probably I would assume, you have similar issues, lack of access to the non- part C providers and in Texas we don't have statutory requirement so they don't have a requirement to feed it data into the system, so they don't have to and they don't recognize the urgency, doesn't always happen. Okay, this is where we really wanted to go. Our strategies. Since 2019, statewide outreach center has had access to the Teddy and I asked because of House Bill 2255, and so, that has allowed the care coordinator which is myself, to have access to this teddy system and be able to pull the data and reach out to families as soon as they are identified. And if so, it is so exciting to be able to talk to families that have a baby that was identified two weeks ago or whatever that is, and be able to communicate with them and explain on the parent of two deaf sons, and now I want to make sure that you get connected to all of our local resources. So that is one of our strategies but that is kind of a broad one. Here are things we've been trying to do in Texas to really make sure that we are getting our families the support that they need. One of them is because we are so huge in Texas, and as you sow we have 42 AC eyes, we have 53 regional day school programs, we have a lot of people and a lot of moving parts. So we have area meet and greets, and thanks to COVID we are able to do these by Zoom so we reach out to providers and maybe those regional days go providers with their parent advisors, and there might be one or two in one area, and then whatever ECI's work with them, which could also be 12 four, there could be multiple ECI's working with them and we are going to bring them all together and we are going to talk about what are the issues in your area, what are the problems? Are you seeing consent problems? Are you getting the paperwork you need? Are you having problems communicating with families or connecting with your parent advisor in understanding what they need to be able to reach out to the families? Whatever the and is really just a facilitated discussion. We don't have agendas for these meetings. We do it to try to help people know who's who in their area and in that arena, so that they can just say this is a problem, it's like that's the person, that's why it's a problem. It might not be as much of a barrier that they thought. They didn't realize something going on behind that. So these meet and greets have been extremely useful. The state lead for ECI has been participating in all of these as well, so that is very helpful for her to kind of hear what problems are going on in local areas, and this just has been a really much more useful than we anticipated and has helped us as the statewide outreach center recognize some of the problems going on in certain areas so that we can try to address some of that as well.

This is one of my favorite things I've been able to do since I became the care coordinator. I'm able to access the data that's in the Teddy and I asked for what babies have been identified, so I will reach out to a regional day school, and we will set up a time to meet and I will have pulled their data and analyzed and sorted it, and then we will me and say how many babies are you serving that our birth to three and I will compare that how many babies are identified in the system and almost always, they never match up. So then I will be able to reach out to all of those families. Again, we have consent issues so I can provide them information but I can reach out to the families because we have that consents. I can reach out to those families and explain this is what the school does, this is what is the eye does. You interested in becoming involved? It's a great way to provide information to them and it's a great way to partner with our regional day schools as well to make sure to make sure were getting all of the babies and support so that they can support the families. We can partner with our non- part C providers. Peer? Are always trying to find new ways but right now we are able to meet with them and try and determine what families they are serving, or when I'm reaching out to a family and they tell me they are receiving non- part C services I can update the MIS so we are getting more accurate data. Of course it's not a perfect system you and we always have room to improve, for now at least it is a place to start. Again, the same as a regional day school, we will connect them with the local provider's first we want to make sure they are getting whatever they need locally before we get them anything else because we need to know who is in their area, who is the school, what does that mean? We want to make sure they are connected with their parent too parent support as well because we are more than likely going to have parents in the area that are going to be able to support them so they can connect with other families as well. That's one of our biggest strategies is always to make sure that the family is reached out to and connected to all of their local services, and we are really seeing progress in this area, but again, we have to have all of the data entered to be able to make further progress. Okay, I did that really fast. Sorry. That was a little faster than I anticipated. So basically what now cream you guys can ask me questions but what I was hoping once you guys can use some of these ideas or ask questions about how we did that, and think about ways that you can use those in your state, or share with the people here another idea of strategies to be able to improve the care coordination, because this is always the goal. We've got to get more families into the services, and if we are not able to do that, we are not accomplishing what we set out to do. Sorry, that was real fast.

Yes?

>> Hi. You talk about a couple slides back, you take a list to one of the schools or the service providers of who has been identified in the system and you kind of compare but don't share.

>> We compare numbers. Compare numbers. So are your numbers always higher than their numbers? Have you ever come across their number being higher? Because we are always worried that there's people getting services that we don't know are identified.

>> I wish we had that problem.

[ LAUGHTER ]

We I kind of think.

>> I kind of think that would be a good problem to have.

>> So I was wondering about how your audiologists reporting at the data to you, because I would say we have the same problem where we sometimes have kids who are getting services thankfully but we don't necessarily know about them at the state level, so what's the system to make sure that all of those kiddos are coming -- that you are knowing about them?

>> If it is in the Teddy system I know about them, so if the audiologist is updating the system, then I have access to that. Because of our partnership with the Teddy and the House bill. If they are not updating it and I don't necessarily have access. Except that with our family support advocates if there is not updated information yet, we know that when they are reaching out to a family, let's say they have not passed their newborn screening and a family support advocate reaches out to them. It could be that they have already had their outpatient screening done and they passed, so then we are going to have another partner reach out to those providers to say could you please update the system? Or it could be that the family said the Dr. Told me don't worry about it, come back and a year. Or they can say I can't find a provider or I don't know what to do or I've just been too busy. All of the different reasons it could be so we are going to try to soak at the system updated, but if it's not updated and I don't have access to expects of the family support providers are following up the kids who haven't had their screen so you have that other input resource.

>> They are working all. Identification around the state making about 600 to 1000 contacts around the state to reach out to all those families to try to get them to identification or at least to the next step.

>> That makes sense, thank you.

>> You're welcome.

>> I have a couple questions for you. The statewide outreach Center, is that correct? How is that funded?

>> We are a state agency, so we are a part of the Texas school for the deaf on the same assigned to provide resources and supports to the rest of the states to students who do not go to Texas school for the deaf and then we are partnered because of the hospital with early detection to be able to have access to the Teddy MIS. Sorry, I'm sorry. That part is HRSA funded.

>> That's great. Have a couple of more questions. So what is the database that the state EHDI utilizes?

>> [ INAUDIBLE ]

>> To have access to the entire database or do you get a listing of the babies that are identified?

>> Specific access that is assigned, that is given to the SOC to the house bill. Specific area and that I have access to families that have given consent.

>> Are you the only person man who contacts the families?

>> Post identification, yes.

>> So what do those numbers look like just out of curiosity?

>> How many do I reach out to? Ideally all of the much right now is about 400. They don't all reply of course. And at some point we are going to have to add another me to be able to when we have more families.

>> Your methods of communication. I'm sorry, I have a lot of questions. Is it phone call, e-mail, text? Because you have to have consent for text, how do you collect e-mails from the hospital level? Lots of questions and how do you contact those families?

>> All of the above. I will try to reach out to families by phone but we know lots of families these days don't answer their phone, so than I do text with them, then we have text -- I don't get e-mails from the system, but if they provide me their e-mail, then a lot of times what I will do is follow up with an e-mail of information including if they have unilateral loss may be provide them information about unilateral loss, and then give them an information and follow-up again with a phone call to answer any questions from the information they have received.

>> Okay, one more question on the text. How do you get the cell phone information? Is that collected at the hospital level?

>> Yes, that is from the Teddy system.

>> Okay, and once you are in contact with them and provide this information, windows part C kick and?

>> That is a good question. In theory, they've already been referred to part C. I can see if they have or have not. If not, I have the access to be able to refer them in the system but I'm also going to do it personally when I try to reach out to the family.

So that is part of the issue with our consent in Texas, is that part C providers have access to the system but don't necessarily go back in and feed that data, so I have access to be able to update the data, so if I communicate with a family and find out that they are receiving part C services, I am able to update that part into the MIS.

>> So you're pretty part C in terms of contact with the families were simultaneously it looks like from your diagram, if they are nonpassive they get automatically referred to part C.

>> They get referred on a suspected loss in Texas, which also kind of causes issues because they are referred on a suspected loss, and if they been reach out to, they might not want to get services yet because it is not a confirmed loss, and then hopefully I will be able to reach out once they are confirmed, to get them back -- to get them started and services picked does that make sense?

>> Yes. I have one last question. In terms of your contact, like you said, you contact so many families and they don't answer or you may not reach them. How many times -- is there a process or standardization in terms of how many times you contact the family and then you sort of closed the case, or you just put another referral into part C and hopefully somebody from their agency will contact the family and get in touch?

>> Teaming on my side or a part C side?

>> Probably your site, many times would you contact family before you sort of give up?

>> I won't give up. Until they tell me now. If they tell me now, do not contact me again, then I won't, but I will just kind of regularly go back, maybe in a month. Here's a great example. I reach out to a family in November, nothing. I tried again in December, nothing. And then I didn't in January, and then just last week Mom reached out to me and she said I'm ready to talk to somebody, can you give me a call. So to me, I want to give up, because I'll just keep going until they tell me NO.

>> That's when you're able to leave a message but for example if you have no voicemail or the voicemail is full, so than what do you do in those situations? You just text?

>> Text. Not everybody, but there's a lot more responsiveness to text. I will also leave a message and say feel free to text this number.

>> Hopefully this will be my last question. I'm so sorry. If there's other questions I will have to give up the MIC.

>> Where are you from?

>> Ohio, State EHDI. We don't have early intervention under our umbrella so we have to make a referral to part C and we don't have any contact with families. I mean, we do, but we can't offer any hearing information. We can say this is like nonpassive newborn hearing screening, here is your referral to audiology, connect to them. We do have a group that does make phone calls, but similar to what you are doing, to provide a referral too early intervention, but we struggle with the same challenges, like we don't have consented to text, we may not have cell phone numbers. We may have one phone number, we don't have any e-mails. We send letters from the Department of Health to the parent and physician, so we end up unable to contact by phone, no response through letters to the parents or pediatrician, so we struggle with that piece of like we follow them for a year, and sometimes they surface at a year and sometimes a surface later than that and sometimes they don't. So that's why I'm curious as to what you're process looks like.

>> I think our state coordinators here, Ryan Hutchison, also one of our audiologist is here, Renee, and our parent too parent support coordinator [ INDISCERNIBLE ] so I think we did have that problem prior to this house bill passing and allowing SOC to have access to help families, because we just don't have enough people in our EHDI system to be able to reach out to families, but we have that capacity, and we have that desire and passion because that is all we do. So I think that makes a difference, to up here because we have the ability, whereas our EHDI people didn't either. Do you have anything more to say to that?

>> It's about kind of pipelines and knowing what we are good at, and making sure we have our mission, working with public health entities and a SOC is our statutory responsible in Texas for supporting families and children from birth to 22, so they are the perfect partner for us post diagnosis so it's that partnership, and they understand the landscape of support and resources across the state that us as a public health agency never could.

>> Thanks. Any other questions? I will put my e-mail up here, too, if anybody has any questions later.

>> Sorry, I just wanted to ask how often are you holding your meet and greet discussions and your data review groups?

>> Great question. Our meet and greets, remember we have 42 ACI agencies and 53 regional day schools. Ideally, we are doing one a month, but we are not able to do all of them every year obviously, so we are doing different areas each month. Doing the regional day school reviews, I'm trying to get to all of them this year, and then it is up to them when they want to do it again. Because this is a new process, I'm doing all baby's birth to three, but then after that we won't have to do birth to three, it's from the last time I pulled the data that should be faster and easier but ideally at least once a year. Some of them want to do it every three months, some want to do every six months or a year. I kind of leave it up to them.

Any other questions? Thank you for coming. I hope this was helpful. Have a great day!

[ APPLAUSE ]

>> Thank you so much. If you guys wouldn't mind filling out your surveys, that would be much appreciated. Thank you.