>> Today's session will run for 30 minutes or 9:40 AM to 10:10 AM. It's important we end right at 1010 because there's a second session that begins at that time. If there are questions afterwards maybe reach out to the presenters with the email address if there is time. I'm sure they would be more than happy to answer your questions. If you have questions regarding the conference you can find me in the back of the room. I serve on the EHDI student committee so happy to answer any questions if you need assistance but as of now I will turn it over to Karen and Darlene.

>> Is this on? I can hear myself. Perfect. Hi everyone. I am Darlene Freeman. Karen and I are from Maine and I and the quality improvement specialist for our HRSA Grant in Maine. I'm also on the board of Maine hands and voices and I have a daughter who is 27 and Deaf. So that's why I have been involved in our system for quite a number of years.

>> Hi everybody I'm Karen Hopkins the executive director of the education for the Deaf and hard of hearing and principal investigator and EDHI [indiscernible] hearing child so we both bring a lot of perspectives.

>> That's right so when we first started talking about this presentation what we are doing for resources in Maine, one of the things I thought I would start out doing is having all of the parents in the room close your eyes and try to remember when you first found out that your child was deaf or hard of hearing and how many resources you received in the beginning. And how overwhelming that might have been for you. That I thought, wait a minute. Nobody needs to close their eyes and try to remember that, right? I am 27 years out and I can remember like yesterday how overwhelming it was for me way back then getting resources from everybody that we were working with, whether it was a doctor's office, audiologist, weather it was the early intervention is coming to our home. All needed information, but that information was in paper form for me way back then and it was in a stock on my counter that at the end of the night after my children went to bed I try to find a half hour or 45 minutes were I could pull a few pieces off of their and tried to read through and learn as much as I could before the next day when I might be going to an appointment that I felt like I wanted to have that information so I sounded like I had some idea about what I was talking about, right?even though I didn't feel like I had any idea what I was talking about. So that is really where this project came from. And that feeling of overwhelmingness that I had way back 27 years ago that is still going strong.

>> And that was me. I was the one that brought all those resources to her. I was her early intervention is 27 years ago you said? Yet we are kind of old. But anyway, back then I was so uncertain and I thought I kind of knew what I was doing. But I was young and inexperienced and depending on all the print to make sure that I was doing my job by giving this new mother all the resources I had at my disposal, which was a lot and I wanted to make sure I gave her information on hearing aids and cochlear implants and spoken language and ASR and cued speech and and and and so I would give and give and give because that is what we are supposed to do. We're supposed to give information remain unbiased and become defensive. All those things. I was not apparent at that time so I don't think I really had the perspective of a new mom with a baby trying to navigate all of life's things and then throwing all these things on top of it, in my dissertation study originally I'd been interviewing a lot of parents. And it's all been through Zoom. So one mother I was asking about resources and she said hold on just a minute. She picked up her laptop and said you're going to go in the bedroom with me. So we went in the bedroom, she opened up her closet door and there was a pile from the floor up of papers that she had received. She said I just get them and I put them and I put them and I put them and they layer and layer and go up up up. And I don't read them. I don't have time to read them. And she has guilt because she hasn't read them.

So years of experience, Darlene and I experienced together her experience in hands and voices, my experience with many many many families, we've simply got to do something about this week this isn't working we have to come together at the state and come up with the one document and audiologists and the doctors and hands and voices and early interventionist agree on this one thing.

>> So fast forward to the time when I was actually working in the system and not just a parent and many years had gone by. My daughter was in middle school by the time I started working for our EDHI program and the complaint we got still after all of those years was still too much information. Still too many resources that they are getting. Still too little time to be able to look at things. And technology started entering the picture. So while I feel like a lot of you have a lot of benefit from electronic formats it also adds another layer because you are doing the paper forms and you are also expected to remember all of the websites and what link was that and who gave that to me. So it's almost double the resources that you had before and knowing what to recognize is really hard still.

>> so how do we find the balance? Think about one system for our state the balance is the amount of information with family centered intervention attachment, bonding should happen in the beginning.

>> So, so we knew then and there because the complaints were still the same that we had to go back to the drawing board. We had to find some way to give families the information that they definitely needed. We don't want to hold back information from families, but to figure out a way to do it so that it's not overwhelming. So the people don't have to use their precious little time that they have that they are not busy during the day to sit down and have to read all of that information. So we sat down with our team and we figured out we needed parents need something that stands out so that when they want to go back and find that information they flip through a few things and oh yes. This is that I recognize this. We needed something that we knew would be trustworthy. We don't want families going down the rabbit hole of Google and finding things at 2 o'clock in the morning that are just going to make them more overwhelmed than they were before. So we wanted some way for parents to be able to recognize that this is what I read yesterday from that person that I trust so I know that this information is trustworthy.

>> And we also wanted to make sure that with the coloring and the branding that we talked about with the logo that families got the same look, the same messaging from the hospital, from the audiologist, from the early interventionist. And so on. So that they felt like we had a team. So when we brought team people together and we didn't add a team picture. I forgot. Note to myself.

We had a parents, five parents on our team we had a deaf adult we had an early intervention program which is the EDHI program in Maine we had the audiologist we had the family based organization, we had part C, so and we got everybody together bringing all the perspectives to how do we make sure every step of the way all these perspectives are here.

>> So, from the very beginning we started small. And as you can imagine when you are working part of a team there are a lot of perspectives. There are a lot of opinions of what we should be doing. So the process took longer than a lot of us thought that it would but it was good. It was good to get all of those perspectives. So we started very small with the one logo in the middle that is of different coloring is hard to see up there, but we like that logo but we didn't necessarily like the color so we changed the color to the color down into the right-hand corner of the purpley blue and the pink. We needed something that could go on the top of letterhead so we added the visual up there at the top that goes up both sides that the different shades of the purple and blue and pink and earliest interactions is the name of our HRSA grant project for that is earliest interactions.

We needed something for the bottom of the pages of resources so we could put the grant information, so we came up with the waves and bubbles down at the bottom. So that is where we started.

>> And then we needed more options. We needed different ways to get our message out with this branding. Then we realized it didn't always have to look exactly the same. At first we thought we always have to have that logo and that little continuum color spread but the more we thought about it we said there's going to be different purposes but we wanted that continuity of coloring and of messaging. So you see here that there is a PowerPoint slide. This is kind of the logo for our PowerPoint. We have the letterhead and resources and then today's section pages on the website. Everything flows and it's a similar kind of look about you see that they are not exactly the same. That is kind of okay because it needed to match what the purpose of the resource was for us.

>> So we spent the last year and a half, maybe two years, looking back at older resources that we had for EDHI, going through a review process and adding this design to the resources. So this is just a sampling of some of the items that we have. These are tip sheets that our audiology workgroup made for families so we added the branding there with a little bit of a different visual at the top. And got everything printed.

Then we had to sit back and say okay, we need to remember what parents need, what parents are saying they want. Right?we have all these resources now reviewed and now we have printed them. So do we send them all out, all at once to our parents so that they have them? No. We need to slow down and really be thoughtful about how we are rolling this out so that we make sure parents are getting this at the time when we really need the information that is included in the resource, and that we are not sending things all at once to be overwhelming again.

>> So, branding has really been the focus and again, trying to get the one message to family every step of the way. So some of the things that we have developed were resources that had been really amazing in the way that different groups have been pulled together to do different resources. So the audiology resources that Darlene just mentioned we put together every audiologist in the state that does pediatrics. Almost all participated. There was a couple that didn't for whatever reason but they come together monthly and they are creating their own resources. So it brought a lot of buy-in, and they were part of the perspective of the coloring and the logo and what do you think we should be doing? And by bringing them to the table with our lead audiologist for the state that works for the EHDI program it made a sense of buy-in so everybody thought they had ownership so they want to use the one material instead of giving every audiologist in the state giving something different. So another one that we did was the hearing aid infants and young children brochure. The first one that families get. We did the kindergarten readiness packet. The K document which has the milestones document exploring language and communication activities. Process where families are learning about different language options and opportunities to explore. We had resource guides describing different hearing levels, prenatal brochures. We are working on getting that out to OB/GYN's and classes for families before babies are born. Five more audiologist tip sheets are coming and right now the early intervention team is working on tip sheets related to teams and natural based early intervention. So again, the goal is from prenatal to the hospital to the audiologists and so on. I think I have seen this kind of look before. And having one team together working on it. And our research. So as I shared working on the dissertation we are still seeing this. These are Maine family so I said oh no! we are still doing this. As I was getting more input from families still too much paper still too much information and not enough time so it was hard to see that because you think you're going along and doing it right and then what comes back is not. But that's why we do research, right? Because we always have to be reflecting and always looking back to saying are we doing what families need? Because we may think we are and sometimes we are not.

>> So,as with all of these things that Karen was talking about even though we had other people working on the projects like the audiology workgroup, each one of the resources started in one place but then came back to the big team again. So that we were able to look at that as Karen said we have five parents on that team in different roles throughout EHDI so we were able to give the parent perspective, change some wording if it is not really very parent friendly. We have the audiologist on the team so she can say we don't really like the wording the audiologists use she can kind of tweak it to something that she knows would be okay. Changing it so it always comes back to our original team even when it is originating someplace else, which is nice. The next step for us is to come up with an advisory Council because each step of the way when we were reviewing our resources and putting the branding on, at the end even though there are a lot of us on the team and we bring different perspectives it is still our perspectives. As I said, my daughter is 27 now. I'm not necessarily ground-level with somebody who is just finding out that their child is deaf or hard of hearing. I love paper. I want paper. I'm not good at electronics. But families now are always on the phone. So it should not just be my parent perspective. So we are looking to get, and what was happening was we were calling upon parents that we know early on to look at these things, which was not fair so we are asking them to put this on the their plate on top of everything else we are doing can you look at this resource and give us some perspective. So we would really like to bring together an advisory Council of parents and deaf and hard of hearing adults to be able to help us in this work of developing resources so that we have their perspectives to look at these things as they come up and be able to pay them a stipend for doing that to pay them for their time so that we are not asking. That volunteer time of them.

>> So, what we are thinking about for the future is continuing with the branding because it is kind of working. The feedback we're getting from families is that my mother said it's kind of calming to know every step of the way I have seen that color. Okay, that kind of works, and continue the collaboration between all in the process and when I talked about the different resources we are always bringing in the specialist because I am one person. I am one specialist she is one person, she is one specialist but for example when we created exploring a process for language opportunity we had an ASL specialist at the table with us to help us create the ASL page. We had a listening and spoken language specialist at the table creating the page with us. We had a cued language specialist so when you bring all the people together in addition to the early intervention team and in addition to families and more deaf adults so that lots of perspectives, but bring the perspective so when they go to the families they don't feel they had to bring this much information about their option which happens so much because they are trying to get a family to go this way and understand why and understand the research. When they are involved again they feel okay I did this. And we are good. And we are meeting with lots of organizations to figure out the plans for when and how these resources are given. For example if an audiologist was to give their one pager on ABR and connect to a website on the ABR section is that enough? And is the early interventionists circling back to the same page and the same spot on the website. So trying to work with everybody to see how do we make this flow now that we have this system. And then we are going to see the families in a year because again if we are not checking to see if what we are doing is right then maybe we are way off the mark.

So one thing we didn't show that we probably should have is our website. So we have a brand-new websitethat is, if you're interested that is www.earliestinteractions.com. Easy to remember. And the goal of the website was to have a one-stop shop because every agency in Maine came up with their own website as we do, but we were hearing from families that they were going to this website and that website and this website and getting kind of conflicting information sometimes or overwhelming information trying to sift through it all. So what we did with our team was start thinking about the hospital. So I had a hospital we need a tab what do you do at the hospital and went to the hospital providers need to do. Then what happens when they go to the audiologist what do the audiologists need to do. And our intervention and so on. There's a whole section for families, but our goal is to have families always being brought back to that one website. And it's been interesting seeing how that website is evolving. It's not finished, but to take a peek and give us feedback, but it's been interesting thinking of where that person in the hospital that did that screen use it? And where have the audiologists use it, and sit with that family and were early intervention used it and sit with that family. I think there might be something to this. To again the concept of one team in the whole state, one journey, one togetherness. And I think it's going to bring a sense of calm for families in this really crazy time that they are in. That is our hope. That is our hope. And this is just Arlene and I. We go way back and have had a lot of fun to get the creating different things over the years and we started on her living room floor so I love that.

>> And maybe we will be back in a year to be able to give you some feedback about how we did or whether we need to change. I think that's a really important piece of this is that we keep looking each step of the way at what parents are saying. So we are not stuck on this. We've Artie made a plan that in two years the resources that we reviewed and updated are going to be looked at again. Because we waited too long this last time to update our resources and if what we are hearing from families again is that it is not working we will go back and try to tweak again. One of the interesting things that we did here from people was from families, was that a lot of people still want both. A lot of people still want paper, but they want an option to look at these same things electronically, which is exactly why we did that connection to anything that we have made for a resource goes onto the website as well. I don't know if you saw on our examples up there. Most of our resources have a QR code on them or a link so that they can get to our earliest interactions website and also the Maine newborn hearing program website for those resources are also on the Maine newborn hearing program website so that professionals can order the resources for free. So everything that we are creating is in packets of 25 on the Maine newborn hearing program website and they can get them whenever they run out in an easy process. I am saying that because our EHDI coordinator is in the back and she has to do it [laughter] so it's easy, right?so thank you.

>> The one on the right is a one pager about the apps that was developed and with the QR code there. And the app again is to get families and audiologists and doctors to all go to one place. So if a doctor has a patient, a child that is identified as Deaf they click on the app and it tells them what to do next so now they get messaging out about that, but it is a step step steps, right? We will see where we end up. Any questions or feedback?

>> Do you need the Mic?

>> I am curious what you see as the feasibility of doing something like this at the national level. Rather than all 50 states doing something like this and applying for funding. Separately and taking their resources and pulling them and doing something that fits each state. What do you think about that?

>> Wouldn't that be great?I was in a meeting day before yesterday and that came up why are we doing this work. Were we doing the same thing? So I don't know, maybe someday starting, but somebody else that you have to start at the state level. If you start at the federal level they are really big and really busy. The only thing that came up about that is a lot of this is still Maine like go to this person, go to that person, but likely behavioral testing that is standard and everybody does that hopefully but like the app is Maine specific, the early interactions website part is Maine specific in the early kindergarten is in our law some things have to be specific but I think it would be really cool to have the hospital parts like all of that, what do you have to do? That is basic really.b I think some of it may be hasn't had all the perspectives that we need to have. As a paper looking at it because sometimes we have looked and said well that's not how we do it. So we don't use it because that is not how we do it. I think it would be great. Maybe we get a big group together and try to do it.

>> I just want to add to that I do think also state-by-state, and I'm going to try to say this as sensitively as I can, but there are triggers for different people in different states. So when we talk about the wording of things that we put into our resources we try to educate of course and sometimes the audiologists let's say don't really like the suggestions that we have given to put in, so I think if you did it overall you might get into those where some states did not like the wording of whatever the resource was. Are you going to give us kudos, Anne?

>> I wasn't going to check up on you. The session I was going to is canceled that is why I am here. No. What I just wanted to share was that you find that a lot of states if you reach out to them, they are more than willing to share their documents and you plagiarize and use them and just put, no, seriously, then put, even just put where the source of it was. So there is that benefit as well.

>> I have worked on a similar project where it is focused on creating a one-stop shop for resources. And I ran into kind of what you are alluding to where I did my best to get a lot of people at the table but it was really hard to keep the focus on like I want you to understand what happened to your audiology appointment and really quickly we were looking for how to connect in different communities and get these other resources and funding here and there and where are the families that speak Spanish and use ASL and are they just in my region or are they for everyone. So it gets really difficult to keep everybody together in the focus of the original project so I definitely agree with that.

>> One resource that I do want to share, I don't know if anybody else was in the presentation yesterday, I'm from Boston Children's Hospital. And about to go live through a platform that is called open pediatrics. There will be some modules geared predominantly for pediatricians, primary care providers, nurse practitioners, PAs, things like that. It's an interactive module. It will take them about an hour to go through it. There's things about genetics, degrees of hearing loss all sorts of different things more from a medical perspective what are the next steps the family needs to go to because I think most of us who work with children and are relating the diagnosis know that literally the family is walking out your front door on the cell phone calling the pediatrician saying oh my God, my child has reduced hearing, what do I do now? so this will be a module for physicians and other medical providers. The nice carrot at the end is that it's free for anybody but if they want to collect continuing medical education units, which everybody wants their CEUs there is a fee for that but they can also collect an hour of CMEs for that purpose as well. So open pediatrics. And it will be going live she is hoping fairly soon. They are in the pilot phase of getting back some information from their study group. But pretty soon.

>> That's fabulous, Charlotte, thank you for sharing.

>> We were in that session yesterday taking lots of notes.

>> This was fantastic, thanks you guys. Really good. A few years ago we do a survey of families going through one, three, six to ask them if they knew they were going through one, three, six. 65% of them did not even know the timelines they were supposed to be in. So I love the idea of giving families just in time information or responding to families who say it is too much, it's overwhelming. Look if you are trying to fix overwhelming or too much there's part of the process that's just going to be the real nature of it because we didn't create the space in our lives to deal with this. So now we have to add that. So it's going to feel that way. I'm just a huge believer in individualizing information based on the family themselves because sometimes we say okay we don't want to be overwhelmed so we're not going to give them the information at the time of identification. Some families, the very thing that will help them through that emotion is getting that information. So I just always think there's a little bit of a cautionary tale to it. Because we want control of information in the hands of families too.

>> That's why the website is full with everything.

>> Yes. and I love the branding idea. That was really great.

>> Thank you and we are out of time.

>> Yes, thank you very much.