>> Good afternoon everyone my name is Lauren the moderator for this session titled Moving Forward from Either or To And, and EI: Families Share. I am the moderator for the session if you have any questions about the conference you can find me the back of the room. This session will go until 2:30 and we do have a session following that does start at 2:30 PM so we will need to end promptly at 2:30 PM. I will go ahead and turn it over to Bettie Peterson to begin presentation.

>> BETTIE PETERSEN: Good afternoon and thank you for coming and if you cannot see me feel free to move forward. There is a lot of space in the back, come on forward, I won't bite.

And my computer has frozen and is not moving on to the next slide.

We will just get with it as fast as we can. I am Dr. Bettie Peterson and this is my name sign. I want to share a little bit about information that I gathered from my dissertation. With that we will move forward.

This session has three goals, the first one is to look at the reasons why families want bilingual/bimodal approach. Second one is to look at your EHDI programs and identify possible barriers to families. And the third one is to come up with or compile a list of resources and programs to support families in your area.

I will give you a chance to read this slide.

I will open up with this first very important thing to consider and we will add to that is to go along. Instead of an either or, why do we not have an and approach? I think it is threatening, it is risky, we don't know what will happen with a child. Will you be successful or not? Regardless of the approach, we work with families who have an early identified child and they have yet to really figure out what needs the child has an do not think it through. And they think they will be fine with just amplification and realize later on that there hearing level or their loss might be much different than they thought and they may be missing language. They don't want that threat or risk of language deprivation, they don't want those gaps that occur without having language access. And also, many families change their minds along the path, they want to decide what will best fit for their child, those options out there instead of only or only this. They want to have options to see what works best for the child.

This is a lot of information on this slide, I realize.

I will try to summarize briefly here. My study looked at, I initiated a survey and looked at 74 participants, all parents who could hear and they had deaf and hard of hearing children, and they were from birth to 17 years old. Among those 74 participants, I asked for volunteers and from those who volunteered and participated in interviews. It was limited to those families who had early intervention. There were five families here on the slide and they are case studies as part of the dissertation. And I want to share with you now some things that these families told me through this intervention, or this interview process regarding early intervention and or the decisions they made to be bilingual/bimodal.

I want you to take from this, the important part, the last line here in the grid, the early intervention support or barrier and the desires they had for bilingual/bimodal choice.

It is interesting, all five cases are interesting and I did not know before the interview that they would, or had chosen the forms of communication they did.

The reasons the families gave her wondering bilingualism/bimodal communication, the first one was, they wanted to communicate with their child. Pure and simple, they realize maybe in the future their child would learn to sign and they wanted to be able to communicate with their child as an adult. And they wanted their child to communicate with other deaf adults as they got older. If they were oral now and use spoken language, they may then not be able to connect with their family at a later date. They wanted to bond with their child and have that relationship regardless for the rest of their lives together..

Some extended families would not be able to learn sign, or would you be willing to learn so it is important to try to see if spoken language would be successful for the child so that was another reason, the families wanted both. It was not an either or situation, they wanted an and/or, they wanted both.

in addition, families wanted good literacy in both languages, they wanted that access, they saw many children throughout the world who have more than one language. They wanted the same thing and it is very successful to have more than one language so they wanted that also for their deaf child.

Identity, families did mention after talking with -- I had one father who commented previously when he was in college, he dated a woman who grew up oral, use spoken language and she said that, she dated this woman before and they were both in grad school and she said, people call me, I am a success because I can use spoken language, but I struggle so much, I feel left out and isolated I feel like I do not belong anywhere. So that dad said, if that is indeed an idea for a deaf person then I want my deaf child to have both. I want my deaf child to have signed language and spoken language. So that my child can feel like they belong.

Choices, several families mentioned that they wanted their child to decide what they would prefer and use that for the future. They want to do that, not necessarily a bilingual bimodal approach now but they were not sure how they would cognitively process those at the same time, they would, they wanted to provide a bilingual/bimodal choice now because later as I got older they did not want to have to make that decision so that they could choose which language they wanted to use, they did not want to have just one way and be stuck, if you will, and that chosen language.

Unfortunately, four or five families did mention barriers with early intervention. They wanted the bilingual approach but that was not offered in many early intervention projects and programs.

Four or five of them said that they had professionals that said do not sign at all and two of the families had advocates who were knowledgeable about signing but then there was one who worked for a residential school for the death and had a temporary job as an early interventionist for just six months so the family just got a taste of what that was it was not something that went on for a couple of years. Early intervention providers said that there were some negative feedback from the deaf people, and one example is a father shared that the speech therapist said, I know sign and I used to be involved with the deaf community but, their English skills are never any good. Those of you here at the conference, you are presenters, you are deaf people with PhD's, never having good English skills, that is not true. However, that father heard that and thought, you are talking about my child. My deaf and hard of hearing child will be a deaf adult and if you say something negative about deaf adults you are talking about my child.

Also we had a provider who did not respect what the parents wanted. All parents wanted that bilingual/bimodal approach regardless of the language. And they had providers who say, we are not going to do that, their hearing is fine, they don't need sign. And then it would say, that is fine, you can sign on your own time but on my time we will do this. That is okay but there is no other time they have access to sign language, who is doing that support with the family? That created barriers for families.

Only one family hada deaf adult professional working with them. One. The family wanted so much, so they hired a deaf nanny, they hired someone to come in who was deaf to work and tutor and teach inside with their child, they wanted it that bad.

Now, I feel at conferences there needed to be something you take home with you or something to think about. Think about your programs and your families, involved in your programs regardless of your field and expertise, if you want a bilingual/bimodal approach and if those families want that, how will you help support them and meet that need? Just give me a couple of minutes to think about your own programs, think about what you can do, whether it is change the way you talk about deaf adults and letting the families know different resources. I want to give you a few minutes to think about that on your own.

Okay. Are we ready?

I want to provide you with some resources, this is not exhaustive. But there are so many possibilities on this slide you can talk with those groups and see how they can partner with your programs. The QR code there will lead you to another list that has more of these programs listed in addition to the ones you see here.

What I would like to have a size is I put deaf mentors and deaf adults at the top, families want possibilities for their child and seeing a variety of deaf adults and how they live and work and navigate society is incredibly important. If you don't know if your state has a program for that, and is perfectly fine, ask a deaf adult if they might know if there is such a program because they may know where you can find that resource and that is the best place to start.

I will tell you, I had a family who contacted of the deaf school, took the initiative and said my child has hearing differences and I want to know how to learn sign. That is another possible resource as well.

Do you know the resources in your area? If the answer is yes, write those down. If the answer is no, take a picture of this slide and start hunting around for some of these people who might represent these groups. I am sure you have at least some of these groups represented in your state.

This ends the formal part of the presentation,you can scan the QR code which takes you to my dissertation if you would like to read that and if you do not want read the whole thing, it is about 100 pages, I do have each of the five families stories, which are beautiful. They share how they were supported or not supported in their journey.

Was somebody still taking a photo of that slide? I am sorry about that.

Going back to this slide, I wanted to showing how each family had a different educational background, different income, but all five families were opting for a bilingual/bimodal approach. I think it is important for us to recognize that we cannot say, this will not work for this family, we cannot make that decision. I was honestly surprised to see Jason's family, Jayson and his family, the child was not identified under the age of 21 months and at that point had a mild mixed to moderate hearing level. Prior to the identification, it just so happened, they knew the child was not responding or listening well so the dad went online and started looking for what he can do and he found an article on Reddit about language deprivation. Which was related to theory of mind but the dad just said, my child needs to sign. It is fascinating because they were not looking, at this child situation you would not think the child needs to sign but dad opted for that so if there are access to resources they will be able to start doing that and have that language access, but unfortunately dad had at the EI program give him a list of apps to learn sign with and that was it. When I ended up meeting the family and the child, the child was by then 22 months, had been recently identified. That child only had two or three words. That is the unfortunate part, if the family had had resources, and knew they wanted to sign and knew they wanted access, they did not have the resources. And none of us want to see that happen.

Does anyone have any questions?

In the back – for a mic and an interpreter –

>> I am Eddi and we have parents who are trendsetters, we do have parents who have been able to do bilingual/bimodal, until they get out of preschool, but they are having challenges after that. Do you know of any bilingual/bimodal schools, because some parents are willing to change states because they want their child to have what they chose and what they believe will work for them.

>> BETTIE PETERSEN: That is a good point. I do know a few resources. Of course, this changes all the time and that has been the struggle, knowing what is available after a certain point in your child's upbringing so New Mexico does have a resource and Utah also has resources, and Arizona, Washington, anybody else – California? Indiana. There are resources for post preschool age. The important part is to find the people who know and ask around. Good question.

This is more of a comment, I appreciate you using the words hearing level and hearing differences. I appreciate that.

The overall theory of my study relates to the social structures, the social constructs. so I am intentional about using that word,the terminology because I noticed families saying, professionals use these specific words and it feels a little bit jarring. I also had another presenter, I will be presenting more about that, I think later today, today talk about social constructs, tomorrow I'll be using specifically about word choices at professional's use that have an impact on families.

>> I think it important part of social construct is history and what led to something so whenever I hear people talking about of the reading levels of deaf people, never, rarely is it mentioned that, talk about the history of deaf people, language deprivation, limited access to language, limited educational opportunities but in this way to come out and say, the reading levels are terrible, it is a continued lack of understanding of the history of what deaf people have faced.

>> BETTIE PETERSEN: You are absolutely right and it is a self-fulfilling prophecy, and it continues systemically. It is a stigma.

Any other questions – we have a mic over here – thank you.

Any other questions?

Seeing none I want to make one last comment, I will add a great amount of gratitude for University of Connecticut, UConn, giving me the funds to travel for this conference and the University of New Mexico where I have done my dissertation studies. So thanking those two entities and thank you for coming to this presentation.