>> Okay , hi everybody . Are you hanging in there ? It is 2: 15 on the last day, we are tired and having fun . Okay, today we are going to talk about journey again . Journey instead of a choice. I love this topic, we all of this topic . A little bit about us and we can see that we are friends. I am Karen Hopkins, the Executive Director in Maine and also the principal investigator of Maine's grant and trauma coordinator. So many different hats, I'm also a mom of a child is hard of hearing and death myself .

>> Hi everyone, I am Amber Woodcock, I am the guy by her side coordinator for hands and voices and am also apparent of the deaf 10-year-old.

>> Hello, I am - - the mother of maleic who is 27 and he is deaf/blind plus in the president of hands and voices headquarters.

>> To add, Jenae has been doing work for us in Maine on diversity, equity and inclusion. She comes to me every other month or so. This was taken at a family event we had in October. It was a lot of fun. Some of the conversation that happened that day led to this presentation. So we are curious who has joined us today, go ahead Jenae .

>> If you are a teacher, TOD, parent , SLP, audiologist , who am I missing? How could I forget early intervention, deaf mentor, great. Wonderful, we have a very diverse group. Anybody that I did not mention? Alright, welcome everyone. We just hope that we can share some great ideas today.

>> The objectives for today our to support families as they explore language and communication opportunities and to encourage early interventionist to father families lead in supporting family outcomes.

>> Okay, we thought and doing this presentation, is it a journey or is it a choice? As a parent, I remember even 27 years ago , this was before newborn hearing screening and so many things , when Malik was born , granted he had a lot of other things going on medically , there were so many choices that I had to make. I felt the pressure, delimit the right choice, the wrong choice? For us, it was a matter of life or death. For our families, we think it is both. It is the choices that you make along the journey. I worked with early intervention teachers in North Carolina for 15 years. One of the things he both said to the family's is the choice that you make today may not be the choice that you make in five years or 10 years , and that is okay because along the journey you are going to have a lot of choice to make.

>> So, we're going to share our stories with you today as an example, but we love this quote. "Stories Create community, enable us to see the world to the eyes of other people and openness - -" abroad overarching vision of what we are talking about. A little bit about me, this is my home as some of you may have heard yesterday. I was born at the base of Mount - - in the main, very northern Maine . I was only deaf child in my family and at that time the state, I do not know any deaf or hard of hearing individuals. My mom and dad raised me and it was never talked about that I was staff, ever until my best friend said hey, I found a college for you . What do you mean? She found Gallaudet, went down, shopped, all of that. That part of the journey was huge, changing my vision of who I it was as a deaf woman and changing their way of communicating and it turned into one of those college kids that said my voice - - I am signing. That is what I decided to do, I turned to a culture he culturally deaf woman, part of my journey was figuring out the culturally deaf part and being through the revolution of that and protesting . But then, I started having seizures so I had to go back home . When I went back home , nobody knew had to sign . The concept of journey medically , do we have an interpreter? What do I do with my family? I kept going back to Gallaudet, I was a little bit stubborn . I graduated and ended up in the hospital with a massive fall five years later. In and around that with my family and children , the way they communicated with me and the way they do communicate with me is really fascinating . My oldest at night would come to me , turned the lights on and ASL. My middle daughter would hand me my hearing aids and talk. My youngest daughter would come to the room, turn on the light, talk some ASL, jump on the bed and whatever else. I raise these kids the same way, but I use that as an example because we have to watch our kids . We don't know which way they will take us. Journey right? We have seen this time and time again, we have to be open to that and supporting his family journey. Where will I go next? Who knows I am going, Jenae?

>> These are two pictures of Malik and one of my family. Like I said, Malik has a charge syndrome . Our journey started now when he was diagnosed with charge syndrome which was at three years old , it started when he was born , it's connection of the trachea to the esophagus where they had surgery. We did not find out he was deaf until he was one years old. Just some of the experiences I had, with early intervention , I'll think he is hearing . She said I have been waiting for you to say that. Then I felt guilty because what could I have been doing before hand? You have been working to keep him alive. In the first 6 to 9 months they had previous optical fistula surgery , tactical surgery, etc. He was pretty much in the NICU for the first year. Once we found out that he was deaf, one thing he will not die from, that I can accept. What was the focus for Malik is always to live . Quality of life. I will tell you something that most parents will not tell you for children who are very ill, we had already planned his funeral. We know what we are going to do , my girls, if we are not around that they know what to do. It is something that we decided to talk about. That is one of the choices in our journey. It wasn't just Malik's journey or myself or Michael's journey, it was the girl's journey. We make decisions as a family . A little tidbit, Saturday was the 27th birthday . Karen and I have lunch about them befitted toast and Malik face time our spirit I say this for the first time out loud to Karen. Of course Malik was sleeping and was like leave me alone. I said to Karen because Karen asked me, when you die, you and Michael go on, are the girls going to take Malik? That is not even the question that we think about. We didn't think he was going to make it to 27, so that was the first day right here at EHDI that I realized , I am going to see 30. I will probably see and I will see and I will see. We have a joke in our family, this boy just won't die. He did not get Covid, the things that could have killed them in the last couple of years we are like okay, he will be around a while. That's another choice we make , deaf blind moment we joke so much that the girls know yes, is going to be sad or whatever but this is real. The good things in the challenging things . He wanted to make sure he lives his best life and he is now living in a group home, four years he has been there with young men who are deaf and hard of hearing. The first one and only when actually, in North Carolina.

>> This is my little guy, radiant. He is 10 now. This picture is him getting his newborn screening , that is him feeling it and that is our lives changing. I can honestly say that is the moment our lives changed. It is why I am here and do everything I do, that picture right there and that moment. That is him now as the most amazing little 10-year-old that we have that is him at his basketball game, he's about to go play basketball. We have had a journey. He was born with mild to moderate loss, I wanted him to speak and to sign. That kid is not want to sign , he wants nothing to do with it. He is a child that uses cute language, is a cute language - - receptive to it but is not expressive to it. That is a journey, we have done it all. We started with hearing aids , he had hearing aids when he was three months old and got cochlear implants when he was for . We have literally done it all, there has been a journey all over. We had a lot of professionals that have been amazing , we have had a lot of professionals in our lives that have not been amazing. We are very fortunate to have an amazing support system , and I think everyone I can think for that but see if I forgot anything. One of the biggest points, this would probably , I have three children and the oldest 13 so I been doing this for a while. One my biggest parenting moment that I learned was to step back . When he switched over to language, it was not in my wheelhouse of thoughts of what we were going to do. I wasn't against it, I just never thought about it. By a fluke, he ended up doing in school one day and was a superstar with it. It was just meant to be. I had to step back and trust him and his team that he needs to change his IEP and that was huge because it was hard to do as a parent. Even with normal typical hearing children, it is hard to do. It was definitely a big parenting moment to learn that I need to step back there.

>> Okay, audience participation, I will come around this way. As parents and professionals, whose parents and a professional? Are there any parents that working in the field? You are professionals right now, we are deeming you professionals. You are the expert of your kids. He wanted to have a little bit of discussion on I wish you knew. If you process a parent , and or a professional , I wish you knew , something that I wish you knew. Her parents, we just threw these up here, but I wanted to have discussion. Parents want everyone to know that we are vulnerable. That is hard. We want to make the connections and we want the professionals in our life to a vision and hope when we might not have it. Professionals, I am both. I think professionals want to be respected for what they do know we have a lot of information to give, we don't always give it the right way or the way that the parents need, but we do have information that will help and time is a gift , but we may not always have the same amount of time that a family needs , so communicating that is so important. So, if you could finish that sentence , I wish you knew . Anyone? Audience participation .

>> Hi, I wish I knew 10 years down the road that I would be in a position where parenting and professional were I felt empowered. I wish I knew that would be coming down the line I felt very helpless in the beginning . Empowerment comes knowledge and experience .

>> Is a parent and professional, I wish either my child and I need to be fixed , my child need support and to be fixed.

>> Think you can anyone else?

>> I'm a parent and a professional, so as a parent, I was professionals new not to put limits on my child. Like Jenae, I have a child with charred syndrome , so I along with the professionals thought there is no way they could ever ride a bike. They are 18 now, just two years ago we tried. They rode a bike like a champ. I was listening to the professionals say they can't balance and you should not even try . I wish they never told me that were put limits on my child .

>> Who else? What about some professionals ?

>> Did we scare you? Last night. [Laughter].

>> As a professional, now I have moved into early intervention, the thing that I kept wishing parents would do the most is that you do have a voice and we want to hear it. I remember one mom , she was supposed to make some educational decisions and she said I don't know, you are the expert, if you have the degree . I said I have a degree? That is book knowledge, you have the degree of your child. She became bolder because you get into the school system with so many options and choices and what you want matters. If they don't listen to you, find someone that will. You are the number one on your child's team for that IEP or whatever. It matters.

>> Thank you. At what point do you tell them that? In your conversations with parents?

>> When we are going over services and they are like well, I don't know if you could? My background education plan for to push them out for some math , that is my say wait a minute mom, take that away and what do you know as mom ?

>> I is something I would like to add . I wish that everyone knew that your deaf and hard of hearing child is a whole child. I wish that you knew that the deaf community will accept you and you don't have to be afraid . If you cannot sign yet, the deaf community would be thrilled to have you. You are going deaf babies with open arms so please don't be afraid .

>> Thinking about the balance between choice and journey is tough because as professionals , we have to give families all the opportunities. It is encouraging them to start somewhere, but it is really with the messaging is how you as a professional give the information and hold you as a parent received the information. If you are a professional in the room, think about using the word journey, exploration, time, space, all those words that give parents liberty to make time and make decisions on their time and their journey . The parents, spread the word to other parents. As you continue your journey to know that it is a journey and you will make choices as Jenae said , we have to make choices and start somewhere. I relate often to my kids when they were little , I had to make a decision as to how they were going to dress however, when my two-year-old became two, she really had different choices. That was fun, but that is a simple way to explain it to parents try to think of things that are everyday commonalities and helping them understand the choices I just a starting point . We are running out of time and I want you to hear Amber .

>> This is me and my youngest . You do not get to the bottom of her and her presentation . I know that we are running a little short on time so I will skip to what I feel is the most important part in this is the last one . Talk with families as professionals, don't talk at them or for them. One of the biggest things that we ran into is we started this journey with Rayden is a professional that told me that this is what you need to do. As a family or a parent, you only to hear that. You need to hear your choices and to the journey however you need to do it. Because he is expressively an oral child , so here he is with language. I use sign language with them at home. He does it all. If I would've listened to the professional, it would have limited him. He is now reading above his grade level at the top of his mainstream class. If I would've listened to the professional, it would've hindered him in the long run.

>> Real quick, this is a very important message I have. I feel so strongly about this. Again as parents, we make those choices , in regards to language , we have to let the kids lead us as soon as they are ready to lead us. Sometimes there is a one-year-old but pay attention and watch her kids. In Maine, we have a lot of families that are doing it all and we really encourage that. Why not? Why not try it out, try it out. We have families that are assigning, using written spoken language in a specialist with all three. And we are backing up - - we created a preschool program in Maine that has three classrooms. The door is a little bit of magic. Families choose - - enter into English which is spoken language classroom , or ASL which is the American sign language classroom . Often we have language in the spoken language classroom as well . Parents choose how they want to start their day . Typical preschool classroom, there playing, interacting in that language. 10:00 the door opened and the children go back and forth. They play with who they want to play with, they interact with who they want to interact with , but what we are doing is watching . The difference in parents choice and child choice is astronomical . We have never, and all the years we have been doing this model, have a parent except : that one. Which is a must in the first intake visit with the child will make the choice, are you okay with giving up that control ? That is huge, right? We all like to have control, but this is one thing that we are seeing amazing differences in language outcomes . I believe it is because we are following those children. She said can, he is not planning at all and she was doing everything right. She was in the deaf community, had him in the ASL room , that little boy was bolting the spoken language room. Like what am I doing wrong? Nothing, you're doing everything right and more because you are allowing him to live this journey. Think about that, you may not have this classroom set up in your state, but what can you do that is similar? You're taking children to deaf community events, are you working with specialists in your say on spoken language and hearing? Are you exploring all the communication opportunities that are out there , and is your state - - see those language opportunities ? If not, go find them . The scene, back away and watch what your child does. You may see them walk and signing in ASL, or you receive them talking at home , but watch. It's a little bit of magic to see what happens at this event .

>> We were going to have discussion but I don't think we have time, so we are done . But, we appreciate you guys. If you take anything from this, step back, watch your kids and ride that attorney. Have a good day everyone.