>> Good morning everyone. We are glad to see there is there is so much interest in late identification our project and Colorado. I am Sarah Kennedy, a mom of the late identify child. She was born at home the year that hearing screening past in Colorado, but the midwives did not know about it yet so we did not find out until she was about 15 months old. This is a project near and dear to my heart. I am also previous Colorado chapter director for hands of voices and I work for hands of voices headquarters .

>> I am Becky, an audiologist at Children's Hospital Colorado, and I was fortunate to have the opportunity to collaborate on this project.

>> We are going to go over a little bit of the project and the grant background, go over some common barriers to early identification and what we have learned and helpful supports that parents and the project told us they wish they would have had. We hope you will find something useful to take home.

>> We want to start off by just talking through some of the barriers we see moving through the process in a timely way. We know from the literature and research that there are barriers we see in everyday life . I will run through these kind of prickly duty time. That intent having other medical needs that will take priority , parental choice to wait for evaluation for a variety of different possible reasons . Education, both of the providers working with parents, primary care doctors and screeners , and their education of how to share the information with the family and the importance of follow-up and doing that in a timely way. Subsequently, the education of the families if they are knocking the information in the providers in a meaningful way. Access is another big barrier either due to geography, location, transportation, family needs , availability of qualified providers to be able to do that follow-up testing intervention , or scheduling in terms of not just there being someone available, but I'm having the time in the schedules to get it in a timely way. I will lump the last two in terms of coordination of care and communication across the different providers looking at insurance and referrals and that information getting to the place that needs to be. On top of all those barriers, we already had in general terms of getting families the information they need and getting them to the next step in the system if the baby does not pass their screen, Covid 19 happened and kind of shut things down for a little bit into my 20 and added a whole new era barriers to helping support families go through this process. So, we saw in 2020, we did a survey of hospitals in Colorado in June . We just asked him how things were going . Less than 50% of those hospitals rescreening babies if the mama tested Covid positive. That was a big impact for us. Looking at the CDC numbers, they showed a 36% increase in infants were not screened due to medical reasons , which is what they said to able Covid. Definitely, I think we saw that transnationally as well. One third of the hospitals in June also reported that there were not doing outpatient screens . So, on top of more missed screens, babies being discharged sooner, we also do not have that same system in place that we usually had available in some locations. And parental hesitancy, pretty understandably there were a lot of unknowns. We saw in terms of pediatric healthcare visits overall , the data showed that there was a decrease and that they were the slowest a medical visits to pick back up in 2020 as we started to reopen and move to our new normal. In Colorado specifically, we had 60% of our hospitals noting that parental choice to not return was a barrier for their follow-up. Just one more layer in terms of looking at staffing shortages , there is you did a great resignation, quarantining , omicron waves or just the availability of staff to cover was reduced . Lots of new factors that layered on top of the challenge that we have already had that made is pretty concerned that we might see an increase in kids getting identified later. So, I was really curious to see the CDC numbers for 2020 third it was really interesting to dive into them, they came out in the fall. They should overall, things look better than I worry they would. I was excited to see that screen rates look similar to as they looked previously , but we did see a pretty noticeable decrease of diagnosis by three months of age of the kids at the not pass their hearing screen , only one third of them got the diagnosis by three months of age that we had almost 15% in 2019. There is also an increase in referral rates, those without a couple of percentage points related to the earlier screenings that were being done so babies can discharge more quickly. Then, and increased - - 30% , it went up about 4% and the loss to follow-up intervention one of a couple of percentage points as well. Even though they look better than I thought, there were some areas where there were more kids than we had in the past. To tell you a little bit more about our project, along with all the barriers that Becky just talked about , in Colorado we also had an issue with a lot of changes happening in EHDI. Our EHDI database was deemed non-HIPAA compliant. It was aging and people are not kept it up . The powers that be decided that we should not be entering data anymore, so we do not have a database. Then, we had a change in the EHDI grantee, then we had a change in all of these personnel. That was all going on at the same time as the pandemic, it was a lovely season.

>> So, we are curious about late identification and I came upon this partnership grant possibility . So I convinced Kristin Uhler, who is the director at the Children's Hospital of Colorado Bill Daniel center, to come along with me on the journey of this partnership development grant where the real goal was developing a real working partnership between an academic partner and a community partner . Secondary was a little research question. So, the real emphasis was not the research question, but of course that is what we were really interested in . I just wanted you to know that there are these kinds of grants out there , so you can look at patient centered care, outcomes grants in your area. On the relationship development, weeded create an advisory board , so we had quite a few people, audiologists, parents of kids who were late ID , early interventionists , folks from universities to join our advisory committee and they really encouraged us. We had coaches assigned from our grantee to make sure that we made this patient centered or family centered . They were speaking my language there . He really wanted to make sure that the advisory committee helped guide the project . What was chosen was an online parent survey and being Covid, we do that remotely. We did some parent focus groups online at that time in English and Spanish they were offered. We interviewed and try to update , educate two midwives. One was more rural, one was more urban and the same with the birthing hospital. He really looks for both hospitals populations and English as a second language .

>> I will share a little bit of the online survey we put together. We share that information out their hands and voices, pediatric cardiologist and the coordinators who are kind of the entry point into early intervention. A support families all the way from Princeton through preschool in Colorado. With that, we had 38 respondents who completed this survey . Despite our best efforts, there were a lot of similarities between people who chose to complete the survey . We tried really hard to get Spanish-speaking families and put and were not successful . All the families were English-speaking, the majority were Caucasian and the majority were college educated. The majority of families had their child pass their hearing screen. It was about 50-50 between private insurance and families like government insurance or do not have insurance. Looking at age of identification average, that was at 37 months of age and degree of hearing loss was primarily miles followed by moderate and moderately severe. I thought is itching that so many of the families pass their hearing screen , but thinking about the fact that they were identified and looking at the percentage that was miles , that actually made sense as it was one of those things that do not raise any red flags. Then, diving into what we found out from the survey , we tried I like something from each of the different steps . Looking at the newborn hearing screening step, we asked parents how they felt about the explanation of the different information that they got . About 2/3 of the family noted they felt the results and recommendations were explained in either fair or poor , which is pretty notable for us. If that information is not clear, that can delay or confuse the parents in terms of the importance of moving on to any of the next steps from that. Looking at potential reasons for domain the diagnostic testing, this information followed pretty well with the barriers we just talked about a few slides ago. About 40% of parents that let their child was hearing well . There is related to provider education, doing more than two screens, provider saying "don't worry about it" and barriers or relation to access were - - highest reported barriers they experienced . Looking at early intervention, we saw that only 35% of the families were able to access hearing specific early intervention. Much were fortunate to have a program in Colorado where they have therapists who specialize in working with kids who have hearing differences. Looking at the reason that parents reported for not accessing early intervention, there were kids who were too old when identified and also kids who were not categorically eligible because unilateral hearing loss does not qualify you for early intervention in Colorado unfortunately. It does appear other concerns as well. Then, another 30% said nobody told us about it which broke my heart a little bit. That is definitely an area where we could improve . I was excited to see family to family support referrals with slightly better stats at 71.5% , but our goal is 100. That was a positive result that we saw. Then in looking at the helpful resource that families reported, that matches with what the literature shows and the presenters showed here. They really highlighted the importance of the family to family connection noting that the - - hands and voices and the family events were two other that the top three with an early intervention system with the third.

>> Okay, I want to share a little bit with the virtual focus groups. There were only 10 participants, particularly focused on small because you want to spend a lot of time with them. We did about an hour and a half with two parent at a time. It was a small group and having two parents help them remember some things along the way that listening to the other parents story. It was really interesting. The ages, we had two aged 2.5, three, age 3 when they were identified and two eat at age 4 and five. Quite a span of one they were identified. The adapting fall and spring, and like Becky said they were all English-speaking. Some of the themes that came out with the need for intervention amongst OBs and pediatricians. Many of these families had never heard of hearing screening or that it would be done. I wish we could get that out and public health that we count 10 fingers, 10 toes and how is the hearing by the way? They do not know what was typical so they do not know what to expect in newborn hearing screening. They do not know how to choose and audiologists , some were sent to adult audiologists in the rural area , and you don't know is apparent that is a really good choice. They asked for more parent friendly language in our world of acronyms, something to put on our wish list , we asked for more education for screening staff , many times Karen said they do not really feel like they knew what they were doing. They didn't feel comfortable, who issued the comfort language and thought it was probably fluid, and that it was the equipment, the kind of thing. I love this quote "we need specific resources for late ID in our area ." A few more quotes here , I will talk about some of the other emotional words that we heard . He passed newborn hearing screening and office test at three years old , but we know a pass as a youngster is not the past for life. Can't get into the local audiologists, the way in Denver were most of her audiologists are was so long , but we cannot schedule ahead because the weight was three months , but five months out is complicated. We cannot bring siblings enduring Covid , that was a problem dude we had so many medical hurdles that hearing was put on the back burner and the whole issue of military families and less experienced rural audiologists. I got to do the coding which is really fun to learn . In the transcript, I discounted these emotion words. So many times, it was helpless, or guilty, or confused. Some families said I wish I had listened to my intuition, I knew something was wrong but I did not know what. One family said that this was such a DIY activity , isn't there anyone here to help me? Others are so grateful that someone had walked them through and give them the big picture. Moving forward, we took all of his ideas for wish lists and came up with an idea that might help us coordinate care among professionals , with that whole theme of parent feedback. There is a QR code that will leave you to the Colorado hands website. At the bottom of the page families with the late identified child, there's a handout for professionals looking that how can we kind of consider the child in front of us and think about all the things that we might need to go over . If the checklist for professionals, if you will. We also did the Carolina Colorado resource guide update, there will be an act can enlist for parents and I think everything else. Oh yes, there was a late ID parent guide designated so they had the special training and there was the mom of a child who was late ID yourself. We are excited to have all of the resources available to share with families and working to see what else we can do to continue to support this population . We learned a lot of our counseling and education being an audiologist in this hearing screening, focused on the young infants. It is good to take a dive and look at supporting those families, we know that hearing loss increases as think kids get older. We know this happens in general that we might be seeing get even more often in this phase of life . Looking at takeaways as a professional working with these families, one is to be really conscious of language and wording and work with our colleagues in the screening community and the primary care community to really stress the importance of not using conflict language and making sure the parents understand the importance of following up and doing that in a timely way. Being aware of where the family is out on their journey. Like there should with the emotion words, guilt and feeling regret that they had not acted earlier with themes that we see in the literature as well. These families may be processing through a little bit different than what some of those families identified through the typical newborn screening process may be feeling. Really connecting with them and seeing where they are at and making sure that they have supports if they need and want those in terms of processing through those feelings that they are experiencing. Also, looking at how we can ease this process for families. We have heard multiple different talks this week of how much it is at first . Some of these families are being like they are playing catch-up on top of all those appointments that they are trying to learn . Kind of ease that burden intended without, making sure they are connected with the resources with the whole child and the family . Like Sarah said, making sure they are a team and communicating with the family is at, what supports are there so they'll have to repeat themselves in every appointment. We have that communication in place that we are working together . We have the outside of the family having to share outside of us with professionals supporting them. Also, resources for in addition to family support and DHHS support, adult mentors which are so important. Any resources that family needs in terms of finance work in the navigators to support other needs that they have as well. Lots to think about, working with that whole family . One thing we thought was pretty great was that a lot of the families thanked us for hosting this group. They say later to share and talk more for the opportunity to share about their experiences and try to help improve these resources for their families. It just speaks to what wonderful families we have and unpack those experiences.

>> We want to of course think are parent participants and all the folks that help us with this grant project. I think we came up with a really good document shared in the planning with educational audiologist , early intervention is, parents , your whole team . I think it really helps to provide a look at all the specific things that my need to be addressed with the family in a really positive way. I don't think it is something like a checklist where you are going to scare people. It's let's talk about this, that kind of thing.

>> I think some of that stuff on the checklist was a little intimidating to us as audiologist because it is more about speech world. They are really important things to be considering, that I will necessarily talk about semantics but making sure that those conversations were being had and it was back to the partnership with the community partners to make sure they are supported and have those resources to help the family get the information .

>> 20 think about it, some of these families do not even know that they might be eligible for preschool because they do not exit early intervention . It even includes things like connecting a family with the educational advocacy program at hands and voices or at least talking about IEP eligibility or 504 eligibility and letting families know that as an option. Otherwise, they start school at age 5 in some states . I think we have two or three minutes to question . Two minutes says my room moderator. If you have any questions, we will run the microphone to you. He will let Becky answer it.

>> Do you happen to track the 71% the past you if there were any risk factors?

>> We do not ask about risk factors. You probably ask a few more questions than we should have in the survey, it was long so we were appreciative of the parents to take the time to fill it out but we did not get to that one. Other than NICU stay, we did ask about that. Anyone else?

>> I know that you included a Spanish survey . Did your data show that there was a large population of Spanish-speaking families that you needed to survey?

>> There is a large population of Spanish speaking families in Colorado .

>> The demographics are 18% are Spanish-speaking in our state who have hearing loss. We do have Spanish-speaking guide but she was pretty new to the position . While it was all advertise, I do think she had enough time to make the connections . We have gone for a period without a Spanish-speaking guy, so that made a difference. We did do a cut off so we did not take families of any age in that .

>> My name is Liz, I am the EHDI coordinate a for Kansas. We have found through the last couple of years a high percentage of Spanish-speaking families not returning or enrolling for part C early intervention . We do have a Spanish-speaking consultant that we are doing , we call it a Spanish plan. What we're finding is that immigration status scares them and also they were not given a choice to an interpreter . They had no idea why they needed to come back . We are working on a plan, especially like a brochure to give them your babies and their tests for whatever , that sites those things that you do have the right to an interpreter and the hospital has to provide you that interpreter . Also that immigration status doesn't matter. I am wondering why the number Spanish speaking did not respond to that, because of immigration status .

>> That is a big concern, you are exactly right . I forgot what else I was going to say as I walk backwards.

>> I was meant to note that we did do interviews with a couple hospitals and there have been some virtual site visits work in our state as well . [Laughter] Area of growth and definitely anything has like we have an impact .

>> We did learn that one of our larger urban hospitals does not give any information in other languages than English or Spanish. They just to the phone translation service . Who knows what that is communicated? Big issue . One more maybe?

>> I just wanted to recommend one strategy for identifying children who have different hearing levels is assess the hearing of siblings when the baby is identified. When the baby is identified all the siblings have similar hearing levels and have been in the moderate range and it has been a genetic condition .

>> Thank you for sharing that, that has been a great tip.

>> Thank goodness for the preschool screenings, but there is a big gap there and if kids don't go to preschool, it is not until kindergarten which brings us to our neck next topic in the room I believe, so good segue . I am your room moderator so I want to remind you about the evaluations .