>> MODERATOR: Hi, everyone. It is 1:00, so I'll get started. I'm a physician at University of Arkansas and our project is "Understanding Barriers to Newborn Hearing Screening Follow-up in Arkansas Using a Community-Based Approach" and my co-presenters relationship Mandy Jay and Angelina Myers from the Arkansas Hands & Voices.

Learning objectives. We want you to identify important questions to ask parents on their newborn hearing screening experience and learn about the barriers we have discovered until Arkansas and develop ideas to create and distribute a survey in your own state and organization.

So a little background on how this project got started at UAMS. We have the translational research Institute which we call TRI and it was established in 2009 under the NIH National Center for Advancing Translational Sciences, which is one of the institutes you may not be familiar with, but the purpose is to get bench basic science discovery actually into practice.

And so as part of that they have a clinical and translational science award, CTSA -- you thought you knew the acronyms, but you'll learn some more. It is a program that multiple states have where they are designed to turn observations from the lab into actually interventions that affect the people and public. Arkansas is a kind of unique state, although not completely unique because there are others like us. We have high poverty. It's a very rural state with some under-represented populations, and because of that our CTSA is really focused on community partnerships. They really want to get out into the community, and that's kind of their sort of specialty.

So as part of that, they have a community-based participatory research scholars program, and community participatory research, the whole overlying theme of that instead of me as the academic person coming up with my research and taking it to the community and saying, this is what we're going to do, it's to partner with the community to understand their needs to have them have buy-in and to really realize what the actual issue is kind of on the ground. So it's more of a grassroots approach to eliminating health disparities.

So they have a program which we applied for with our Hands & Voices colleagues, and it was about an eight-month-long program. And we learned how to write grants. We learned about health disparities, and we learned how to work together. And at the end of the program we applied for grant and received it.

So why did we choose Hands & Voices? I'm sure everyone here knows it's a nonprofit organization that is dedicated to supporting families and children. They have the Guide By Your Side, but most importantly they have same goals as I do. We want to improve the lives of these kids and figure out how we can detect hearing loss early and how we can intervene and how we can make them be their best selves. That's kind of the focus of the whole meeting.

The issue... I'm sure everyone knows 1-3-6. So Arkansas like most states we do really well with 98-99% initial screening but we do not do very well with follow-up. We have lots of loss to follow-up, loss to documentations and less than 50% of kids are getting diagnosis by three months. So we want to understand from the parent side, why is this so low? What are we doing wrong? How can we make this a better number?

So our team members are myself, an audiologist at the University, and Liana Robins and Mandy Jay, Angelina Myers, and Rachel Glade, undergraduate does the speech program up there, and we partnered with our Arkansas Department of Health with Kim Scott and Nidhi Patel. The focus is we want to improve the life overall but specifically we want to understand what are the barriers? What are we doing wrong and how can we improve it?

So we have three main methods of gathering information. The first was a parent survey, because we wanted to kind of understand what the barriers were and what we did wrong, what we can do right and what we can do better. And also from that we decided to do some parent focus groups to really understand their experiences, what their ideas were to improve the process, and we're also working with the Department of Health to get some more sort of system-based issues, finding out which providers do a good job, which providers don't do a good job, their birthing hospitals or specific demographic groups that we need to really focus on.

So, our survey, we kind of worked it out within our group and then into some of the Hands & Voices leadership. And eventually came up with a survey, which I'll show on the next page, but it was distributed through a number of settings. We have a QR code, and actually I have the QR code up in a second so you can take a look at it if you like. But we did it at some of our Hands & Voices events, the Department of Health sent it out on their communications sent to the family. We viewed social media. We tried to get it out to the people to understand -- so that it's just available, because we want want as many responses as possible. The QR code is actually a clone. You can go in and enter and it's not going to affect the actual real data, so you can play with it all you want. But sort of the main questions on the left-hand side, it was about communication. How well did you get information and communication during the prenatal period? And then the second question, in the hospital, how well was it communicated to you that your child did not pass that initial screening?

And then the information about getting the hearing screening, and lastly the information about how important follow-up was

And then on the right-hand side we asked some of the more barrier questions that I thought were going to be the bigger issue of transportation, access, cost, all the kinds of things that I in my mind had planned, we need to get more screeners out there and we need to do satellite things, and I was already figuring out what the answers were, but I was wrong.

So we looked at the barriers, things like distance, transportation costs, ease of scheduling appointments. The vast majority of people had no problems at all with any of these things. There were some people who had problems, but overall it wasn't really the big issue.

When we looked at communication, there's lots of room for improvement here.

Across the board there was just -- we didn't do a good job at communicating, not prenatally, not about the importance or any of it.

So kind of the summary of our results, the biggest issue was the lack of communication. We actually had multiple kind of comment fields, fill-in-the-blank, tell us what we did good, tell us what we did wrong. And so many people said I didn't know anything about this, why didn't they tell me in my prenatal class, why did nobody tell me this? There was so much of that.

Also sort of the second biggest thing was anxiety and fear of diagnosis. And I think it goes hand in hand with the communication and education. Because if they don't know what to expect, the fear of the unknown, that's really -- that can be alleviated by the communication and the education.

And then those other issues, the have a majority, two-thirds or more had no issues whatsoever with distance, cost, transportation, any of that.

So to kind of expand and delve deeper into this problem, we decided to do some focus groups. I will let Mandy explain those.

>> MANDY: Good morning, everyone. I'm Mandy Jay, and I'm wearing my Arkansas Hands & Voices hat today, but at this moment, but five minutes before and five minutes after if'll be back with the EHDI NCHAM hat on.

So, as luck would have it, I am working on my master's in public health and was taking a qualitative methods class through Utah State University, and I had some fabulous classmates who decided that they would work with us on the focus group. So this got to be our class project, so it helped Arkansas Hands & Voices and it helped our class and we got a lot of good information and learned a lot about the process.

This was a big -- again, as Deanne said, we have the resources on the last page with the QR code, but we have a great big report if anybody wants to see that, of the barriers, and the knowledge that we had beforehand, we did a literature review, we had eight studies. It's interesting to come to this meeting and see some of the people in our literature review, you know, at the tables at this conference, so that is interesting.

We took the time, as the four classmates, we came one a questionnaire, the demographic, and a focus group discussion guide that was part of or our assignment. We also ran it very closely past our team here, so we weren't doing it alone and trying to ask the right questions. And then we set up the focus groups. If you haven't set up focus groups before, I would like to tell you, those are challenging, but we'll get to that in a minute. So we had four focus group options. We offered different times. Obviously they were over Zoom, but we piloted the discussion guide, and then we offer it four times with four different leaders going through. So none of -- we were trying to make sure we were getting unbiased information with who was leading, who was taking notes and all of that information.

We sent invitations through email, social media. I'm not going to lie, I was texting people going, need you on this focus group, because this is our timeline and I've got to have somebody.

So calling in favors, whatever, to get the focus groups set.

We used the health belief model as our theory for setting all this. So we were looking at perceived severity, susceptibility, benefits and barriers to this process of barriers.

I'm trying to not mess up my screen.

okay, this is a snapshot. We've got more data. We had 12 participants. We had two dads. We loved that. We loved having the dads participate. But, again, this is a snapshot of some of the demographics of the focus participants. I do love how this reads out of text. Age when child was born, that was the maternal age of when child was born. You always find the mistakes after you hit submit. Anyway...

What I didn't show here, it's on the next page of our bigger report, is that a lot of these parents were highly educated. I'll talk about it more in a minute when we talk about the challenges with the focus groups.

So the focus group results basically told us the same thing the survey was telling us, that that communication was the issue.

I am a parent of two children who are deaf and one who hears everything, and the oldest child is 22 now. For 22 years I have been hearing "it's probably just fluid." And when I sat on these focus groups and heard a couple of parents of young children saying, "it's probably just fluid," I wanted to bang my head against the wall. Because it was so minimized, the perceived severity was so low because the communication they were given made it seem low.

So what they said through the focus groups was that more education is needed both in the prenatal period and after failed newborn. So I loved this quote from one of our focus group participants.

We have providers, we have parents, and we're not in this together for the most part. So bridging that, it's got to be a team effort. The providers are part of our village and we need help, especially as new parents, because we have no idea.

Another interesting comment from one of the focus group participants... it was her second child who was diagnosed with hearing loss and she had never heard about newborn hearing screening. I mean, how do you -- her first child had to have had it because it was in the mandated time, but she never -- had no knowledge of it.

So the focus group challenges an recommendations that came out of it was recruitment. Again, this was hard, because we were doing it through a class schedule. We had hard deadlines. I'm not saying recruitment would have been easy, but it might have been easier if we could have stretched out a little more time, but we were like, okay, this project is due on this date and we need people at this point.

So we don't feel like we had enough participants. There were 12 participants, and we certainly wished that we had more.

I know a lot of you in this room -- you are going to understand staying within the boundaries of the CVPR goals is hard. Our grant for the CVPR is written up "Understanding Barriers to Follow-up After a Failed Hearing Screening."

You get a bunch of parents on a Zoom call and they're going to want to talk about a lot more than that. So trying to bring it back.

Okay, we understand that's an issue, but right now we're talking about this. That was a challenge.

And then the fourth challenge I'll say, my team told me I couldn't say the parents were too old. I'm going to say it anyway. (chuckling)

Several of our participants had children who were older. So not all of it was reflective of what is being done now. It was from -- I didn't count myself, but it would have been from 20 years ago.

The parents were too old. I'm sticking with that.

But still, even with the people with older children and people with younger children, education, the parents and providers, was key. And create materials and share them wildly, which in the next half hour we're going to talk about more of the materials that we have created and sharing them.

The CBPR challenges. I'm still going to stand here and recommend, if you are a family-based organization, a community-based organization and you have an opportunity to participate in this, I think it's fantastic.

We learned about things that -- you know, we talk about when you're a parent of a newly diagnosed kiddo and you all of a sudden have to be an expert on deafness and hard of hearing and all of that, but then when you're writing grants and you never have heard of social determinants of health and you don't know other terminology about grant writing, and this CBPR, there were lots of challenges, but overall it was a good experience to actually kind of sit through some free classes to learn, and then as our end result we wrote a grant that then if we want we can tweak and -- submit to NIH or other places too. It did have a narrow focus. We did work on the five counties in Arkansas, with the highest loss to follow-up rate. That was hard too. I mean, you want it to be state-wide. We didn't want to just do the -- but our funding was for the five counties, so that's where we tried to stick.

Administrative barriers... let me tell you, there were times that I think all of us thought, just give the money back, we don't...

I cannot deal with this.

But I think it's going to be okay now. I can stand here and say "I think it's going to be okay now." (chuckling)

With the academic partnership you know, they are connected with UMAS, but Arkansas Hands & Voices is a separate entity, so UAMS who received some of funding and Arkansas Hands & Voices received some of the funding, it was easy for the partner who was established. For us, it was almost laughable. The person was out for sick leave, maternity leave or the next person was on maternity leave or whatever, and we're like, okay, we're spending this money and we don't -- we're not being reimbursed.

So anyway, I strongly recommend -- strongly -- that if you have the opportunity to participate but know what questions to ask beforehand about the process of reporting and financing, because some of the things we could have been doing earlier, like getting a SAM number. One person told us we had to have, and then six months later, after that system wasn't working for us, someone else said, oh, no, you didn't have to have that.

So that was fun.

But it's that kind of stuff that you don't know to ask. So it's a learning process.

So Angelina is going to talk some about some our resources. I feel like we have gone through this really fast, but we'll have time to answer questions as well.

Angelina.

>> ANGELINA: Hello! So on the "what's next," this is where I came into play for this grant. So I was in charge of our parent guides, and we contacted every family on our list to get the survey out to families to participate.

So we also -- am I going to mess this up? Okay, whew!

We also created several resources. So we created videos to target to parents and providers on the importance of rescreening. We also added to our Arkansas Hands & Voices page the "Welcome to What's Next." So what does this mean? We took the roadmap for the 1-3-6 and made it clickable and interactable for families so that they can jump right into whatever stage they are at and have the information at their fingertips to be able to understand what is next. Because as families, we don't know what is next. We don't know what that language looks like.

Then we also partnered with an outside agency to create tangibles for us. So that is where the "Remember to ReScreen" infographics and parts came from. We also created postcards that we're putting in packets for new families, and we also created a "Meet the Guide" flyer to have at our local audiologist offices, so that families can know who their guides are that will be calling them.

And on the back of that is what is family to family support and the reason that is so important.

And this QR code will take you to our Google that will allow you to have access to those.

I also have examples of up at the front if you would like to view what that is looking like. If you stay until the next session, we're going to go into more details on what these tangibles look like and what our next steps are outside of where we are going to get these into the hands of families.

Does anybody have any questions?

>> AUDIENCE MEMBER: So I just wanted to say, since we have a little extra time here, I really want to stress that this was a collaborative effort. We could not have done this without the Department of Health, the EHDI program involvement, Deanne, I mean, Hands & Voices, this is not something that we could have easily done standalone. So we have a good relationship already with these groups, and that made this much easier, but like I said, we definitely want to stress it was a very much collaborative effort.

Does anyone have questions?

>> I'm curious if others of you have... what did you call it? Like the trans...

A CTSA? Do you have that? I had never heard of it before.

What does it stand for?

>> Clinical and translational sciences award.

So it's through the University of Arkansas Medical Science. And they had this program that was offering... and it was interesting, like when we were sitting in on the classes, we were there with other partners, academic and community-based organizations, and so like one of them was suicide prevention for veterans. There was something about prison reform. So it wasn't -- this opportunity was not only about deafness and hard of hearing. It was much broader than that.

Yes?

We need the microphone so captioning can pick up.

>> AUDIENCE MEMBER: I don't have a question, just a comment. We all assume transportation and finances as a barrier, but I think it's eye opening that you found communication is really what parents were bothered by. Because we work in our hospitals to try to train the nursing and the screening staff to be careful what they say and to counsel the family and not to minimize the screening.

So I just found that very eye opening, that communication was an issue.

>> Yes, we did too. And I don't think I was good at hiding my facial expressions when we were on the focus groups, and the parents of young children were saying the same things that I heard 20 years ago. You've got to be kidding! We've gone nowhere!

Someone else?

>> AUDIENCE MEMBER: Hi there. I was trying to understand, when you say "survey distribution was done through Hands & Voices, your department health sent them out and you sent it out on social media, can you expand upon how you were able to send it to parents? Did you have email addresses from the hospitals? Like what was the best avenue to distribute to parents? Because we have 136,000 births in our state, and so I'm just trying to understand. And I would like any feedback that you have.

>> I'll let Deanne talk about it, but we did send it to all our families in our Arkansas Hands & Voices database, and so we do have it there. We had a QR code Department of Health, the EHDI program sent it as well, but I'm going to let Deanne...

>> DEANNE: Unfortunately we don't collect email addresses, I wish we had, but on all the correspondence about follow-up, the Department of Health created a QR sticker. So any time they got a letter they said you need to follow up, they would put that sticker on there, please take this survey. It had to get approved by the Department of Health and all that stuff. So, yeah, we had a little sticker asking for their input. It was sort of, we would really appreciate your input, please tell us how we're doing, take this survey.

>> AUDIENCE MEMBER: I was just wondering if you have any idea how many respondents you had to that survey.

>> DEANNE: We had about 40. We want to have more, and that's one of our things that you know, we want to keep it going, because we have made some changes along the way, so we would like to sort of track, okay, you know, this was -- and we have the demographics of how old was your -- is your child now and how old was your child when they were diagnosed? So we can tell who was diagnosed five years ago, who was diagnosed two years ago. So we want to keep this going over time. So hopefully we will see improvements in our communication as we work and get all this information out there.

And we have several ideas to work with birthing classes, to talk to our OBs. There is going to be a lot of provider education from OBs to midwives, to pediatricians, to family medicine, to kind of stress the importance, stress how you communicate this, don't just say it's fluid and like we'll check it in six months. No, that's not what we're going to do.

>> AUDIENCE MEMBER: Hi, thank you for your topic. You briefly just touched on this, but have the three of you now edited or evolved the way that you communicate as a team so that you share the same script? Because we often find that we all have so much wonderful information to share, but I think similar to the theme of many of the talks, this weekend, everybody is sometimes saying something different. So I think part of the communication barrier is also how do we come to the same page. I'm curious what you have done as a team or what you plan to do.

>> DEANNE: Yesterday in our state stakeholders meeting we actually spent most of the time talking about this, but we are going to develop sort of a one-page talking point for our audiologists, for our providers, for our families, so that we can kind of make sure everyone is saying things in the correct words and terminology that they should be saying things, because a lot of -- you know, from the -- you don't want the first thing that you hear about your newborn baby is they failed the first test they ever had. You know you didn't pass this first test, we need to do more tests. Not "it's just fluid, don't worry about it," but there might be something going on, there may or may not be, we need to do follow-up testing to see if there is a problem or not. So a lot of that is sort of how we communicate. That's part of what we need to re-teach and train.

>> I think we have time for one more question.

>> So if there's not a question, just to... oh, there is?

Okay.

>> AUDIENCE MEMBER: I love what you guys are doing. This is so exciting. Maybe this is a follow-up question for afterwards, but are you compiling your information so that those of us who are interested in doing something similar would be able to learn from you, partner with you? I'm at the University of Georgia, and a lot of the things that you guys encounter I think are very similar to our area.

>> Yeah, I'm happy to interact. So come catch me afterwards. If anyone wants to repeat this, we did this on Red Cap, which most universities have. So it's really easy. We can clone it and I can work with you to add and edit and anything.

>> Is this QR code to all our resources or...

>> So there's three QR codes. The first one was to the survey. The second one, during the results of the focus group, goes directly to the focus group. And the final QR code which will be in the next meeting as well, is to the folder that has everything in it.

>> Okay, that's time. Remember to fill out your evaluations.

Thanks, everyone!