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NATIONAL CENTER FOR HEARING ASSESSMENT AND MANAGEMENT
FAMILY ENGAGEMENT STRATEGIES FROM THE BROADER MCH COMMUNITY
MARCH 22, 2017, 12:45 P.M.

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>> Once again for those who have signed on early, you are in the right place for today's webinar entitled family engagement at HRSA/MCHB. Today's webinar is hosted by the Hearing assessment and management at Utah State University. You can adjust the volume on your computer headset or computer speakers to your liking. You don't need to worry about calling in or being micced today. You will have an opportunity to communicate with today's presenters through a text field that will reveal after our presenters have completed their remarks.

>> For those of you who have just signed on we are happy to have you present from the broader MCH community. We will be starting in a minute or two. You can adjust the volume on your head using your headset volume setting or your commuter speaker settings. No need to worry about calling in today or being micced. You will have an opportunity to express a comment or a

question to our presenters through a text field that we will reveal after our presenters have completed their comments. So for now just get your volume adjusted to your liking and we will be starting in just a minute.

>> I'm going to start the recording of today's meeting.

>> Hello, everyone. I would like to welcome you to today's webinar brought to you by the National Center for Hearing assessment and management known as NCHAM at Utah State University. My name is Will Iserman, I'm the assistant director and I'm delighted to be able to introduce our presenters for today who will be speaking on the topic of family engagement strategies from the broader MCH community. Today we have Treeby Brown who is the chief with the integrated services branch at the division of services for children with special health care needs at MCHB. She will be our first presenter and in the wing next to Treeby is Michelle Koplitz who is a project officer for the university screening program with Treeby. And Tigisty Zerislassie who is a project officer at U.S. governments Department of Health and human services HRSA. Both of them will be supporting Treeby in responding to any questions that might come up that they can help address. Once Treeby has completed her comments, we will then hear from Michelle Jarvis who is a specialist in family engagement and leadership development so she will be presenting second. And then after Michelle is done we will hear from Sarah Wainscott who is from Texas and in the EHDI follow-through guide project where she is the coordinator. Each of them will be offering different perspectives on issues pertaining to family engagement and leadership.

So without further adieu, I will hand the floor over to Treeby Brown.

>> Thank you, Will. Hello. This is Treeby Brown. I am delighted to be here. For those who don't know me, I joined the maternal and child health bureau in late June after more than 20 years at the Association of Maternal and child health programs AMCHP where I worked primarily on issues for children with special health care needs, family engagement is an issue near and dear to my heart. I started the family scholars program at AMCHP in 1996. As one of the last projects I was working on at AMCHP before I joined the Federal Government, I did work on the family survey that Michelle Jarvis is going to talk about and she has worked so hard on. I am very excited to be here today

to talk about our division's leadership in family engagement and some of our key activity. I'm also excited for you to hear from folks in my branch who work very hard on family engagement. Michelle Koplitz who is our project officer for our new cooperative agreement for family and leadership language and learning and Tigisty Zerislassie who is our team lead for the family to family health information centers and our National Center for Family professional partnerships. So we have some great work and I'm excited to talk about this. So I have some sort of slides that I will go glance over really briefly. We just wanted to have those in the presentation. I think you are all familiar with HRSA and also the Maternal and Child Health Bureau. In terms of the Maternal and Child Health Bureau and our commitment to children with special health care needs we have a vision for optimal health and quality of life for all children and those with special health care needs in their families and we do focus on creating an effective system of care for all children with special health care needs. Within some of our condition specific programs like autism and epilepsy and newborn hearing screening, we really feel strongly that if we can improve the system of care for that population, we will improve the system of care for all children and youth with special health care needs.

One part of the maternal and child care bureau that's not in our division is administered out of the state and community health is the family and consumer partnerships that are part of the title 5 MCH services block grant. We work closely with dish, as we call the other division on serving title 5 children with special programs with title 5 MCH program in building the capacity to support family and consumer partnerships. For those who are not as familiar with the title 5 MCH services block grant, title 5 programs are required to report on family consumer partnerships and their annual application and are asked to include a description of their efforts and initiative to build and strengthen family consumer partnerships. The third bullet talks about how we define family consumer partnerships. It's that intentional practice of working with families for an ultimate goal of positive outcomes in all areas and it reflects the belief in the value of family leaderships at all levels. And just an addendum to that is we are in the process and we are working closely at the maternal and child health bureau on revisions to the block grant guidance. One of those areas that we are looking closely at is that family consumer partnerships piece and how to really best capture state title 5 programs

activity and involvement and commitment to family and consumer partnerships.

Just a little bit more about our division, we as I said before, we have a number of different programs that do focus on six core outcomes and I won't talk long about this, but hopefully if we press the button, it will spin around and I take no credit for this this was developed before I joined by far stronger technical minds than myself.

And the next slide highlights what the six goals talk about.

One new piece I didn't want to highlight is we have revamped our website for the division and services. Take a look at that because we are trying to better capture what we do in the division. I also wanted to highlight some of the definitions that we use at the Maternal and Child Health Bureau in the division. You will find them in our funding opportunity announcements as well as guidance. But we do talk about family engagement and working across at different levels across the health care system. We talk about the importance of family and youth leaders and their leadership in navigating through service systems. Then we talk about what a meaningful support role is for family members which is beyond a feedback survey and beyond just checking the box to have a family member there. Really having a solid contribution to the process.

One area where we are trying to increase our reporting on family engagement is through the new DGIS family engagement measures. These are measures that are discretionary grants. We will use to report on activities in a number of different areas. The measures were really designed to better capture the work of our grantees. So one of the areas that is highlighted is family engagement. And one new piece of these measures is that we are asking about family engagement along four tiers So from the basic just promoting family engagement to specific information about how they are promoting or facilitating family engagement and then who they are reaching. Stay tuned. I believe those grantees will be reporting on those in the next fiscal year. So it's not this year, but it's the next program period.

Now before I pass it on to Michelle, I just wanted to talk specifically about the programs that incorporate family engagement within our division. Michelle is going to talk about

the activities in newborn hearing screening, but we also have a national genetics education and family support center. We have the National Center for Family professional partnerships, the F2F, family to family information centers and we have other programs that have very strong family engagement components such as our state epilepsy grants and our state autism grants. So I think if you look through the guidance for the programs in the division, they will really reflect the strong commitment to family engagement.

Now let me pass this off to Michelle to talk about family engagement and our newborn hearing screening programs.

>> Thank you. My name is Michelle Koplitz and I'm one of the project officers here at HRSA. And within the universal newborn hearing screening it's a program that we have our state grantees and our state program and we recently released a new funding opportunity for the upcoming fiscal year and within this program the purpose is to develop a coordinated system to ensure that newborns and infants receive appropriate and timely services including screening, evaluation, diagnosis and early intervention. And that's the core purpose of the program. One of the key three activities within this program is improving family engagement partnership and leadership within the EHDI programs. So a few -- a number of requirement for the state grants to meet in their new programs and a few key ones that call out families are ensuring that there are state based communities with pediatric health care professionals and family are working together to increase knowledge and engagement within the EHDI system across both parties. They were also required to develop and maintain active family engagement leadership efforts for families. Then also work with the state in conducting outreach and comprehensive education to stakeholders.

I'm now going to do through all of these objectives here but one of the key objectives is in the upcoming program that was new is to ensure that all of the programs developed partnerships with identified statewide family based organization or program that provides family-to-family support and here we require that 25% of funding level will be dedicated to this family based organization in order to strengthen family engagement within the state level EHDI systems.

And then the family leadership in language and learning or FL3 program is a new cooperative agreement that we developed for

the upcoming -- for this fiscal year as well and this is -- this was developed to provide more support directly to families with deaf and hard-of-hearing children within the EHDI system of care. The EHDI legislation also calls out the specifically that program and system child establishing foster family-to-family support mechanism within the EHDI program. The purpose of the program is to promote inclusion of families, parents and care givers of deaf and hard-of-hearing children identified through the newborn screening programs at the state and national levels and to support their children language literacy and social and emotional development. The key three activities they are charged to work on is supporting the state organization and providing support to families. They will be coordinating with our international resource centers which is NCHAM in supporting family engagement and the state and national levels and then also collaborating with established deaf mentorship program to further support family support activities.

I'm going to pass this on to -- I have one more thing I want to add is our new for the family leadership in language and learning cooperative agreement is our national hands and voices organization. So they will be starting their project within the next week or so as of April 1. So we are looking forward to working with them in starting this new project. I'm going to pass this over to Tigisty.

>> Thank you. Hi, everyone. I'm Tigisty Zerislassie and as mentioned I am the team lead for the family-to-family health information centers and I will be presenting on that as well as the National Center for Family professional partnerships. As these are the two programs that focus primarily on family engagement here at MCHB. So the purpose of the family-to-family health information centers is to provide information, education, technical assistance and peer support to families of children with special health care needs and professionals that serve those families. F2FHIC are legislated to perform activities. Help families make informed choices providing information regarding health care needs and resources, identifying successful health delivery models, serving as a model of collaboration between families and professionals. Providing training and guidance. Conducting outreach activities to families and health professionals. There is also the only program that is legislatively mandated to be staffed by families who have expertise as well as health professionals.

So we award 51 grants. So there is health information center in all 50 states and the District of Columbia. We award each center approximately 95,700 per grant per center per year and the current project period is from June 1, 2015 until may 31 of 2018.

Overarching organization for these is the national center for family professional partnerships and the purpose of the National Center for Professional partnership is to provide assistance and support to the HRSA funded F2F HICs on the topics of family engagement and cultural and linguistic competence. This is the national TA center to the F2FHICs. Their purpose is implement family youth leadership development and training activities specifically for racially and ethnically development families for the children and youth with special care needs who serve in a leadership capacity. The activities at the national center include facilitating the work of a community of family leaders through assistance. It contributes to the evidence based documenting the value of family professional partnerships and family centered care and also engages in reciprocal learning and partnership activities with the national centers, grant programs, state and local children special health and MCH programs and other strategic partners. The current grantee for the National Center for Family professional partnerships is family voices and located in New Mexico. They are awarded through cooperative agreement in the amount of 600,000. Another activity that national center has undertaken this year is providing support to family organizations in the territories in Puerto Rico and the territory to provide Zika information and resources and direct support to those organizations. And in order to do that they were awarded two supplemental funding in the amount of 250,000. And that will be it for these two organizations.

The next slide basically has our contact information so if you are interested in contacting us, please do. Our information is located on the slide. Thank you.

>> Thank you very much. Our next presenter -- and for those of you who are participating today, you will have an opportunity in just a bit to be able to make any comments or raise any questions with today's presenters. But we will do that after all of our presenters have concluded their comments. Our next presenter is Michelle Jarvis who is with family engagement and leadership development. Michelle?

>> Thank you. Hi, everyone. Today I will talk to you a little bit about who AMCHP is. That's the Association of Maternal and child health programs. We will lay foundation what family engagement is and why it's important. I will share some of the backdrop on the survey project with a brief overview, then we will discuss some highlights from the survey results and finally I am going to leave you with some things to think about for how you might be able to get more involved.

As I mentioned, AMCHP stands for the Association of Maternal and child health program. We were national resource advocate for public health leaders and those working to improve the health of women, children and families including those with special health care needs. We are a membership organization and our members are really diverse, from state government to directors of maternal and child health programs, academic, advocacy and community based family health professionals, all the way to family leaders. AMCHP builds successful programs by disseminating best practices, advocating on our member's behalf in Washington. Providing technical assistance, convening leaders to share experiences and ideas, and advising states about involving partners to reach our common goal of healthy children, healthy families and healthy communities. AMCHP received support from a variety of sources such as the Maternal and Child Health Bureau. The center for device for prevention. The Lucile Packard Foundation for children's health. W.K. Kellogg Foundation in addition to the dues paid by AMCHP members.

The foundation of having families engaged in public health systems stems from the principles of community engagement. There is selfed regarding community engagement which indicates the incidents of illness within a population can be influenced by their lifestyle and behaviors in addition to the social environment. It's prove than when people work together for change and they are involved in their community, that population then has the ability to experience long-term improvements in their health. Families are one example of a specific population. As with community engagement, similar factors contribute to successful efforts of engaging families in public health issues and efforts. Some of these are environmental so is there a history of collaboration or cooperation in the community? Membership. Families need mutual respect, understanding and trust. Process or structure, are there clear

roles and guidelines? Communication, so there needs to be open and frequent interaction information and discussion. Purpose, is there a shared version? There really needs to be a shared vision and then resources which include funding and stakeholders.

Language from the appropriations for the amship block grant speak to family centered care and children need with special health care needs in the following and this is a quote from the appropriations. To provide and promote family centered community based coordinated care including care coordination as defined in subsection B3 for children with special health care needs and to facilitate the development of community based systems of services for such children and their families. There are ten components which have been identified as hallmarks of family centered care and those are acknowledges the family as the constant in a -- in a child's life. Builds on familiarhy strength. Supports the child in learn being and participating in his or her care and decision making. Honors cultural diversity and family traditions, recognizes the importance of community based services. Promotes individual and developmental approach. Encouraging family-to-family and peer support. Supports youth as they transition to adulthood. Develops policies, practices and systems for their family friendly and family centered in all settings and of course celebrate successes.

Talking about the history of family engagement in title 5, there is a rich history of families being involved. So dating back to 1921, we see the official beginnings of legislation focused on maternal and child health with the shepherd towner act which was originally named the maternity and infancy care act. This really was innovative legislation being it was the first federal aid program for states regarding health and although this legislation was only in effect until 1929, it really set the stage for passage of title 5 of the Social Security Act shortly thereafter which was in 1935. Families have been involved across these efforts in a variety of ways. It wasn't until the late 1980s the importance of their role in engagement became more formalized. A report from the Surgeon General in 1987 focused on children in youth with special health care needs launched a campaign using family centered and community based care to improve the lives of children of youth with special health care needs. From there the omnibus budget reconciliation act in 1989 increased the accountability of

states to have a commitment to family centered care. Since that time, the focus on the importance of engaging families has only gained momentum with things like the addition of form 13 in the '90s. Expanding the definition of family centered care to include all of MCH in 2002 and as Treeby mentioned revisions to the block grant guidance in 2015 which increased the focus and the accountability for family engagement.

So family engagement is important for a number of reasons. First and foremost, the entire reason why most of our programs and activities exist is to serve and benefit families and consumers. We really need family leaders to have a seat at the table just as much as they want to have one. It only makes them to design initiatives around the needs of those that they are aimed at helping. So with families aren't part of the inception, design, evaluation and the evolution of programs and services, we aren't going to know if we are truly helping being effective or delivering what is necessary Considering the benefit to families of being able it to help move forward programs and services that will meet the needs of their loved ones, they bring energy, passion and real investment and they are ready to do the work. Making families a meaning part of the process from the start in every step of the way is the exact definition of a win-win.

I know that many of you have heard about the family engagement survey that AMCHP did over the last few years. Treeby also referenced that. So talking little bit about how that program started and and how it came to the survey. So the survey was resulted on a grant from Packard and we started out with key informant calls to get a sense of what was important, you know what don't we know and where the holes and the information that we have. From there we convened a stakeholder work group to assist with the design and layout of the survey. I do want to note that survey was designed with some anticipation of the revise title 5 guidance that was coming out in 2015. So this legwork started just before that, but we knew it was coming and we took that into consideration.

The work group determined the need for two versions of the survey. One for MCH and one for CYSHCN programs. They are similar but there were some nuance differences between the two. The survey was launched in November of 2014, and it closed in March of 2015. There were broad categories within the survey that looked at defining families, compensation for staff or

other roles. Types of opportunities including title five needs assessment and block grant process. Working with other family organizations in the state, training barriers and benefits. We received a 64% response rate for MCH programs and a 73 response rate for CYSHCN programs. The survey report entitled sustaining and diversifying family engagement in title 5 programs and its comprised of a summary result with a series of briefs that detailed the results in specific areas and those specific brief areas are family engagement executive summary, create agriculture of family engagement, levels of family engagement, roles of family staff or consultants. Family members employed as staff. Sustaining and diversifying family engagement. And evaluating family engagement. The information gathered from the survey prompted in-depth interviews with five states which resulted in two additional case studies and the case studies are engaging diverse populations and family engagement. And all of those can be found on the AMCHP website.

>> Next I will share a few of the highlights from the survey, but I really encourage you all to take an in-depth look at the report and those individual briefs. We asked how family is defined just to get a sense of when we say family, are we talking about the same thing? On a immediate family, step mom, mom, step dad, dad, siblings, primary care givers, guardians, foster parents. MCH responses was a bit lower at 36% and the other was 95%. However, both MCH and CYSHCN responses reported similarly on extended family which is grand parents, aunt, uncles and so on at 78 and 73% respectively and on including youth and young adults as appropriate at 81% and 86% respectively.

These here are the top five responses from each of the survey. Three president same in variation of response rate. So those are recurring culturally diverse families, a lack of resources, lack to pay family and recurring representatives across geographic areas or remote areas. So those three are consistent again across the MCH and CYSHCN responses and are in varying order of degree to what extent they are a barrier.

Generally a number of outcomes have been identified by family support organizations and public and private programs. When consumers of family support services so for example parents and other family members are an integral part of planning and program development, many benefits have been noted including the services are better delivered more cost effective and more

culturally sensitive. Also that customer satisfaction is improved. The likelihood of positive family outcomes is higher. Communities are healthier as their capacities to better support families are enhanced. And parents model for children ways they can be involved and contribute. Through the survey our members have specifically identified many benefits that their programs have experienced as result of families being engaged in the work. Most commonly identified benefits are increased awareness and understanding of family issues and needs. Increased family professional partnerships and communication. And improved planning and policies resulting in services more directly responsive to the family needs. Some other benefits that were identified are assistance in evaluating program goals, objectives and performance measures as well as increased understanding of programs and issues by legislature, state officials and the general public. And here I wanted to share these were the top five training needs that were shared between MCH and CYSHCN programs. The sixth one was specifically identified by the CYSHCN program.

Finally I wanted to share a couple of opportunities as you think about engaging families and family partnerships. One you can connect with your title 5 CYSHCN director in your state You can connect with your AMCHP family and they are a member and a delegate spot or seat that is reserved specifically for the family liaison to the title 5 program. There is also the leadership lab which is a unique leadership program for territorial title 5 staff that have a desire to pursue greater leadership responsibility. The leadership lab is structured to allow title 5 staff from across the work force so that is family leaders, new title 5 and MCH director, CYSHCN director and next generation leader and MCH title 5 epidemiologists to learn from each other the lab also provides opportunities to learn from role based peers and the program uses a three pronged approach, which is learning, second mentoring and coaching and then third is peer-to-peer interaction. If any of you are interested in hearing more about those AMCHP opportunities I am happy to connect with you. From here I will just thank you for your time and allowing know share all of this information with you and I will pass it on to the next presenter.

>> Thank you so much that was Michelle Jarvis from AMCHP. Thank you.

Our next presenter is Sarah Wainscott who is from Texas,

the EHDI follow-through guide project coordinator through their contract with the Texas Hands & Voices. Let me complete stretching your slides here. And you are ready to go, Sarah. Thank you.

>> Thank you. Yeah, my job here is to bring a practical perspective so I'm excited to tell you about what we have been doing in Texas in terms of family engagement. Couple of messages I want to share is that it can be done and done well. The reality that it's not is simple, but it is absolutely effective. All our organization is a Texas hands and voices and we partnered with our state EHDI system and we had a couple of targets. One was -- that I wanted to talk about today. One is to really develop an effective partnership. The other is to talk about the program itself and its effectiveness. I also want to be able to touch on some of the unique contributions that parents make within our EHDI system.

Our focus was lost to follow up and documentation. Is that problem across the nation, it's certainly a bigger problem in Texas. We are the second largest birthing state. We have over 400,000 babies a year and we improved significantly over the last several years, according to CDC data but we were well behind the nation. These numbers reflect the loss of follow-up at the point of diagnosis and our numbers are even more troubling when we look at intervention. We have a CDC numbers are at 71% for loss of follow-up at the point of early intervention. It's a priority in Texas and that's why we partnered with our state. Our partnership with Texas Hands & Voices in our state is funded through a HRSA grant. And again focused on that loss of follow-up and documentation. There are two primary objectives to that project. One is leveraging parent-to-parent support to facilitate those transitions from screening to diagnosis to early intervention within that one-three-six window. In addition to supporting families, we want to be able to follow-up with providers to re-enforce protocol to report on parent resources, to share experiences. So really the project is two pronged. One is to address the parents and the other is to address providers.

Just an overview of what we do within the project, every week there are a number of through our system there are a number of families who have failed to transition as they should have from either screening to identification or identification to early intervention. So we are given a bundle of those numbers,

those confidential ID numbers and parent guides that contact those families to identify next step. And it may seem counter-intuitive to have the family calling instead of the provider calling but it's a different feel for the parent to call to say I'm another parent and I have been there and let me help you get to the next steps ratter than having a -- rather that having the provider call and say you are out of compliance. We had gotten great feedback from the families. We do use some Scripps. One is to ensure the data collection is complete. And that it's consistent across families so we are gathering information as we engage with these families. There is flexibility that enables those guides to follow the parent lead.

There is a specific follow-up plan in place. So once those next steps are identified, the parent -- the follow-through guide is able to call back that family and do some follow-up as well as share information specifically with our state EHDI system.

Our state system receives data. Some of that is quantitative. How many families were called, what providers had failed to refer. We are the -- where the families are terms of their processes. There is a lot of pace notes and narrative data that really helps to identify specifically what the barriers are for those families in terms of follow-up.

And even for families who are on the right track and we simply didn't know about it were able to update the MIS system which not only assist us of the loss of documentation but it's re-enforcing the next step to the families even for the families who are on track. And we are going through and identifying those providers who have seen the families and who have not made an effective referral to early intervention and we are going back and providing coaching to those providers from the family centered perspective.

The perspective sometimes compete. A family based organization and a state organization, even though our objective is the same in terms of positive outcomes on the project, as we started this collaboration we came from really two different world views. As a parent organization, we were really focused on parent support. And we were all about informed choice for those families and resourcing those families. And the state program the EHDI system was focused more on the providers. They were really trying to address things from a compliance

perspective. They were looking at training the professional. And so there had to be some negotiations as we began working together. Some of that included the language and the Scripps that were used. So for example it certainly important from the beginning to identify who you are calling and who you are and why you are calling. But we had our families particularly our guides who were from Spanish speaking families who were saying, hey, we can't just call and say we are the state calling. We have to be thoughtful about the Scripps that we use and how we identify ourselves. We had to be thoughtful about the kind of data we were collecting and what we were reporting. We didn't want to collect any data from the organization that wasn't going to be effective or to be used by the state. But there had to be some protocol that was in play.

Timing was an issue. And as well as partnering realities. So to communicate to the state that we hired parent contractors and while they are well trained and experienced, they are not sitting in a cubicle next to a phone for eight hours a day. So we have to be flexible and intentional about how we plan our time together and about what our expectations are. Everything from e-mails to data reporting. Some of those changes came within our organization. Changing our staffing structure in terms of supervision. Participating in partners. So far example as we were within our organization as contractors, we meet every week we have the person from this state EHDI system in our meeting on phone call with us. And so that those connections are more natural.

There has been to be honest those natural stages in any kind of team building that forming, storming, performing, things have not always been easy. But the reality is that we really built a healthy collaboration and parents have earned credibility within the state.

We have been intentional about those parents we select. Certainly we want parents who are already experienced with children who are deaf and hard-of-hearing. So we are not looking for somebody who has been identified two years out. We are looking for somebody who has walked the path for awhile. Typically we are selecting people from our team who already have experience with our organization and have demonstrated effectiveness in guiding other families. It's critical to us that they are philosophically aligned with a parent's choice. Especially in those early fragile months where parents are very

uncertain and vulnerable. We want to be thoughtful about the information that we provide them and it's effective and that it affirms a variety of parent choices.

A parent guide goes through a training within the EHDI system so all of the EHDI training they get as well as Texas Hands & Voices. Then there is ongoing professional development. So these are parents acting as professionals, paid as professionals, hired as professionals and cultivated as professionals.

We've also selected team members that are culturally competent in Spanish as well as American Sign Language. And some of the unique contributions that those parents bring, they are absolutely practical. They are really sensitive in how they engage with families and they are passionate about our mission.

What I'm going to talk in a minute about some of the results of our project, we are getting ready in April to start our fourth cycle. This has been a gradual process. We started in April of 2014 and we expanded and strengthened as we progressed. And so just developing Scripps and protocol initially was critical. How are we going to share data and maintain HIPPA compliance and how are we going to do this effectively. How will we initiate the phone calls and how will we follow up? What about those provider calls to be honest we were really initially anxious about that. How is a provider going to receive a call from a parent? What kind of credibility do we have? We have chosen our parent guide well. She is very effective. And has a real credibility with those providers. Pushback has not been a problem.

We do have in our protocol now if we are not able to connect with that family over three phone calls we have a protocol for texting. We expanded our outreach strategies to other things like can our family guides help identify ways that the screeners can effectively communicate with non-english speaking families, for example. How can we help develop resources for providers?

And we really moved into at this point care coordination so as we begin to enter cycle 4, that's going to be a critical part of our project as it expands. The results, the families that we engage with are provided just in time support and those vary. Often it's just guidance on how to facilitate

the transition to the next step. And sometimes it's explaining what those test results meant. How do I identify a provider that takes my insurance? What about transportation? Addressing all of those barriers. Many times particularly for our Spanish speaking families they have gone through that process of screening or even identification but not understood the results. So some of it is explaining what's already happened. Not every time, but sometimes the families are asked to share a personal story when requested. And they are coached specifically how to do that in a way that doesn't place any less value on another decision path.

A lot of these families haven't been effectively referred to early intervention and we make that happen, making sure they get to that place or referral for long-term parent-to-parent support and in Texas that's the guide by your side program. There is a plan to consistently follow up with those families. We are also reporting from those families directly to TEHDI. Our state EHDI. It could be specific information about how that referral situation went well or not. That narrative data we get from the case about what the families are experiencing and what their barriers are. I should say that access to Spanish is critical. More than a third of the calls that are made within this project are Spanish speaking families. So that's been a big deal.

And in addition to supporting the families, we provide support to providers. And so some of that is updating that MIS system, connecting them with ECI. Identifying the providers that aren't reporting and informing EHDI about training needs. And then going back to those providers again. This is what the families heard or didn't hear. Let me tell you about protocol and let me share resources. And the outcomes have been measurable Over a 2500 families that had been lost to the system have now been contacted. We've gone back and provided coaching to 120 providers which again expands our reach. And at the time we began this project in 2014, we were connecting with families whose babies were nine months. Now those babies are four weeks and so our opportunity to stay within that one-three-six window is optimized.

When we began the project we were identifying that about 32% of those families had not been effected and referred to ECI. That has been cut in half because we have been able to share with those providers. And as we said before, our credibility

and what we are able to do has really expanded across the state. Really building our families and our parents into leadership role.

Those patiences are really uniquely qualified and I think this is my take home message. EHDI has important things to say, but unless the parents hear the message you aren't effective. The parents are uniquely qualified and are most effective messengers. They have credibility and comfort based on their lived experience. Our families are more likely to share with our guides what their barriers are, what they didn't understand. These parents are accessible on the phone and sometimes that means an hour long phone call from being emotionally available or being able to call back when another parent is there to hear the story again. Their communication is understandable. They don't use the jargon, they are tuned in to checking for understanding and making sure that message is clear. And they are not just looking at one piece of that EHDI system. They have the big piece -- big picture because they have that lived experience. And then again to emphasize the importance of having that fluency in Spanish. There is a lot of things we can't measure so every time the phone call is made, sometimes it's just collecting data and moving them to the next step. But a lot of times they are very significant conversations that happen that really are changing the trajectory for the families. We were pleased with what we are doing in Texas and pleased with the results and I would love to tell you more.

>> Thank you, Sarah. I'm going to go ahead and open up our Q&A field now. And while we do that, I got to stretch a few things. I'm going to make the information available about our presenter's contact information there in the primary windows so you know how you can reach them if you have any questions that you aren't able to have adequately addressed today. While we wait for some questions to come in, I want to encourage everybody to read the AMCHP family engagement report. The link to that was provided in the webinar description that you saw in being able to register for today's webinar. And also alert you that if you want to learn more about the F2FHIC, view the February webinar that is posted at infant hearing.org where you can learn a bit more about that.

The first question that came in, are there any tools available to states to use in measuring the quality of their family engagement to guide systems improvement. Would one of

you like to take that question? Are there any tools available to states to use in measuring the quality of their family engagement to guide systems.

>> Will, this is Treeby. I wished I had a perfect answer to that wonderful question and I don't. There are some places that I would suggest looking and I also think that this is the opportunity for a great conversation with our new national center on family leadership and language and learning who worked closely with the national center for family professional partnership, family voices. There are some tools on the family voices National Center for Family professional partnerships website and then I had thought of a couple of other places to take a look. One would be the website for the Lucile Packard Foundation for children's health. They are the folks who funded the AMCHP survey on family involvement and they have done a lot of work in the area of family engagement Then the third place I would look would be on the AMCHP website and the work on the standards of care for children and youth with special health care needs because family engagement was a piece of that and they are -- there are some assessment tools on that website. So that's not -- that's an imperfect answer to a really good question.

>> There is probably very few perfect answers to good questions. So thank you.

The next question is a question that I believe for Sarah because it references Texas. Does Texas have an enabling legislation that helps to bridge HIPPA concerns and barriers related to follow-up?

>> Yeah, this is Sarah. I would say that there is no specific legislation, but what I would say is that Texas Hands & Voices is acting as a contractor. And so when our follow-through guides are calling, they are being -- they are representative of our state EHDI system. They do not have open access, if you will, to the state MIS system. There is a confidential ID number that is shared with that guide. She is able to go in and pull up only that family's information and only a limited amount of information. So they are able to see that the baby referred and where the family lives that nature of information. The consent when the parents have that baby's screened covers that initial contact. We do not follow them beyond that scope of our project. We are only contracted to provide within that

screening. I did a vacation intervention piece and if we were to refer them outside of our project to Texas Hands & Voices, we would have to have their permission. Again we are acting as contractors as a part of that state health system.

>> Great, thank you. This next question comes in as two questions with a pres have saying are there -- preface. There are two questions regarding the -- first, will states be held to the specific requirement for designated activities given our funding was cut? And the second is, will states receive updated guidance regarding budgetary allocations in light of the funding cuts? P are you able to address that question?

>> I'm able to give another really imperfect answer to a really good question. What I will say is that I think you received guidance as a result of the Federal Government's continuing resolution status that NOA reflects the reduced level of funding and in accordance to they are duction be funding has been adjusted proportionately across the requested cost categories. So I can say that. And then I'm missing the second part. Can you scroll back up.

>> Yeah, the second part was will states receive updated guidance regarding budgetary allocations in light of the funding cuts?

>> As soon as we are able to share information, we will.

>> Okay. Thank you. I know those are tough questions at tough times. So thank you for answering that.

The next is a question that reads, can you please share more information on the AMCHP community of practice on family engagement webinars? Do you have the dates?

>> Hi. This is Michelle. We don't have the dates right now. The community of practice there is a flier that went out about that so I'm assuming that whoever asked the question received it and so there is a link on that flier to fill out an interest sort of questionnaire if you will. And then we will go ahead and select participants from there and then the dates of the webinars -- or not webinars, calls really, as well as topics will be determined at that point and if you have any sort of more specific questions about it, then I absolutely encourage you to follow up with me offline and I'm happy to answer

anything I can based on the information that we have to this point.

>> Great. Thank you. I will try to go through the final questions fairly rapidly since we are at the top of the hour already, believe it or not. This next question is directed to Michelle. You talked about the family engagement survey. We saw that family satisfaction was a common -- a very common evaluation method. Outside of the briefs you mentioned, are there plans to share more 360-degree evaluation measurement tools with MCHB programs and CYSHCN programs?

>> So I have to be honest, I'm not really clear on what that question is asking so my sense is that the question is getting at the importance of hearing from families and we certainly -- if that is the direction that you are going with the question, then we absolutely value the importance of family input and getting that sort of that side in the 360 and looking at how things are going and what is happening in states and we do communicate with our family leaders all the time. You know we are hopeful and look for opportunities where we can replicate a survey like this or something similar with family leaders, but that wasn't the focus of this specific project in funding that we received from Packard. This was really looking from the state perspective and having that conversation via survey with the state directors. So that's my answer based on what I think is trying to be asked. Again, if the person that submitted that question, if that wasn't your intention or you would like to follow up with me, I am absolutely happy to discuss that more and you can contact me and we can set up a time to chat about that.

>> Thank you. And I posted a comment from Sharon Ringwald over in the left about a resource some of you may be interested in. Take a look at that and copy and paste that if that is of interest. The next question is for Sarah. Did the guides call the family without knowing the family? Or did they get permission from the family first?

>> Yeah that goes back to what we talked about with consent. They were acting as contractors and so the follow-through guides are calling as a contractor representing the state. The consent they have signed at the point of screening covers that initial contact.

>> And here is another Texas related question. Did Texas implement a loss to follow up, loss to documentation protocol starting with parents? Or did they start with other EHDI staff?

>> You know, because the -- loss to follow-up is a dramatic issue in Texas, our state EHDI system has tried a number of things so this is one specific project. I will say -- and I don't know the difference between following up with this -- I know they have some interns and folks, and I also know that they have -- that our early intervention system has tried outreach to families and that our outreach has been more effective. And I would point to not just the fact that they are parents but the nature of training that they have. And they are simply able to engage well. Not every time but most times. I will also say that we see a difference with those Spanish speaking families. And I think that you see they are reflected in the literature as well when we look at that parent to parent support that often the engagement with the Spanish speaking families, it looks different. It's more off the within fathers, for example. It tends to be more intense and longer and so some of what we are seeing may in terms of difference may reflect the fact that a third of those families that we are connecting with are Spanish speaking.

>> Thank you so much. We are at the top of the hour and passed. Thank you so much, everybody, for the excellent information that you all provided and for the great questions that were shared. If your question didn't get addressed, our presenters today have offered to respond via e-mail so you see their e-mail addresses on the screen. Couple of you have asked about copies of the PowerPoints today and those will be shared as well with you after today's presentation. And this webinar is going to be posted on infanthearing.org within the next week. So that you can share it with others that you think may benefit from this. Before you go away, as we close out today's webinar with a final thank you so Treeby Brown and Tigisty Zerislassie, Michelle Koplitz, Michelle Jarvis and Sarah Wainscott, I hope you will just wait one second as I close the meeting and a very short evaluation question is going to pop up on your screen that we hope you will take a moment to answer so that we can improve our practices of delivering information via this format. Again, thank you to our presenters today. We hope to see you at future webinars from NCHAM.