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NCHAM - FAMILY TO FAMILY HEALTH INFORMATION CENTERS & EHDI
PROGRAMS

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proceedings.

>>For our presenters today, just as a reminder, mute
your phone when you're not intending to be broadcasted, and
also to remind yourself that when you do want to say
something to unmute yourself.

You have the phone number up in the upper right-hand
corner as well as my personality contact in case you have
any significant need that you need to text me about.

I will be helping to keep some time on everybody today
and so when we reach the one minute point in any given
group's presentation, I will move this thing, this flag,
field up and down to capture your attention and hope that
will do the job in helping you know to wrap up.

Does that sound okay?

>> Can I ask a question, if I don't have a mute on my
line, on this particular phone, is there -- is it star six

or something that I could push mute.

>> I am now hearing a background noise and I'm not sure what that is.

Are the rest of you hearing that? It's almost like an occasional wave sound.

Is somebody at the beach?

>> So this is Bev and I am not hearing it.

>> Okay. Well, that's good. I'm glad.

I wonder if anybody else is.

NOTE: I can hear it

>> This is Gina and I don't hear it either.

>> Diana doesn't either.

>> This is Cherry, I don't hear it either.

>> It's the waves inside my head.

For those of you who have turned on for today's presentation, we welcome you. If you can give us a little feedback that, in fact, you are receiving our audio transmission, that's always reassuring. If you have any disruptions in the signal that you're receiving, I can let you know that people are telling us that they are, in fact, hearing the audio transmission fine. So if you're not, that's probably a sign of something on your end. So adjust the volume on your computer, make sure that you have done that. If you're still having a problem, then you might want to sign off and come back on and hopefully establish a stronger Internet connection.

Once again, you should be hearing audio right now, and I believe everybody is, but just to be on the safe side, I posted about this. We'll be starting at the top of the hour, which is in about twelve minutes.

Did one of our presenters have a comment they wanted to make?

I think I talked over somebody for a moment there.

>> This is Diana. I was just mentioning that sometimes the sound of a like wave in your ear is a notice to get your hearing checked.

>> (chuckles) thanks. I appreciate that.

For those of you signing on on a fairly rapid pace right now, which is always great to see, we'll be starting at the top of the hour. Today's Webinar is brought today by the National Center for Hearing Assessment and Management, also known as NCHAM, at Utah State University.

For those of you are who have signed on, my apologies for being redundant but people are signing on fairly rapidly right now. For those of you who have joined our Webinar today, you don't need to be worry about being miked. You will have an opportunity to express a question

or comment if you like through a text field that we will be displaying once our presenters have completed their presentations.

For now, just adjust the volume to your liking on your computer speakers or head set. We'll be starting in about ten minutes.

NOTE: I hear the noise again. It sounds like machinery moving in the background.

Is somebody in a warehouse?

>> For those of you who have just signed on, we welcome you to today's Webinar, brought to you by the National Center for Hearing Assessment and Management at Utah State University.

We'll be starting at the top of the hour, which is in about seven minutes.

You can adjust the volume on your computer speakers or headsets to your liking. You don't need to worry about being miked today. You'll have an opportunity to interact with our presenters through a text field that we will display once our presenters have completed their presentations.

So if you have a question or a thought you'd like to share while they're presenting, just make a note to yourself and then we will reveal a text screen through which you'll be able to submit that once our presenters have completed.

[PAUSE]

>> Alison, could I ask you a favor?

>> Sure.

>> Could you just kind of keep your eye on that presenters list in the attendees pod.

>> Mm-hmm.

>> Just in case somebody is suddenly not there, to then look for them below in the participants list.

>> Sure.

>> If they were to sign back on and then to elevate them back to a presenter level?

>> Yep.

>> That will be helpful to me. Thanks.

>> Mm-hmm.

>> So for our presenters, if that were to happen, know that you remain connected by audio, hopefully, if you were to get kicked off of line, and Alison will be looking for you to reappear in the list and elevate you back to the status that you are now.

So for our participants, welcome to today's Webinar. Thanks for signing on early. It will be so exciting to see

people conscientiously joining our Webinar. This Webinar is brought to you by the National Center for Hearing Assessment and Management at Utah State University. We'll be starting in about five minutes.

You don't need to worry about being miked today as a participant. Just adjust the volume on your computer speakers or headset to your liking. You will have an opportunity to share a question or comment with today's presenters if you like through a text field we will reveal once the presenters have completed their comments. So for now just get your audio adjusted to your liking.

If you were to have any disruptions in the quality of the transmission of either the audio or the visual transmission today, first you would want to check your volume settings but sometimes if you have a poor Internet connection or disrupted signal, it may require you to sign off and come back on.

I'll also mention that today's Webinar is going to be recorded and posted on infanthearing.org. So you or others that you think might benefit from today's Webinar can go back and view this at another time if there was something that took you away from today's presentation.

One way or the other you will have access to our presenters' information today.

Once again we'll be starting in about three minutes.

[PAUSE]

>> I'd like to do one last roll call of our presenters, if that's okay. So those of you presenting today, please unmute your phones. I'll just call you by name and just ask you to let me know that you're still there.

Bev Baker?

>> Yes, this is Bev. I am still here.

>> Great.

>> Diana?

>> I'm here.

>> Tanya?

>> I'm here.

>> Cheri?

>> I'm here.

>> Gina.

>> I'm here.

>> Kathleen?

>> I'm here.

>> And Dana.

>> Dana just stepped out. She'll be right back.

>> Okay. You're together though.

>> Yes.

>> So that's all good.

Wonderful. So it's always good to know that we're all lined up and ready to go.

So we'll be starting in about two minutes.

[PAUSE]

>> I'm going to initiate the recording of today's Webinar now. I'll be silent for just a moment.

>> Audio recording for this meeting has begun.

>> I'd like to welcome everybody to today's Webinar that is brought to you by the National Center for Hearing Assessment and Management at Utah State University. We are all in agreement that family organizations play a pivotal role in ensuring that families with children who are deaf or hard of hearing get the support that they need in a timely and appropriate fashion. The National Center for Family Professional Partnerships is one such organization, and today we are joined by various people from different states who will be sharing their perspectives on family engagement.

Today's Webinar will start off with presentations and then once we hear from our presenters we'll reveal a text screen through which you will have the opportunity to raise a question or share a comment. So if you have a thought as you listen to today's presenters, make a note of it and then when we reveal that field you will be able to share that. So without further ado, I'd like to introduce staff from the National Center for Family Professional Partnerships who will introduce themselves and their perspective.

Bev?

>> Yes, thank you, Will. This is Bev Baker, and I'm one of three codirectors of the National Center for Family Professional Partnerships. I'm going to share a little bit about the national center and about the state funded projects.

So first of all, for those of you who don't know Family Voices, Family Voices is a national family run organization. It's a nonprofit organization that started 25 years ago. It was started by family for special healthcare needs. Our focus really is on promoting family engagement at all levels with the purpose of improving healthcare services and systems.

So the box -- the small box below, the National Center for Family Professional Partnerships, is a project of Family Voices, and we are an NCHD funded project working in collaboration with SPAN. And also serves as a family

health center. And the center's focus is to coordinate and provide support training service to this network of Family to Family health information centers. The top right box here gives you a little bit information about the Family to Family health information centers, which we call the F2F, and these are also NCHD funded. There's 51 F2Fs across the country. These are also family staffed organizations and their purpose is to assist families of children with youth -- children and youth with special healthcare needs and the professionals who serve those families.

Many of these organizations are within another organization that you might be familiar with, another family organization often, and parent to parent is one of those organizations, the parent training and information centers are also, and there's other organization that is many of these are joined with. The small box at the bottom here is about the Family Voices state affiliated organizations, or the SAOs, and we have SAOs in 44 of the 51 -- well, the 50 states and D.C.

I'll tell you a bit about the partners. Our funder who is the national NCHD, and SPAN who I already mentioned work on this project, this cooperative agreement, and SPAN is the statewide parenting network in New Jersey, AMCHP, along with all other funded partners. We have as partners youth and why you think adult organizations. One of these organizations, kids as self advocates, is also a project of Family Voices.

And partners include the national, regional, military, and Native American parent technical assistance centers, and most importantly the 51 Family to Family health information centers.

So this is a map that shows which -- explain this. There's 51 centers, 44 of which are also SV SAOs for a total of 56 statewide family organizations that are connected to the work we're doing.

The yellow states are ones where the F2F and SAO are together in one organization. The green is where the F2F and SAO are separate. In the blue is where there's not currently an SAO in existence.

The last slide here will provide a resource link actually to a resource, to a map, an interactive map that takes you directly to the organization in your state so if you want to look up contact information or go to the Web site, you can use that map. As I say, we'll have that link on the left and on our resource page.

So just a little bit about the work of F2F and FV SAO. We are provided supporting support for families. We

provide training and mentoring to family leaders within those organizations. We have many projects with providers. That would include healthcare providers and family faculty programs, et cetera. We have a focus of the Family to Families is really also on policy issues. So we work with policymakers, and specifically working to improve policies and programs to better meet the needs of families. And then of course to the general public. We have various resources available and information. Again, this will be displayed on the last resource page and will maybe be some things you'll want to connect with.

So this slide gives you some idea of the reach that Family to Families has. So there's an estimated 995,000 families that were supported in fiscal year 2016, and another 324,000 professionals, that's an estimate, that were served in that same fiscal year. So this -- you can see the numbers here and it repeats a little bit or a little bit differently some of the work that the F2F and SAOs do.

I'm going to turn this over now to Diana Atin who's also a codirector of the center to talk about some of the training.

Diana?

>> Thanks, Bev.

I'm just going to give a brief overview about some of the training opportunities offered by the National Center for Family Professional Partnerships. This three-year cycle the maternal and child health bureau really wanted to focus on the development of diverse family and youth leadership to participate at the policy systems level to help improve policy and systems for children and youth of special healthcare needs, particularly those that faced the greatest challenges.

And to do that we are offering regional face-to-face trainings and train the trainers, as well as some other services.

Each year of the three-year project we'll be doing three to four regional face-to-face two-day trainings. One will be a regional in-person train the trainer course to develop family leadership, especially diverse family relationship to participate in decision making groups at a system level. And what we're doing is providing this train the trainer to Family to Family health information centers, Family Voices state affiliates, and other family organizations in the regions, and we've already done this for regions, maternal and child health regions one and two and so we'll actually be doing four this year.

And then we'll also be doing a full day training, and that training is using serving groups that make curriculum. You can see that by going to WW.serving on groups.org, which is a crick will you please that was developed specifically to prepare parents to serve on decision making and advisory groups.

We're also doing regional in-person training for title five and other state agency leaders, as well as family organizations on effectively engaging diverse stakeholders at the systems and policy level, and we're using an adapted version of leading by convening the partnership way, which was developed by the IEDA partnership but has been used by many other systems to help state agencies and other conveners to be more effective at really partnering at a very deep and meaningful level with stakeholders.

In years two and three of the project we'll also be doing some intensive state teamwork. Three to five states each year that bring together a state agency and a family organization to really work more deeply around authentic stakeholder engagement and family organization state agency partnership.

We're also going to be doing each year a series of Webinars. This year we'll be doing Webinars for family organizations and state agencies on telling your story for public policy purpose and engaging diverse parent leaders and systems change. And with the automatic self advocacy network, kids of self advocates and youth move which is the national mental health young adult leadership organization we'll be doing in March, April, and May 3 workshops by Webinar, telling your story for public policy purpose, serving on groups, and working with adult allies.

The next training event is coming up February 22nd and 23rd in regions six in New Mexico. Then in region eight. May 3rd and 4th in Salt Lake City. And you can see the other maternal and child health regions.

Of course you're welcome to participate in a region that is not your local region if the timing works better for you in another region.

In conclusion, some of the contacts and resources we have, an interactive map to find the F2F contact information by state. We have a brochure about F2F health information centers. We have a national center for family professional partnership brochure and Web site. He can follow us on Twitter or join our Facebook. And then if you have questions for NCFPP you can send it to myself or Bev or Nora or Richey at Family Voices.org. And also we encourage you to sign up for the Washington update for a

week update of resources that are helpful for people who work with youth and special healthcare needs and their families.

Thank you. And I'm going to turn it over to the next presenter.

>> Thank you.

Our next presenters are from the state of Maryland. Tanya Green and Cheri Dowling.

>> Good afternoon, everyone. I am Tanya Green, the EHDI coordinator for the state of Maryland. I sit under the office of genetics and people with special healthcare needs.

I have worked together with Cheri Dowling of the Maryland parent connections, parent to parent mentor program for as long as I've been an EHDI coordinator, which is six years. Now you will hear from Cheri Dowling herself.

>> And I'm Cheri Dowling and I am a parent of two young men. I have a 22-year-old son who is deaf and has some intellectual disabilities, and also a 19-year-old teenager.

I've worked in Maryland for the last 18 years in family support and have worked with parent connections for the last six years. Always been very involved with our Maryland EHDI program. I began by attending the meetings to get an understanding of what was happening in our state and then I served as one of the parents on the council. We actually have two parents on our council, which is very nice.

Some of the history about our program. Maryland parent connection is a parent to parent mentor program. The program was initially funded through the Maryland EHDI program with the Maryland Department of Health and hygiene office for genetics and people with special healthcare needs. Parent connections was created in response to call for family support activity, family trainings and advocacy.

A subaward was provided to our Maryland parent training and information center which is the parent place of Maryland. It made perfect sense because the relationships were already developed. They were strong and it was a win/win for everyone.

Through the subaward parents place create parent connections and I was hired as the parent liaison. We developed a program to provide parent to parent support, education programs, networking, and social events to provide also the annual EHDI stakeholder meeting. We then hired five parent mentors to provide support to parents and

families and to assist with developing outreach activities regionally around our state.

Our activities not only have a social element but they always have an educational part also. The majority of our events are family events. They're held in family friendly locations where children can meet other children and parents can meet other parents in the same areas. Some examples of the events that we've had, we have family fun day at the farm every year. We do fire safety at the fire stations around our state. We have fun days at parks. We also collaborate with other organizations to provide events.

One of our favorites is a collaboration with connections beyond sight and sound. That's our Maryland deaf/blind program. We provide a family weekend learning program. We've done that for the last five years.

Some of our other collaborative activities. We did a collaborative effort with NICHQ collaborative. I was part of the team. We worked on quality improvement methodologies using PDSA cycles, standing for plan, do, study, and act. We used these PDSA cycles to guide our work. And we still use these PDSA cycles to improve our programs because they work so they're great to use.

Our parent mentors are our parents and children all over our state. They're all parents of children who are deaf or hard of hearing, and they have a wide variety of children and experience. We have a dad who speaks Spanish, a mom from the military, and a mom who's deaf.

Our mentors also have children that have a rarity of needs. We have some who have additional special needs and have cochlear implants, some use hearing aides, some are hard of hearing, some are deaf, some use American Sign Language. Others use spoken English, and some use both.

So we have a nice variety of families.

We are also very proud of our annual stakeholders meetings. We hosted some of the top professionals in the field at our conferences. Those are some of the presenters on our slide that we've had over the years.

For the last five years our conference attendance has been at capacity and we've had a waiting list every year. We pick topics and presenters that are based on the national EHDI conference and also on evaluations from our past conferences.

This year's conference we're very excited about. Going to be a bit different. It's going to be -- our topic is celebrating past, present, and the future of deaf education. This year the American school for the deaf,

which was the first school for the deaf, is celebrating their 200th year, and we have the school superintendent, Mr. Jeff Braven who will be talking about the history of deaf education. During that conference we'll also be celebrating the success of our Maryland EHDI program.

It will be held on May 4th and we're already at the capacity for our registration and it's just beginning of February.

We also provide outreach to professionals, to physicians, audiologists, and providers. We work really hard to get the word out to physicians not to delay hearing screening. The importance of early identification and early intervention, and we also try to make them aware of the 136 guidelines.

I attend the EHDI council meetings regularly to report on parent connections and inform the council members about any upcoming events we may be having or any issues or concerns that come to my attention.

So some of the lessons that we've learned, one important lesson that we've really learned is that one of our goals with parent connections was to match a parent with a newly filed with another parent of a child who's deaf or hard of hearing. We always thought this worked well but we realized they were artificial matches and didn't always work into those friendships that we were hoping for. Sometimes when you match parents it can be just awkward. So we always received really great feedback from parents that the parent mentors were very helpful, that it was great to have someone to call when they had questions or concerns, but we just didn't see those relationships happening the way we wanted. What we found was that when we invited families to attend free family fun events that they were making more matches, that the friendships that we hoped that would be created were being created on their own. And families naturally gravitate towards families who have similar experiences. I would watch them at these events and watch them exchange their information and I watched those friendships that were being formed naturally and all that awkwardness was gone. Many of those friendships are still actually in existence and we know this because most of those families still attend our events and many times they come together, which is a very nice thing.

So what is the future for parent connections? Well, we're obviously hoping to be awarded for the 2017 Hertz grant and that will allow parent connections to continue with a stronger and even more robust program. During this

new grant cycle we will be working with some new partners, some additional partners. We're looking to work with the University of Maryland, division of behavioral and developmental pediatrics, Maryland title five children and youth with special healthcare needs program, our Maryland chapter of the American academy of pediatrics and our state led program. We also have a few other state and private agencies we'll be working with. We will be expanding parent connections by hiring additional parent mentors and this will allow us to expand the reach around our state.

We will also be providing additional leadership training and activity for parents and I should also mention that the majority of our parent mentors have graduated from our special education leaders program and that we provide this yearly through our parents place in Maryland.

I have to say this is a very intense six-day training that we provide free for families in Maryland. That is amazing training. So we will also be looking at using some new technology features to reach out family. We will be developing some learning communities in the future and using this form we will be sharing more information about our EHDI program. We'll be talking about early identification, early intervention, and promoting the importance of those 136 guidelines. And in conclusion we're just very excited about the possibilities of the next three years to improve our services even more so to families in Maryland.

>> Thank you. Are you complete, Maryland?

>> I think so.

>> Okay. Thank you.

Our next presenters are from the state of Utah. I'd like to introduce Gina Pola Money who will be talking about their experiences. Gina?

>> Thank you. Today I have to say that you'll just be hearing from me. Unfortunately our EHDI director is out very sick, but this presentation was developed in partnership with all of EHDI staff.

So to go over a few of the pieces about each of our programs, the EHDI program sits at title five under children with special healthcare needs, and Utah Family Voices has also -- I'm sorry, I'm not advancing the slides. So rego. That first slide as you can see, it's not hard to tell where we're from.

For Utah Family Voices, we are the Family to Family health information center as well as the Family Voices state affiliate organization. We actually sit under our parent training and information center, which is the Utah

parent center, so that we feel like we have a knowledge base of education and healthcare. Our Family to Family project is closely aligned with the Utah Department of Health. Part of these relationships came from -- in 1997 we had got a pilot to start looking at what a Family to Family health information center would look like for all families and children with special healthcare needs, and as we grew that with some small contracts and funding and then eventually our maternal and child health bureau grants, we were able to also be incorporated into our children with special healthcare needs bureau under Title V under some medical home initiatives, which has helped us really get to the point of our collaboration partnerships and integrations as they help to support my position so that all of our grants could go to helping to bring on more family navigators, parent consultants and so forth to help statewide, since we have a majority of our families, about 85 percent of our families live on what we consider the WASATCH front and then the additional 15 percent are in rural but more so in Frontier communities.

Some of our collaborations, we were talking about, you know, how they developed and how we sustain them and such, and I think we kind of laughed because we just kind of taken it for granted that we have always been there, and it really actually challenged us just to sit there and really think concretely about outcomes and some of the measurements over the last few years on different activities that we have done as well as just parent input, family involvement in general. Our EHDI program has had parents involved for number everything that they have done and the connections with our Family to Family or our parent training and information center have also been closely aligned as one of the main parent mentors in Family Voices in some of the EHDI initiatives and programs is also currently sitting as our chair of our board of directors at our parent and training information center. And through that we have made more connections into developing relationships with other family organizations, such as our deaf blind organization and we collaborate every year on bringing together the families for a retreat as well as the training and information that we can provide on an educational basis as well as the healthcare and financing pieces of those.

We also both Stephanie, the EHDI coordinator for Utah as well as myself are cofaculty for our Utah regional lend program. We bring in new families every year to match with our pediatric audiologist trainees so they can learn about

the day in the life of families through their eyes.

We also have a few unique opportunities due to some of the activities and initiatives of EHDI throughout our state. We have many of the families in rural communities and Frontier communities that have out of hospital births and so the follow-up or LOSTA follow-up was extremely high with the midwives. EHDI really did a lot in making sure they could get equipment to the midwife so we could make sure that these families weren't being lost to follow-up. In 2016 the data showed that 82 percent of out of hospital babies received a screening, and that started at a mere 2.5 percent that were screened in 2007.

Where families were really involved in that was we were able to help with as a Family to Family organization help with outreach and the parent perspectives of those families and mothers that use -- or had out-of-hospital birth to really get, you know, their feedback to know how to best market this and market it with the midwives. So as you can see by the data that I just stated that it's been a very successful program.

Utah's newborn hearing screening program, their time line is earlier than the national guidelines. In Utah families need to complete hearing screenings process by 14 days of age in order to allow for the CMB testing to be completed before 21 days of age. Naturally the guidelines are to screen by one month of age. So the parent involvement is critical to help extreme line the decrease the time to follow up.

Part of that with CMV with a lot of the publicity the marketing and such, we had families that actually told stories and we had signage on the Utah transit authority buses and such to really get the word out in CMB. And families that actually have had a child with CMB in such have those thoughts and we have a 32nd and 902nd and I believe a three minute thought that tells the general public about CMB and hearing loss.

Some of the other pieces that we, of course, do are the grant proposals. One of the ones that we recently worked on was in hopes of getting fund through EHDI are having two specific parent consultants that will be supervised by our Utah family voice project but will actually be placed in the EHDI program to work specifically with families newly diagnosed. And we chose to have more than one parent that -- so we could get many different perspectives of the culture of having a child that is deaf. And so we are expanding out to that. Another piece of that we have been doing, it's not written anywhere in a grant

proposal. It is more of a memorandum of agreement is we participate as a family health information center in our neonatal program. And those families are coming through there. We're providing that first peer to peer, parent to parent support to get to those families that have a newborn that have been diagnosed with multiple different issues, but as well as having a child that has been diagnosed as deaf or hard of hearing.

And part of that piece is as you're talking as a peer to peer, you find out a little bit more information and what the true needs are and we always get permission and we share that with our EHDI program so we can truly meet the needs of the families that are coming in.

And with that I'm hoping that you gave you a few of the ideas that we do as a state program as such and again our end conclusion is you have to do the purposeful integrations. It's one thing to say that you have parent input or family involvement. It's another thing to make sure that they're there every step of the way in the special needs and disabilities world we always say nothing about us without us.

>> Thank you Gina.

Our last state representatives come from the state of Virginia. I'll turn it over now to Kathleen Watts.

>> I'm going to start this out. This is Dana. And then Kathleen.

We're from the commonwealth of Virginia. Not a state. I am the director of the center for family involvement at the partnership for people with disabilities, which is Virginia's university center for excellence in developmental disabilities at Virginia commonwealth university.

I'm also the parents of a young adult, daughter who has a variety of intellectual physical and sensory disabilities.

I'm a fan of Carrie Grant and I like long walks on the beach, although that's probably part of another Webinar Kathleen and I are going to below through about 90 miles an hour in the next ten minutes we're allotted. So please post questions in the chat box.

You'll see on this first slide that we have a little bit of a snapshot for the family engagement, the progression of family engagement activities in Virginia in collaboration with the EHDI program and the center for family involvement. So since 2000, the EHDI advisory committee has always had parent representation. About 2005 we started this dialogue with the EHDI program advisory

committee about parent to parent support. It was certainly the desire of the zen EHDI program coordinator to start some type of a program and use some funding to support parent to parent support. From 2007 to 2010, about four years, we received annually funding through my office to develop and pilot what the guide by your side program would like like in Virginia. We then moved in 2011 to a more generic family support program. Again running through my office here at the center for family involvement. We also service the Family to Family health information for Virginia. And during this time frame we were provided some additional dollars in our contract to support the development of Virginia's hand and voices chapter. A little bit of the nonprofit development and any kind of guidance our expertise we had a little bit of funding to pay their director for a shored period of time. We also had funding during this time to pilot a cultural broker program. It was unique in that the Title V office, not the EHDI program but the Title V office through the money into the pot for us to really take a look at minority healthcare disparity. We were able to bring two culturally and livingly diverse parents on board and looks at cultural brokering. And then in 2015 we really shifted. We continued to provide emotional informational and systems navigational support but we really began to expand our family engagement and leadership opportunities to bring on parents who could conduct visits to hospital newborn hearing screening team and local audiologists. You're going to hear more about that. I'm going to stop and turn it over to Kathleen.

>> Hi, this is Kathleen Watts and I'm with the Virginia Department of Health and I was lucky enough to come on board about two years ago, which was just sort of when this project was taking off, and it's a fantastic project that I've sort of seen grow and make some differences for both the people who were involved in the hospitals and the state.

So we have at this .6 one-three-six family educators. We started off with three. They are throughout the state and we do have a map. We'll show you that in a minute.

The first part of that job description is to visit local hospitals and to do a site visit and everything is very organized. As you can see from the slide we have lots of forms they're filling out. They don't take long. They promise they won't take more than a half an hour for these visits and so these are not like long detailed forms that they have to fill out. Everything's very organized for

them. And the other thing they do when they go in is they let the hospital or audiologist know they're going to be able to provide some resources as well, some things that the stakeholder may not have come across in the past.

Part of what they're doing is, from my way of looking at it, they're being ambassadors for the EHDI program. They have no agenda other than gathering information. So the hospitals especially, the family educators have found they really open up when they realize this isn't a compliance visit or something; it's a parent who's trying to learn more about their program so they can palace along useful information. It's not done like a cold call. I will send out an e-mail or letterhead of time so that the audiologist is expecting them. That's the gathering information for us but they're also gathering information to pass on to other parents, so that's more along the family support family end of the project. But the first part of the project is more just the gathering and the somewhat helping to educate some stakeholders.

>> Great. So you'll see just a quick visual if you're not familiar with Virginia. Here's the commonwealth. We are about 65 percent rural. In northern Virginia we have over 100 to 50 languages spoken in many of our schools. A lot of diversity.

We have 30 part time staff. That includes our six 136 educators. We have about 700 to a million dollars d.700000 to a million dollars from a variety of funders to support kind of larger efforts around family engagements. I mention we're the state Family to Family health information center. Our blue circles or gray circles on this screen are where our local F2F offices are located. The yellow are where our cultural brokers. Red stars are where family educators are located. We tried to strategically place them across the state. And then the green stars are some other liaisons that we have on hand. What's not on there is the 350 volunteers are family navigators. You'll see that we tried to -- we intentionally put them near other offices so they'd have supports.

>> Okay. What we learned through this project is that there's a real need for on-going meetings face-to-face meetings with the 136 family educators just to keep everything clarified because we were sort of developing processes as we go along. We're also finding that we need -- there definitely has to be a liaison from the EHDI program to the Family to Family side of things, especially with things like hospital visits and things, someone who can help the parent if they run into any glitches or

anything like that. And then we also learned that it's helpful and I think Dana just referred to this to have the family educators. So it's really important that they're part of a bigger effort for Family to Family engagement and for building leadership among parents.

And future work in terminates of what we're going to do.

First of all, we're going to continue with the hospital and audiology visits. We've learned a lot of important things. Just one really quick thing that I'll throw out is that the rescreen -- the hospitals that rescreen have eleven .5 percent roll-up rate. If hospitals will just give the families a list of audiologists it's 31.5 percent. So we're gathering data. We're also gathering pockets of information about services that may be available that we need to be aware of in different places.

A purple folder that one hospital uses just for the newborn hearing screening and the birth certificate information, they give it to the parent and say these are the important papers. Anyone who's had a baby knows leaves the hospital with a ton of paperwork.

Those are the kinds of things that we're learning. So we are really excited to have the family educators on board, being able to have some expansion of the program with the next grant cycle. They are going to be an integral part of learning communities and the information that they have gathered is going to really be useful for us in terms of setting up learning communities.

>> And I would just add as we're closing up that we're really committed to treating the one-three-six family educators as we do all of our center for family involvement staff and we will be working with them, taking them through a leadership academy that we do with our staff around their innovation styles, brain science and how that -- how stress can affect where families are. Things like reflective questioning and motivational interviewing leadership talent and strengths. So we're excited that they'll have some additional kind of leadership trainings this year. So thank you.

>> Well, thank you.

I have gone ahead now and opened up the questions field so that our participants can submit some questions.

The first one we have is designated for Gina. You mentioned an emphasis on CMV. Can you explain more about that and what that's all about?

>> Sure. And, of course, I like to say CMB. I'll let somebody say the whole word because I get caught up on it

every time. But it was of course the --

>> (Away from microphone).

>> Thank you.

That as pregnant moms are exposed to if they have kids and such, part of even the learning process for me as a family leader and getting that information out was we as new moms are so used to kissing our babies on the lips and our younger kids on the lips and such and the changing and such and not even realize that our children or other people's children may have that virus, which exposes the unborn child. And hearing loss is -- could be an outcome of being exposed to that virus. So part of the information education was to let new moms know about that because I had never heard of it as a family leader all of these years. What we did was we have moms that of course a part of all the disability face brook groups but we knew that wasn't necessarily the population we needed to get to. As a Family to Family we got to all of those new mommy blogs and kind of put that information out that was developed by EHDI and others in our URN program as well as all of the publicity they did. You can actually Google CMV. Utah and you can see those clips that were developed for the outreach and the PR for the media.

>> And one of our participants is asking you to say a bit more about that regarding the 14 day time line for testing in Utah regarding CMV testing. Can you talk about that?

>> I cannot. That would be the part where -- and I don't know if maybe Alison would want to step in because that would be something that Stephanie would address more so than I would.

>> This is Alison. I would be happy to. I'm not sure. It could kind of take the conversation a little bit away from the family engagement discussion, but I can definitely post my e-mail up on the Webinar and whoever asked that question can contact me and I can follow up with them.

>> So the next question is, as family organizations develop they run the risk of becoming so professionalized that they may end up feeling just paternalistic as some service providers feel to families. How do you prepare families to support one another while also preserving the benefits of organic sharing that can occur when people explore each other's experiences and sort through what is and isn't relevant to their own lives and circumstances?

>> Anybody want to take a shot at that?

>>

>> This is Diana. Both in terms of my role at the National Center for Family Professional Partnerships where I talk with a lot of family run organizations and also my role at SPAN where we're a parent training information center and a Family to Family and a parent to parent program and a federation of children with mental health, I think one of the things interesting to note is that more and more the federal and state organizations that are funding family organizations are expecting family organizations to be more professional, the kinds of -- having to do logic models, the kinds of evidence based practices that we're expected to use all are leading to the need for family organizations to demonstrate, you know, real evidence based -- the use of evidence based practices and also quality outcomes for the work that we do.

On the other hand, I think that, you know, many family organizations, most of the ones that I know who are staffed by family members and I see another question which says Family to Family are family staff that is a requirement of the Family to Family health information center grant that they be staffed by children with family healthcare needs. We're staffed by families still involved in those systems on a day-to-day basis. And most of us also have volunteer programs, whether it's parent to parent support parents or volt tear parents from other programs available to provide support on the ground to families from different parts of the state.

We continue to have access and use of families who are continuing to experience same systems that other family members are calling to get help with.

I think having that network of parent volunteers that are available to provide that emotional support and in that very individualized and personalized way is one way to help that.

>> This is Dana in Virginia. I would just add we spend a lot of time talking to our staff and our volunteers every month, whether face-to-face or through list serves and through Webinars and conference calls that it's a reminder we're not here to tell people what to do. We spend a lot of time having those conversations about how do we use reflective questioning and have parents really think through those decisions they need to make on their own and so you have to put in mentoring for your staff.

>> That's absolutely true.

>> Thank you.

The next question is in light of HIPAA how are you able to share info with parent volunteers.

And another question was, are you having any problems with the sharing of information given privacy laws?

>> This is Diana again I'll give a short answer and maybe some of the states can respond. As an attorney I can tell that you parent volunteers can get information if they're pardon of your system of care, but you have to make sure that they're trained in HIPAA and they sign confidentiality agreements that show they know what information they can or can't share but there's nothing in HIPAA or even FERPA, the education privacy law that would prohibit sharing information with parent volunteers with those volunteers are part of your system of care, trained and they sign agreements noting they will abide by confidentiality agreements.

>> Anybody else want to add to that?

>> Well, this is Dana again in Virginia. Part of our contract does allow for the submittal from the EHDI program to our office and then we use like file locker or encrypted software to send any information to our staff or volunteers or we use telephone and we have a safe database that's also HIPAA compliant to maintain all of our data.

>> So the next question is at the beginning. Presentation it was mentioned that F2F chapters are family staffed. Is this a requirement of the organization or just a recommendation?

>> This is Bev, and actually Diane referenced that question as well. And that is a requirement of name to family.

>> One of our participants asked are there training site locales for 2018, 2019? I'm not sure of the context of that question. Does that -- is anybody prepared to answer that question?

Okay, I'll move on.

Virginia mentioned new leadership training being developed for one-three-six family educators. Can you talk a bit more about how you were developing that training?

>> This is Dana. I won't spend a lot of time because I see questions continue to roll in. We developed a training based on some things that the AMCHP, they have leadership labs for emerging leaders in the field and family leaders. And many of the tools they used I brought back and piloted with our staff last year and we picked the tools that made the most sense. We're really talking about leadership not being a job but leadership being a behavior and so that's our focus. We're looking at the things of understanding people with different styles of how whether you're creators or doers or connectors. Are you -- what

are the leadership 2.0 in using that resource to underidentify your talents and strengths and bringing in experts to talk about mindfulness and brain science and talking about being a super parent versus -- and wearing your super capes versus wearing your cloaks of humility. We have a session each month for over eight months. I'll be glad if anyone wants to -- I don't know if our e-mails are available but center for family involvement.org all one big word. Reach out to me and I'll be glad to share some of our resources.

>> And I will be -- whoops, are you there?

>> You cut out, Will.

>> Oh, I'm sorry. In a moment I will be showing all of the presenters' e-mail addresses over on the left there. It's just taking up space where the Q&A field is right now.

So one of our participants today wanted to add a comment to what was just said and she said that I'm a one-three-six family educator in Virginia and I just have a comment. It's been very rewarding to witness professional seeing Virginia's resources for the first time to see how grateful and excited they have to have them and to receive their feedback one-on-one. That's a nice comment.

The next question is about underserved, underrepresented populations.

In what ways have you found families of underrepresented populations have unique needs or require different strategies to reach them?

>>

>> So in Maryland we actually go to those families. When we do different events regionally around our state we may take one of our events to an area that we know is an underserved part of our area, very rural part of our area and we bring those families in. Sometimes we help to pay for transportation for those families to get to different events. We also have done events solely in Spanish so our Spanish speaking families have the information that they're looking for also. We try to go to those families and make it so they can participate any way possible.

>> Have any of you worked with any mic grant families or migrant programs, like migrant head start?

>> In Virginia that's what our cultural broker model is. They're parents of refugees, immigrants, various cultural and linguistically diverse cultures and part of their role as parent to parent support. Like Maryland going out into the community with which they represent and meeting parents where they're at, speaking the same language and quote/unquote translating information into a

way that makes sense for them. We also work with Catholic Charities, migration and refugee, migrant health, migrant head start and make sure they're aware we're there as a resource and we know what they do.

>> The next question is this: When you shifted from guide to your side to a more generic programming prior to your current one-three-six parent engagement program did the provider parent have children who were deaf or hard of hearing? If the no, how do you compare or contrast running family support programs with disability specific mentors versus more general special healthcare needs?

>>

>> I think this is probably for us in Virginia. You know, we have -- I wouldn't say there's much of a difference. Our philosophy has been we're just one of a host of family led programs in Virginia and that we -- although we tend to be more disability generic, we have liaisons that are very disability specific. Autism projects, the EHDI project which allows us to bring in staff who are parents of children who have autism or who are deaf or hard of hearing. So that's why having 30 staff part time staff allows us that flexibility to be able to serve pretty much anyone that connects with us. And we always, always refer back out to community organizations as another resource. Again we're not the only ones in there and people may get something from us and we'll certainly get something from other programs.

>> One of our participants is asking for clarification. I don't know if this is going to be a complete enough question, but I'll give it a shot.

How do you define part of your system of care? That phrase must have been used by somebody, that families are part. Any thoughts to that comment?

If the person who submitted that wants to clarify the question, that would be fine.

The next is a question regarding leading by convening. Where in the regions will these be held in 2018, '19? Anybody know?

>> Sure. This is Diana. We're planning to hold region four in the fall of 2017, region nine in the winter of 2018, region seven in the spring of 2018, region ten in the fall of 2018, and then regions three in the winter of 2019 and region five in the spring of 2019. M so that's where we'll hold the trainings, but we will be happy to share the trainings, you know, for other regions because, for example, the upcoming training in New Mexico we're having people come from Colorado and Iowa even though

they're not in region six because they want to get the training right away. You can go to an area that's not your area.

>> Great. Thank you.

>> This is Bev. I'll just add we don't actually know if the question was within those regions where it will be, other than the first two that are planned, listed on the slide that are planned in Albuquerque and Salt Lake City. We don't know where the other regional trainings will be within the regional. We'll decide that closer to the time period.

>> Where would they go to find that out?

>> On that same slide that we just referenced that Diana read from which has the regional trainings and the general time period, at the bottom of that slide is the link to the -- a link to our Web site, that has the updated trainings as they're available. The updated dates and location and information for registration that you need.

I think somebody is taking us there.

>> I'm trying to. Am I getting close?

>> Is that it?

>> No, I can get it. I can find it.

>> Okay. I'll let you drive.

>> Here it is. Right at the bottom of this page.

>> Okay. Great. Thank you. And our final question is just asking for Gina. Gina had mentioned that -- you mentioned the L.END program. Can you explain what that is?

>>

>> So it looks like somebody has typed out what the LEND stands for and it is funded by maternal and child health bureau. It's a training program they're across the state. It's a competitive grant. For ours, ours is a regional model. We have five states participating. All of the trainees are masters level or practicing professionals interdisciplinary likely have 15 different trainees in our programs, from social work to pediatrics, nursing, et cetera.

You can find out more information by going and learning about it through either AUCD or you can even Google LEND. It is a wonderful training program. Ours goes through the academic year and our trainees are required to complete 300 hours a year that is divided up into didactic seminars, leadership, and clinical experience. We also in our training, we also have family trainees as well as self advocate trainees.

>> And just so everybody knows, the acronym LEND stands for leadership, education in neuro developmental

disabilities funded by maternal and child health bureau.

Well, we are at the top of the hour and I'd like to thank all of our presenters today for all of the time that it takes to prepare a presentation like this, and obviously for your time doing it. So we thank you for that.

Today's Webinar has been recorded and will be posted in the next several days on infanthearing.org, which is NCHAM's Web site. We're going to close out the meeting and invite you to see the screen that appears next which will ab short survey asking for why you feedback about today's Webinar. Thank you everybody and a special thanks to our captioner for your services.