It is the top of the hour. This is Robbin Bull with NCDB. I am going to do a few housekeeping items to get us started before I hand it over to Megan who will kick it off. As you experienced coming in, all phone lines are muted to alleviate background noise . We will be taking questions at the end if you want to type questions in the chat pod as you are going, feel free to do so. I am going to set the recording and then Megan, you can take it from there. >> Hi everybody. This is Megan Cody. I apologize for not being on camera today. My computer is not implying -- complying. I would like to welcome everybody to this webinar. I would like to thank Carol Darrah from the Georgia sensory project and Toni Hollingsworth from the Mississippi Hearing-Vision Project for joining us today to share about their family to family pilot projects in the results that project in their thoughts about potential expansion for the future. Welcome everybody and thank you for being here.

This webinar is one hour-long . Depending upon how long our conversation goes, we may finish up a little bit before. Everyone's phone lines have been muted. If you would like to ask a question , please put it in the chat pod and we will try to monitor the chat pod and answer your questions as they come. At the end, if there is time, we can open it up for an open discussion. We look forward to the opportunity to engage in deeper conversation once they have shared their information about their projects and what they learned. Without further ado, I will turn it over to Carol and Toni. Thanks again for being with us today.

Thank you, Megan.

Thanks for having us, Megan.

It is a joy to be able to share this information with everyone today . I want to give a little backdrop on the pilot . Prior to the 2013 writing , some of us were talking about how to have families connect with families to decrease on the intense alone feeling that they all express . We thought we could gather together and do this. Prior to the 2013 writing, we have been thinking and listening and planning all about this.

One of the things that I really paid attention to in that time was to what Claire Berg had to say about what she was experiencing on of the calls that they were having out of New York and all the calls that she was doing around families who are Spanish speakers. Some of the points that she made really stuck with me . There were three main ones that I want to share with everybody. One of them was not to try to control the entire time that families are together , but to allow them to have the space and the time so that they can drive their own conversations . Maybe every three or four meetings that they might have, from that time together, a common theme might be realized throughout each of those. You could then offer to them to have a speaker or a presenter come in on a call with them. If there was a guest speaker , have them on only for about 30 minutes or half of your time frame and then turn it back over to the families so that they have the safe, insulated space again to continue. With all of that in mind , once we got funded , we started in the southern region to pursue this idea as a pilot. The southern states at that time included Alabama, Arkansas, Florida , Virgin Islands, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee and Texas. We all signed an MOU together at the grant writing as an umbrella that we do all of our activities collaboratively together. This is one of those activities. The National Center on Deaf-Blindness also signed an on this -- in on this project and the national families Association for deaf-blind as well.

We asked them to join on one because we wanted their support . They were part of the MOU already . We asked for the support from the National Center on Deaf-Blindness on how we could possibly fund this from state to state to state. We wanted to have regular access to the same kind of phone numbers, etc. It was early in 2013 . Technology -- we did not have all of our Adobe rooms and the online conferencing spaces that we have now. We did not have the resources in place to be able to share from state to state . We felt like we needed that extra support from NCDB and they came through for us to run this project . Then, we also asked the national family Association for their support in that when we envisioned that the family -- that the facilitators for this pilot would need to have training and would benefit from it. We wanted to provide the moderators some -- and facilitators some training. We thought that we might need were members or someone from NFADB to be focus group facilitators to be able to help us evaluate the project.

They played a vital roles with all of us in the process . I might have said earlier, our intention was to build capacity of the state project and bring families together and connect them and allow them to build trust and confidence amongst each other. We also thought that some might emerge as leaders and wish to connect with other families as well.

It might lead to states having their own calls or additional leadership opportunities for the families. It takes a minute to get to know one another before you can really build a community or build a solid team. We structured the pilot to include calls that lasted 90 minutes in the beginning so that people could get to know each other more quickly. We had two calls for the first month. Then, one call after that monthly for an hour. Every single community, which was made up of 5 to 6 family members also had two facilitators and one moderator. The facilitators were there to welcome everyone, provide ground rules for respectful conversation , and informed them of anything that they might be interested in. They were the host of the space. We thought a moderator would be useful in that they could keep attendance or watch the energy of the group and be able to later report out on that . They were more a recordkeeper for the group.

Be facilitators and moderators were told to hold the space but not drive the process . They were to follow the lead of the family members. We also offered an online space for families to connect outside of the call. That is another area where NCDB supported us in -- in providing that workspace on the website. >> Once we laid out the structure and everyone was on board and ready, we had a flyer and a registration form and we recruited families . While we were doing that, NFADB wasn't doing the training for the facilitators in the moderators. We ended up having nine families participate . They were divided into two communities . That was based on when the communities of families could make the calls. Facilitators reached out to the families and said they were ready to go . It took us from the beginning of 2013 , October 1 when we knew we were funded for this cycle until July 2014 to actually get to this place . It can take a minute in our process to prepare everything and plan everything. Then, we were ready to begin. Carol, will you talk to us about the pilot evaluation or anything I forgot about the pilot process?

You have been very thorough so far explaining the process in the background information. Thank you. I will dive into some of the results of the evaluations that we gathered . We wanted to gather some information to evaluate the project to learn what worked and what did not work. We wanted to make things that are in smoother along the way. We also wanted to gather data for our APR and all about that we needed to report. We made this comprehensive evaluation plan that we ended up deviating from a little bit because it ended up being a little too frequent and a little too much for the families with the feedback that we got. We made some adjustments along the way. We created a brief online survey that I sent out following each call for the first four months . After about four months, I was getting very little response and people were telling me that it was too much. I stopped sending that out after every monthly call and just sent out another online survey at the end of the year-long project. That was the online survey information we collected. It was things like be useful, relevant quality kinds of questions. We always asked if they had any comments or suggestions or things that they wanted to share that they may not have wanted to share during the call. Those were the pieces of information we gathered online.

Next, what I really thought was a rich piece of our evaluation was two rounds of focus group -- groups that we had. We had a wonderful facilitator who was a NFADB board member volunteer who jumped right in and facilitated these calls for us . In April. In April 2015 , midway through the pilot, we conducted two separate focus groups , one for each community. Then, we shared that feedback anonymously with the call facilitators and moderators so that they could make any adjustments that they wanted to make to the structure and format of their group. We did that again at the end of the project in November 2015 , the same volunteers

facilitated two focus groups. Toni and I facilitated a focus group discussion with all of the facilitators and moderators for both groups. We did that together. We had some really rich discussion about their reactions and feedback about what went well for their groups and where they thought we could go with this project in the future. >> When I did the data calculations for our quality relevance and usefulness measurements , the families all rated very highly. Quality was 4.54 out of 5, relevance was 4.65 , usefulness was 4.41 and beneficial was 4.70. They all rated us very highly. That was through those online surveys.

Another thing that I forgot to mention was that every call that took place, the moderator completed

a call log that kept attendance and documented the theme -- themes that were discussed during the call and what emerging things were coming up that they might want to talk about again in the future. Some of the most common topics that they talked about included communication, calendars , transition , IEPs , resources . One thing that they did quite often was brainstorming ideas for individual situations that they had going on with their own child and family. Once they started to get to know each other and feel comfortable, the family would bring a situation to the group and ask for resources or ideas . Sometimes they just wanted someone to listen and give support. A lot of that went on that happened organically. One of our benchmark in the project was to encourage families to join NFADB. I know that at least four out of the nine joined that were not already members. One anticipated outcome that we had was that states may begin their own calls within their state. Last I heard, South Carolina and North Carolina were establishing calls. In Georgia, we have been trying . It has not really taken off . We are still trying. The third part of that is today, we are looking to present this information to you all and talk about how we can continue this on a national or multistate format . >> These are some of the comments that the families shared with us during the final evaluation. I thought that these were really powerful statements , especially given how isolated sometimes our families are.

It was like this little hour of sanity where you could talk with people who kind of understood where you were. >> Being able to interact with other parents that have children with death likeness as well as share information and stories and just the support was really important. >> The bond is very critical because you build that trust and that relationship in your opening up -- and you are opening up .

The bond that she was referring to is the bond with the other families in the call community. This then takes us to our timeline of where we see this going. After I share this, Toni will talk about our ideas for moving forward.

In a January

In a January 2016, I shared a lot of the same information with a group of family engagement coordinators who work together and today, June 2016, I am sharing this information with you in this trend -- NCDB webinar. In July, we are planning to share this information at the NFADB symposium and FEC meeting that will happen there. In at the end of July, we plan to share this information at our summit meeting , especially in the family engagement meeting if that is how the agenda ends up working out for that meeting. Those are our plans for sharing. In August, to keep the ball rolling , we are planning to host a meeting for any state partners , family members who are interested , family engagement coordinators , or whomever is interested on August 17 on an online format . We will be sharing information about that meeting as the time gets closer. I will now turn it back over to Toni so she can share our ideas for where we are going with this. >> Thanks, Carol. That was a great overview. Our idea is pretty much the same. We learned some things that we want to change. One is that previous communities were made up of five or six members . We found that , has light happens, people have to miss the monthly calls. There was just one or two people on the phone at best. We decided that we would up the numbers to 8 to 10 members. Previously, I had advocated for small core group's cause that way you could get to know one another. I find it so difficult coming from a family of six kids myself , everybody is always trying to talk over each other. I have thought that the same thing might apply. We found that not enough families were consistently able to be on the calls and it left just a few making the calls . To have a nicer group, we are enlarging the membership work

We also thought that it would be nice to be grouped by age or by hot issues such as the challenges of the children . It is a nicer way to share and give people opportunities to group by similarities. Also, we moved from 60 minute calls monthly to 90 minute calls . It was a surprise to me . I was afraid that lengthening the call would be too much. It is a pleasant surprise for sure. 90 minute calls are the way that we are going to go. We also offer the option for alternate technology and ways of meeting together or using a combination of those things. The last pilot, we had one group that wanted to be together online and another group who absolutely did not want to do anything other than be on the phone call. In addition, we might have more of that structured topic and open forum for brainstorming and supporting each other . I think that is where the real feelings of cohesiveness came about and feelings of community came about . Because of the larger number in the group, we need to make sure that all members have an opportunity to participate and have an opinion. They should be able to contribute in whichever way they wish.

One interesting feature that we are going to modify slightly is that once the pilot groups were established, they were closed. We held it close on the premise that once you get to know everyone, you don't want another new person coming in. Having an open door policy would water down the relationships of the community. This time, since we had some that wanted to have other people join in , we are thinking that we will have this group get started and once they get established , we can open it up to each group to make that decision for themselves for new members to come in. Amongst all of us , we have something set up for online conferencing like this Adobe format . We are going to be exploring what our resources are amongst ourselves and what else we need. We are opening the door to not just be the southeast in this process . We welcome everyone . >> Some of the things that we did last time worked well . We thought that we would make some modifications. We really like that to be facilitators completed the call log for each call to keep count of attendance, the topics that were discussed and to help plan for each or call topics that they wanted to address. Rather than do

online surveys every month after every call, we thought that asking families to complete those once a quarter would be a little bit more doable for folks with their time . We included our measures for quality, relevance, usefulness and any other comments that they wanted to share. We really liked the focus groups . We got some great information from the families who participated in of those. We would anticipate hosting a focus group for the community after 6 to 9 months of meeting depending on how well we get the project launched and running again.

I know that you are all waiting to know how you can participate with us. We really would welcome any and all state projects who want to participate with us on this. Some ideas that we have to make this manageable and doable is how you can contribute to the project. One way would be for you to share information in your state to recruit families who want to participate in facilitators who want to participate . Another idea is if you have a family engagement coordinator on your staff , you could allow that person to use part of his or her time to facilitate one of these communities . Another way is that if you have a conference line or a web meeting service like several of us do, you can allow Family-to-Family Communities to use your conference line or the meeting service. For me, we have a service and it would not cost me anything to do that. I would be very happy to schedule a block of time to allow a community to use our service. The other thing that you can do is, if you are willing to jump in and participate in some of the planning and/or evaluation pieces of this, I would really welcome you to do that with me. I have enjoyed being be behind the scenes coordinator of this project, but I could certainly use some fresh ideas and help with all of that stuff.

We are welcome to hear other ideas as well for people who want to participate and contribute what you think you could bring to the project. >> We will take a moment to look at the fire that we have -- flyer that we have that we would be able to share. I don't know how well you can see this, but we can post it on the spaces on NFADB where we showed -- shared information about this webinar. It outlines the history and the purpose of the Family-to-Family Communities . A couple of things I want to point out. I have drafted a registration form that is online . It is live right now if anyone wants to go check it out and see if there is any

thing you want from it. I have my contact information here as well. During this pilot, I was the contact person for the project. I am happy to continue that. I left a space on here . In the Microsoft Word document, it is a text box or you can put your own states information on this flyer before you send it out to families in your state if you wanted to do that. >> The last slide of the PowerPoint is just my contact information. This is my contact information and Toni 's contact information . Please contact us if you have any questions.

Carol, I want to jump in for questions if it is okay. We had a question from Maurice in the box. He asked , you mentioned setting ground rules at the beginning of the calls. Can you give us some examples of the ground rules? Was ensuring confidentiality one of them? What is said on the call stays on the call? I want to defer and invite Diane Foster in. She was one of our facilitators. Diane, could I put you on the spot? Will you answer this for Maurice?

You have to un-mute yourself . Diane, you would hit star six page -- \*6 .

Hello, ladies and gentlemen. One of the main things about our group is the confidentiality. I enjoyed it tremendously. We had -- there were things that we talked about. We did have our structured calls. We personally got involved with each other . To keep the integrity of the group , what stays on the call -- what was on the call stays on the call. We do not share contact information or even family information. We kept it very strict to our families . We really built a great relationship. I can honestly say that I made five other friends on our calls that I still stay in touch with . It really helped. We also to the ground rules . Our group set them together. What did we want and how did we want to talk about them? It really helped our group. Our group did really strong -- state really strong the entire time.

Diane, other than confidentiality, was there anything unique that you remember?

We did have a very big spectrum. We had some two-year-olds all the way to transitioning. We didn't lose a family and I think it was because of the age difference.

Four of us were very close. It was nice to have the separation because there are mentors. When we all start out, we look for anything that someone can help us with, even if it is one person. Having that span of people that have walked a mile in our shoes really did help as well. >> [indiscernible - multiple speakers] >> I will share with the other group of facilitators. Some ground rules at the beginning were to make sure that there was an opportunity for each member to speak up and say something, not just the folks that were more outspoken. One of the facilitators made a point to go around and ask everybody to share something . They also made a point to say something positive or some kind of a celebration to keep a positive vibe going on the calls as well.

Nice.

Any other questions?

I am ready to get started again. I honestly miss it. It was a fun thing. I looked forward to it as well as the families in our group. I think that they looked forward to it also. We had some structure. I don't know if anybody -- all of you who don't know me or do know me, I keep it very interesting. That is for sure. There were days when we longed for some more time. There were days when we needed to hurry up and get off the call. Life does happen. We definitely had a great group. I can't wait to participate in any way, shape or form again.

That is terrific, Diane. >> I show another question in the chat pod.

Was there any consideration in using the mastermind model for the groups?

Yes. The group I was just speaking about , one of the facilitators was familiar with that model and she did use that in the group.

Very good. I noticed that Jana is on the line also from Arkansas . She served as a moderator for one of the groups . I would like to ask if the Jana has anything she would like to say about this process.

This is Jana. Hi everybody . I think you guys have pretty well covered it. Like I said, it was such a positive experience to be able to, from my perspective, see the growth that can out of it as each call progressed. The amount of trust and relationship building

was great. The only other thing I can think of in terms of ground rules that Maurice asked about is that there was a discussion initially about realizing that this was a commitment . While life does happen, we wanted everyone to commit for that one year. There was a beginning and an end. I would like -- I think everyone lived up to that to the best that they could. That was expressed openly. Everything else , the other important thing really was that it was driven by the members of the group. I think that is key. Like Toni had said , there was no hidden agenda. It was basically what we want to talk about and when we want to talk about it. Realizing that everyone had input was pretty cool.

Thanks, Jana.

Sorry to put you on the spot. I also want to celebrate you by putting you on the spot. You and Diana -- Diane and all of the others who did such great work on this project.

It was a gift.

We appreciate you very much. It takes all of us for sure . Heather has another question in the box.

Were all of the moderators and facilitators parents or family specialists ?

We had Ellen Bowman from Alabama who is not attached to a project. I co-opted her into doing this work as a volunteer for me. Being in Mississippi, the lines are blurred between us . I pulled her write-in.

I will add that all of the facilitators were parents . They were not all employed as family engagement coordinators. One was a volunteer . >> Any other questions? >> Silence must mean we are all complete . There is no more in the chat box.

If anyone would like to unmute and ask a question, you are welcome to do that as well. >> Susan Bonner from the Missouri says thank you in the chat box. >> Toni and Carol, this is Megan from NCDB. If nobody else has any more questions, I would like to say a huge thank you to the two of you and for Diane and Jana jumping into answer questions as well. I really do look forward to having delivered discussions about this when the family specialists are gathered together in July in Texas. I also want to follow up with the conversation when we're altogether in Summit. I think this is a very viable way of expanding connecting parents with similar needs across our country. I really want to thank you for your time and your bravery in stepping out and sharing this pilot work with the network. I know Robbin has a polling question she will put up to get feedback for us.

This is Cindy Robinson in Arizona. I am wondering how many parents altogether were involved. >> There were four facilitators . In addition to nine other family members participated.

And there were how many states? Six or seven?

There were 12 states if you separate Florida and the Virgin Islands. From that, we were able to identify nine families . The structure of the pilot was that each state would identify one family only to participate in this initial project . Three were not able to find a family who were able to commit to the pilot.

That is very helpful to know. What would you project for the future if this were to expand?

I don't know. The responses that we have gotten from folks when we share it out to the network has been very positive. It is just a matter of whether we are able to turn that interest into actual numbers of families to participate. I would really love to have six groups if we had enough families who wanted to participate . I really don't have a sense of it at the moment.

Great. Thank you.

Does anyone else have any questions? I will take that silence as a no. You also have contact information for Toni and Carol to follow up with them if you have additional questions. Again, we look forward to having continued conversations about this exciting work in July at the symposium as well as at Summit when we're altogether in Washington DC. Thanks again to Toni and Carol and thank you everyone for putting your polling response up . We look forward to having more discussion about this soon.

Thank you all. Everybody have a great day.

Thank you. >> [Event Concluded]