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Please stand by for realtime captions.

- >> If you hover over the picture on your screen, there is a pause button and you can click a nice picture of yourself.
- >> I will probably take it off altogether.
- >> We have about three minutes until it is 12 PM.
- >> Welcome on camera, Donna. Can you hear everyone okay?
- >> We have about two minutes before we will start.
- >> If you are just joining, welcome.
- >> There is about one minute until we are straight up at 2 PM central time, 3 PM Eastern time, 1 PM Mountain time, and 12 PM Pacific time.
- >> My clock says it is go time. Robin, do you want to start with housekeeping? Do you want me to start?
- >> This is Robbin. I will start the recording and you can go ahead and cover any housekeeping.
- >> Perfect.

>> Hello, everyone. My name is Megan Cody. For over a year, I have been serving as leadership lead for early education and referral as well as family engagement. I want to thank everyone for joining us today for this second webinar where we will be highlighting the partnership and parent centers across the country. The first webinar that we did of this kind was held on April 13 and the archives -archived recording can be found on the NCDB website . At the webinar in April we heard about the collaborative work in New York, West Virginia and Pennsylvania. I encourage you to watch that. If you have yet to be able to view it, do so if you have a chance. With us presenting, we have Carley Fredericks and New Jersey, Mary the court and Dottie Snyder from North Carolina, [name indiscernible] for Michigan and Donna and Cheri from Maryland. I want to let everyone know that when people come into the room, your phones should be muted. If and when you guys have questions that you would like to ask, you can either start 6 to unmute your fine -- phone or you can put your question in the chat pod and we will monitor the chat pod. We will make sure that your questions get answered. The folks that have come to present today are wanting to make sure that their sharing is organic and you are able to get from their presentation what you would like to know. Before they share their stories, I just want to give you a really fast back history to how this webinar came to be and why we are here today. Back in the fall of 2014, we sent a letter to the state projects in the parent centers encouraging them to work together to provide training and support for families of children who are deaf or blind so they can successfully advocate on behalf of their children. As a result of this, a family engagement technical work group comprised of representatives from NCDB, regional parent centers, state deaf blind projects, cadre and the charge syndrome foundation was created. In June 2015, a form created by this group was sent to the state deaf blind projects and parent centers to complete together to describe the current collaborative strategy. By August 2015 we had

received 21 completed forms back. These forms were carefully reviewed to identify specific collaborative strategies and activities sorted into the rolling four categories. Networking, cooperation, coordination and finally, collaboration. This report can be found on the NCDB website and it is called working together for families , state deaf blind project and collaboration. For those who have yet to see the report, I was going to quickly pull up our NCDB website to show you where it is located on the site so that you can find it. Then you can see the layout. While she is pulling that up, what I would like to tell you guys is that if your state is not represented in the report and you would like to be interested in sharing your state specific information, please send it our way. We see this as a moving target where there is a continuous opportunity to share and that successes and work that is being done between parent centers and state projects can be highlighted. Feel free to send us updates or share your first initial ideas about your story for how you all are working. This is the actual report. What I wanted to point out to you all was that the buttons that I mentioned called networking Corporation ordination and collaboration that are along the bottom, if you click on those, individual examples of what state pairs are doing are put within each of those sections so that you can learn more about what states are doing and possibly try it in your own state. That is how the report looks. You can find it on our project website. I just wanted you to see what it looks like. See the button right there on our landing page? That is how you can click on it to get to it. That is that. We are going to watch the chat pod for questions. We are also going to try to hold the questions between each state pair presenting and answer those questions that you have for that state pair if we can between presenters to help the flow of the webinar. Without further ado, let me turn it over to Diana and Carley -- Carly. We thank you for being here with us and sharing your story.

- >> Thank you, Megan. I want to thank you and the entirefor having us on the call. Diana and I are very excited about our collaboration. >> This is Diana. I was privileged to work with NCDB on this project representing the region one parent technical assistant Center and I am thrilled to be able to share the partnership between the parent Center and the deaf-blind project in New Jersey, which we think is resulting in some very positive outcomes for families and children with deaf blindness.
- >> On the first page, you will see the information for our centers and how contact information. I will scroll right over to our next slide. Diana is going to start out with who we are.
- >> The PTI directors are myself. I the executive codirector of the organization. Carolynn Heyer, to my right, is the director of parent and Professional Development. Maria Dockery, the director of technical assistance is also there.
- >> For the New Jersey consortium of deaf-blindness, we have Peggy Lasch broke who has 25 years of experience with people with disabilities and deaf-blindness. She was the director of the Delaware deaf-blind project and is now currently the acting director for New

Jersey. We have Michelle next to her and she is the program coordinator. Michelle has 14 years of experience on the deaf-blind project. She also worked with the cerebral palsy of New Jersey as a case manager and advocate. Myself, Carly, I am a recently new to the project person. This will be a third-year . I started out as an advocate and running my own nonprofit supporting families and developing small workgroups and support programs for families and sharing resources and advocating here at the college. I am very excited to be here.

- >> We thought it would be important to share each of our agencies missions. You will be able to clearly see some significant overlap, which makes the collaboration easier. I also want to let you know that as you see the pictures going through our presentation, these are actually pictures of parents of and children with deaf-blindness. They reflect some of the Latino, African-American and other families that we have worked to support.
- >> SPAN 's mission is to empower families and informed and involved professionals and other interested in the healthy development and education of children, to enable them to become fully participating and contributing members of our communities and society. Our motto is empowered parents: educated, engaged and effective. We provide families and youth with disabilities with the knowledge and the skills and the capacity to build relationships that they need in order to advocate for themselves throughout their life span.
- >> This is Carly. The NJCDB mission is to ensure the provision of high quality education programs within natural environments and supported inclusive settings and appropriate services for infants, toddlers, children and youth who are deaf-blind. Our goal is to be accomplished through a menu of discrete initiatives within a responsive statewide approach for families, educators and community service providers. Overall, we are definitely with the inclusive mission of supporting our families, educating them as well which overlaps with SPAN 's mission in empowering families to advocate for those resources for their families.
- >> Our priority area at SPAN is to children who have the greatest need due to disability, poverty, discrimination based on race, six, language or immigrant status, families who are involved in the child well for or juvenile justice system, families who live in underserved geographic locations, or family or other special circumstances. Because of this form of commitment, when we look within the population, we know that families who have children with deafblindness face all the challenges that families that children with disabilities face. We also know they face additional challenges because this is a relatively low incidence population. There is not a lot of knowledge or expertise within school district about it or even within the medical community. There can be many other kinds of the physical and health challenges in addition to deaf-blindness that may be impacting the child and family. SPAN has for some time now prioritized serving families of children with deaf-blindness especially those who are from immigrant or African-American or other

low income families in our state.

>> This is Carly speaking. NJCDB 's priority area, in addition to what Diana said, our goal is overall the implementation of a statewide community of practice on the education of students with deaf-blindness focusing on evidence-based educational practices which include families. We want to ensure that they are professional and they support staff being trained with our students, but also that the families are being trained as well. We wanted to carry over into the home. We also develop and implement a well coordinated and responsive system for Professional Development, including on-site coaching and support. We are hands-on. We do not provide a direct service. We provide technical assistance. We are in the classroom. We feel it is extremely important to know the student, noting that is working with them and be in the classroom and be able to witness these practices so that we know how we can support that team. We also developed a statewide initiative for the early and ongoing identification of infants, students and young adults with step blindness which is where we rely heavily on SPAN. SPAN has an amazing rapport throughout the state and families. That is a lot of the time there go to for resources with any condition or diagnosis. SPAN is very important to identification and helping us support our mission as well. >> For our funding sources, as the PTI for New Jersey, our annual grant is \$454,835 per year. We have a five-year grant. With that, we provide statewide information, training, technical assistance and support for families of infants, toddlers, children's, Utes and young adults with disabilities including death wideness ages birth to 26 with a special focus on underserved families. In addition to the grant, we also have the family to family health information Center grant from the U.S. Department of Health and Human Services maternal Child health Bureau and that funding is \$95,700 per year to provide services to families of children with special health care needs and deaf-blindness is one of those special health care needs that is included. We have other support from our state department of education and other state agencies including Audi permit of health to provide training information and support to families of children with disabilities. These are our center designated in New Jersey. >> This is Carly. Under funding sources, -- the New Jersey Consortium on deaf-blindness is under the center for sensory and comics disabilities. That is within the school of education here at the College of New Jersey. It is fun to do my introduction and name all of those things that are going on. It is definitely a collaborative effort. We have a wonderful partnership at the college. The college was awarded a five-year grant which is \$1.3 million to continue and expand the activities to support the education of infants, children and youth who are deaf-blind. We also have our federally funded under the US Department of education with a cooperative agreement awarded to states for purposes of improving those outcomes for our children. >> Here is the SPAN and NJCDB shared issued areas. identification. Here, we do rely heavily on all the partnerships that we have throughout the state. New Jersey is a large state, sometimes

we see that the state is broken down into three regions, the North, Central and South. We really are relying heavily on our partnership with SPAN to identify these students . The mission is around underserved and underprivileged families. We want to make sure that we are supporting these families as the state deaf-blind project. When we go down to resources, that is key to providing these families with the opportunities for advocacy. We utilize each other's website, all of the trainings and things that SPAN has done in the past are being shared as well as new things that are being implement it. We are working together in a collaborative effort. There are many wonderful things that are going on throughout the year both for SPAN and NJCDB. We try not to reinvent the wheel or to do the same type of workshops. We work hand-in-hand to make sure every opportunity for families to attend workshops and conferences are scattered throughout the state to ensure that families have the opportunities to attend. >> Family to family support is a huge area in New Jersey. Families are seeking other families. We find that sharing those resources or getting families to connect is truly important to continue those advocacy skills. When parents feel that they are being supported by other families, they gained more confidence. They feel that they have a daily contact, whether they can get in touch with them, the family to family support is important for the day to day. Technical assistance, we want to make sure we are in the classroom. We are supporting these families. Sometimes, it is a wonderful thing when they notice that someone has not addressed a certain thing. We get the state deaf-blind project involved and we make connections to make sure that we are supporting the school district and helping the students. >> I just want to mention before I talk about this slide back in our statewide parent to parent program, which is also Houston in SPAN, we are able to connect families of children with deaf-blindness who are newly diagnosed or who are going through a new stage of their education or development with another family who has a child with death wideness -- deaf-blindness so they can get the emotional support as well as information about NJCDB.

>> A couple of the kinds of professional and family development that we collaborate on include an annual statewide miniconference for families of children with deaf-blindness. We also do an annual family learning day which is for families of children with deafness and hearing loss. Since our collaboration with NJCDB, we have reserved scholarships and slots for participation in the conference for families with children with deaf-blindness. Two years ago, our keynote speaker at that conference was a young man with deaf-blindness who had graduated from high school and was going to college and who really told his success story in a way that was very moving to everyone who was in the audience. We also do a teleconference or webinar each year focused on issues of interest to families. That is something that we decide to get collaboration with each other so that if there is some new development in services for children with deaf-blindness, NJCDB can highlight that as a topic for the teleconference, or if there are new resources available for families, we can also highlight that as a

resource. We make sure that we are engaging in ongoing activities together so that we keep the relationship vibrant and be meaningful to families and professionals in the state.

- >> One thing to add to that, this is Carly. SPAN has a huge support staff. I believe it is weekly, but correct me if I'm wrong. Weekly, there is online or teleconference trainings for their support staff. There has been many times where we have jumped on that call. We made sure that new staff or old staff is up to date. We keep it alive. We keep it vibrant. We make sure they know that they have us here as a resource.
- >> That is right. We have weekly calls. Later on, I will talk about another exciting issue in that area.
- >> SPAN and NJCDB each provide technical assistance to identify families . When we are seeking specific to deaf-blindness, we are making sure we work hand-in-hand. A lot of times we have SRP's that may have identified a child that is in need of technical assistance, working with the family directly or working with the team and the district. That is an ongoing thing. Sometimes families require individual assistance for some time and then may not be that they were support but are continuing -- continued to be followed by the project and checked in on periodically to make sure that assistance is not needed still. We collaborate on assistance with a particular family when needed. Working hand-in-hand and having the collaborative relationship and making sure that we are updated on any changes with the family is really important. Sometimes, families may get a little closer to their SRP or vice versa. We want to make sure that we are sharing that information with permission of what is going on with the family.
- >> I want to say that if you want an example of individual families with whom SPAN and NJCDB collaborated, there is an example of a success story on the NJCDB website -- NCDB website.
- >> NJCDB provides guidance and information to help our SPAN staff be able to guide families. They have done presentations that are all staff meetings, but also NJCDB is a representative on our statewide PTI leadership Council. We have representatives from NJCDB who, to those meetings and provide information and insight on new developments, resource tools that it be useful to families, either on the web or back streets, upcoming events, and how to make our services more meaningful and useful to families of children with death wideness. Deaf-blindness. We work with NJCDB to work with families who have traditional be underrepresented of underrepresented or underserved. We are on the NJCDB advisory committee. We have representatives on each other's statewide advisory committees or leadership teams so that we are able to advise and inform each other of new development and maintain a close relationship.
- >> This is extremely important, not only for our families to access the resources, but to also keep up to date with what the SPAN initiatives and what else is happening. We have the wonderful opportunity to meet in person, sometimes there are day-to-day changes going on. We want to make sure that we are up to date and following

our partners when there is questions and things that are happening, we are always involved with new initiatives. We have links to each other's websites. We codevelop on informational resources, which does happen during those PTI stakeholder meetings. We sit on smaller councils, development initiatives, and we participate in that. There is wonderful footage that SPAN has available on their website as well as what we share on hours. We co-present information on workshops and conferences. This has been a great relationship tween SPAN and NJCDB. Especially during the SRP training, in the past, NJCDB has participated in those trainings so that all of their SSP's that are throughout the state are knowledgeable about NJCDB 's resources. We have a little caption therefrom Helen Keller. Alone we can do so little, together we can do so much. I can speak the truth on that. Coming onto this project, I am only 10 hours per week. Having the support of SPAN and learning about these resources early on made me enhance my ability to do my job to the fullest. I love this relationship and this collaboration because overall, it is successful. >> What makes it work? Clearly, when you look at our mission statements, you can see that we have some strong shared values. We have mutual respect that has been formed over many years of collaboration. We try to engage in intentional proactive efforts to maintain relationship after changes in leadership. There have been some changes in leadership at NJCDB and I recently got an outreach from SPAN saying our new person will be coming on. She will come on this week. We would like to have a meeting with you to be one of the first thing that happens because our relationship is so important. That makes a big difference to really believe that we are an important partner and a valued partner and that we will have the opportunity to maintain this relationship even in the leadership changes. I think we have developed a very deep understanding of each of our mandates and what we are funded to do. The strength that we each have other limitations that we have, some of the limitations may be because of what we are funded to do. Some may be the amount of money that we have to do the work we are funded to do. I think we really have a very clear picture of who we are and what we each bring to the table and what are the opportunities as well as the limitations. Because of the limitations of resources, we have a very strong commitment not to duplicate effort and to maximize scarce resources that exist. That is very important for both of us as partners. One of the most important things that has happened is that several years ago, we clarified our commitments and responsibilities the average in a formal memorandum of understanding's which we submitted along with our application to be recognized as an exemplary partnership. NCDB has that or you can get it from either one of us. It is very clear what we each agree to do and we know that we are committed to that. We have done things above and beyond that MOU at least we know we can expect that from our partner. The collaborative work that we engage in on an everyday basis, we appreciate the partner and partnership and are committed to maintaining a.

>> -- Committed to maintaining it.

>> We know our limitations. Many of our employees here at NJCDB are only part-time. Sometimes, it is challenging. We want to make sure we are meeting the needs and supporting the families throughout the state. New Jersey is a big state. It can be broken up into several regions . Identifying families in those underserved areas throughout the entire state has been quite difficult in the past. Relying heavily on the partnership, we have developed and have noticed struggles and challenges. We have established a parent advisory committee which is known as our PAC which includes parents throughout the state to serve the regions. The way we have formulated this is we developed a threepart training series for these parents to ensure that they have the skill set to be able to identify families and support them and to make referrals to NJCDB. The first part of that initiative was going through our part one training. Instead of re-duplicating training, we had them participate in the SRP training which is SPAN 's resource parent training. It is a succession training. They go over basic rights and resources, laws and regulations throughout the state and the inclusion. IEP and transition to adulthood, student support and self-determination, advocacy and leadership skills and health advocacy and manuals are included. By providing our families with this training, it gives them the core foundation to carry out our mission as what their roles and responsibilities would be as parent leaders. We collaborated, we spoke to SPAN about this idea and the initiative and they were fully supportive of the mission which is so important to me and making sure that I am supporting all of the families throughout the state. A second challenge, disseminating the resources available for deaf-blind children and their families, we have our PAC. They work closely with the SRP's to support and technical assistance for families at risk.

>> The last thing we wanted to highlight was having an annual opportunity for our staff -- we have 60 staff around the state. We have the capacity to reach and touch more families than a much smaller staff than the NCDB -- NJCDB project does. They have the knowledge and expertise around deaf-blindness and emerging issues are affecting the education of children who are deaf-blind. We make sure that it is an annual opportunity for us to get that information about new developments and about emerging issues that are affecting children who are deaf-blind and their families so that all of our staff and all of our 200+ families around the state are prepared to provide the support that families need. We do have a series of materials that we developed with the national Center for deaf-blindness that are in English and Spanish around evaluation, IEP and transition to adult life that are available free of charge to families to help them be able to understand their rights in the process and some effective interventions and services that can be used. We also have a guy that we developed for parent centers all over the country on how they can help their staff work more effectively with families of children who are deaf-blind. Being sure that we are up to date is really important

>> That is it. Those are our students. Someone had to ask if those are

real students. Yes, they are. All of the pictures that you saw in our presentation today our students that we are currently serving. >> Thank you, hugely, both of you for all of your information and sharing that. That was really great. I did not see any questions come up in the chat pod. If there is anyone on the call that would like to ask a question, please feel free to press *6 to unmute your phone and ask your question.

- >> Mary and Dottie are up next. Robbin will get your PowerPoint up .
 >> I am Dottie. I am the project director. I have been with the project for six years. I am going to turn this over to Mary.
- >> I am on speakerphone. Does that sound okay?
- >> You sound great.

>> Okay. Thank you. We are delighted to have been invited. We like telling our story. First off, we are excited in our relationship with NC -- we have collaborated with a number of things. Just a few years ago when it was time to write for the deaf-blind grant, ECAC , the exceptional children's assistance center is the PTI for the state. We have been since 1983. I have been around 30 years. It surprises me to say that out loud sometimes. Our relationship with EPI has been strong for all that time. That has been an enormous benefit to working collaboratively. We have good relationships. We have good partnerships. For this grant, we are a strong component of the actual grant. When it was written, we have our partners with East Carolina University and the teacher support program there. Department of Public instruction. We have three partners. Even though we're here to talk about the PTI and how we collaborate with the project. One thing that might be helpful, and hopefully the screens are large enough, we each have discrete activities that we do. For the teacher support program, very discrete activities to support teachers. The family -- we have a statewide family to family healthcare Center along with a number of other projects. What we find is that those things make us richer and help us serve families that are and more completely. What we did is we collaborated. We have three family specialists. I am a parent of a middle-aged adult with deaf-blindness along with other multiple disabilities. As each of -- we have got a three part-time staff that her family specialists. One is there as we need it and the other two our employees of ECAC. They're both parents of children who have deaf-blindness. We believe that is the richness of us being able to serve families. We partner, and since I screen is small, I will look at the brochure to talk about some of the things that we have codeveloped. We have information packets that we provide to families who are new to learning about their child's needs which are with -rich with resources about deaf-blindness and the PTI. On the East Carolina side for the teacher program, that provides consultants into the classrooms and into the school buildings to help teachers more effectively serve the deaf-blind learners and get new ideas and support the students. Individual assistance as SPAN described, our PTI has a long history of providing individual assistance . That is expanded to some of the specific work to children who are deaf-blind. There are other things you can see here. We thought it was important

to develop the brochure together. All of the images are families that have been served and continue to utilize and access services. Parent to parent support is huge. This is the inside of the brochure that we developed. The map used to signify some kind of regional thinks. We are getting ready to revise it. We have contact information for Dottie . She is the project director of this whole project. We have the teacher support program and the family education. We really know and believe in our hearts that without these three problems, we don't -- prongs, we don't think we would be as successful for the families. >> In the development of the brochure, one of the foundational reasons behind it was having a hard time getting the word out. The families in North Carolina, it is a very white state, and the children are spread out. There is often children who are in classrooms and teachers may have never heard of the dual diagnosis of deaf-blindness or who have that image of their mind that only these children are going to be Helen Keller type children. They are not seeing some of their students as being able to be eligible for deaf-blindness services. We began working on this pressure as an effort to inform families and parents and teachers but to also get the word out to the communities. We send these brochures far and wide and we're working on a new dissemination project. The inside is resources and services for families. The outside is to help others in the community and people who are touching families where they are. What is deaf-blindness and who is eligible for services? We have found that there is confusion about who is eligible for services and what a typical deaf-blind child looks like. That was what was behind the development of this brochure. >> From the work that we are doing for families on the grant in collaboration with the Department of Public instruction, we have a family newsletter. It goes out to every family on the census. It goes out in mail and electronically. We also have staff on at ECAC that work as needed on the project who are multicultural , bilingual staff members to serve families who have those needs. We have our activities. These are all part of the state grant that we have the most responsibility for. We host monthly parent calls. That just happened last year and half. Families said they really wanted to be connected. In years past, the state deaf-blind project conducted a four-day family conference which is not happening now for a variety of reasons including funding, but what they found out is that there was an opportunity to network. We thought about having the monthly parent calls. They are private. It is just parents talking with other parents and one of our family specialists. Those have been very popular and a great way to reach families and help families feel comfortable asking questions, reaching out, and maybe even talking about things that feel a little personal. As they develop the relationship, they are relying on one another. That comes down to where it says Pierce. That is our parent expertise and experience resource. This helps the families connect as well. Families who have experience raising a child with deaf-blindness are more than willing and excited to help another parent who may be going through it. Whether or not it is someone from TPI who is looking for that or parents who find each other naturally,

that has been very popular and very helpful for families to be able to connect with one another. We hope it is meeting a little bit of the need that has been a void without the big conference. One time we may be able to get back to it. We also have workshops, webinars. Being at the PTI allows us to offer any of our trainings to all families including families who have children's with deaf-blindness. We customize a lot of specific activity workshops, webinars and institutes just for families. We recently had [name indiscernible] come in and do a full day training on transition to adulthood. He did a wonderful job. As we were planning together, East Carolina had to do a lot of work also. We do a lot of duck tell dashed up to work. Any of the activities —— many of the activities that are held for involvement are made available to the families as well. We are able to support families to participate to get their, travel, child care if needed, and any way that we can support them to go. They are able to participate in professional development activities that are offered to teachers. Very often, we are able to support the parents and their child's teacher to go together and learn together. Over the years, I have been the only one at our agency to go to a conference. I come back enthusiastic and it is hard to share that with people who have not had the experience. When a teacher and a parent can come and learn together, it is powerful. It makes a difference. This is our third year of this grant. We will be offering deep parents and collaborative leaders leadership training. After talking with Megan about some of the concepts for the upcoming family specialist conference, we think that we will be able to tap into some of those components of the curriculum that will be offered. We are holding off a little bit there. We want to agency. Another thing that we do through the grant is support a whole section on the ECAC website for the North Carolina deaf-blind project. Right now, we are switching over. We have not been able to update it in a while. We started talking with families about what they wanted. We did surveys with families. Like other service, we never get a huge participation. Families who responded wanted more ways to connect. They wanted to be able to connect at a time that is convenient for their family. Most families who have children with any kind of disability have limited time. Sometimes, it is the middle of the night where they want to connect, whether it is these letters that they can access or archived workshops, they can connect with another parent through Facebook. That has been extremely helpful. We also have, as part of the ETI library, we have a section that supported by the deaf-blind project for families who have children with deafblindness.

>> Another thing that I wanted to mention was that, and Dottie, you can jump in at any time, we have been exploring Pinterest and having boards to help families. It is for us —— we collaborate, we work well together and all of our thoughts go around where are the families and how we reach them in ways that are meaningful. These are with the families have said. We are on Pinterest as well. We have been able to reach even more families that way. It is not so much that it is a moving target, but families needs change and we change to address

that. When we send out a newsletter electronically, about 60% of families are accessing some of these things. When they access them online, they are using mobile devices. We collaborate with EPI the census data so that as new families come on and are able to keep up with them where they are and make sure that they know that this project is out there for them and help them understand how they can access it.

>> I do want to jump in and say that sometimes it is hard to separate PTI from the project. The PTI is part of our project. Our family specialists have been very instrumental over the years in helping boost the numbers of the deaf-blind census by the families that contacted them. We in turn are able to track down the schools or the staff that are working with the children in order to get them on our census.

>> That is exactly right. That is why it is so important to talk about how we use the census. One of the discrete goals is to reach out annually to every single family on the census. When information is missing, what we do know and what we do have especially with the history and longevity of our family specialists, we are able to track them down and no that -- and know that we can find out where the kids are. It works really well. We do have some desires. We say we dare to dream. We really want families and youth -- we serve a wide range of disabilities and a broad age group. What we know and hear all the time is that families say they wish they would have known about this sooner. Why didn't we know about you sooner? We need these services. We really have this hope. Tran10's logo is about empowering families. We want family venues to Novell support and we want them to do that as early as possible. The only way to get to them is to find them. We routinely find students and buildings -- students in buildings have not been considered eligible for deaf-blind services just because of lack of information by the people who are making those decisions. We really want families to know about these. The more they know, the more effectively they can participate. We want them to effectively advocate and participate. It is their life. We are there so support -- to support them. We want no less from the educators. We want them to access these services early and have high expectations for their students. We want them to have the resources and skills. This project supports that. We have known about the importance of the census. We want them to know about the importance of the resources so they can get that data entered correctly and completely. We know it is a big issue around getting the award and getting -- getting the word out. We try to take a multipronged approach. Dottie, anything else? >> No. I think it is a very good relationship that we have. I don't think more than a couple of weeks go by that we are not talking to each other on the phone. It really makes our whole project stronger. >> That is especially true because if we are trying to do problemsolving around a particular family's needs, we have each other at our fingertips.

>> This has been hugely helpful. Thank you both. We have about 10 minutes left for Jennifer and Kelly to go. Hopefully, we will have a

little bit of time to hear from Maryland. Forsake of time, we will keep moving on. Thank you again.

>> Jennifer and Kelly, you are up.

>> This is Jennifer. I am the family support coordinator with DD central, Michigan's project. I will try to keep things moving along quickly. As you see, this slide here, I can't take credit for this great. -- For this quote. This is part of our report that was submitted for the NCDB deaf-blind project and TPI collaboration report. The Michigan alliance for families and DD central both believe supporting parents is the most important service we can provide. We also have a we are better together working agreement. I thought that was worthy of sharing. I think what is unique in that is that we don't have a formal agreement. Our knowledge of each other's work and expertise has really served us well over the years. With that, I will let Kelly take over and she can tell you a little bit about the Michigan alliance for families which is our PTI in Michigan. I will then tell you a little bit about DV central services and you will see the other projects that there is overlap with what we do. We will give you a brief history of how that relationship has developed and then we will quickly highlight some of our work together.

- >> Kelly, I think you may still be muted. Go ahead and press *6. >> Kelly, this is Robin. Can you type in the box what your number starts with? I might be able to unmute you from here.
- >> I can go ahead and jump in two DB Central.
- >> My name is Kelly. I am the state way trainer for the Michigan alliance for families. We are the center for the state of Michigan. We have all family initiatives and we partner well with DB Central because we know exactly what they do. We service all families. We make sure the information is available to all communities. We our local community connections. We have 25 throughout the state. Every single person who works for the Michigan alliance for families as a parent or family member of a child with a disability who has received services. They work in their communities. Sometimes their communities can be six or seven counties.

>> The other thing that we do is we report emergency leaders. We listen to the leadership starts in the own IEP. That is when parents are the leader. We look to support the parents I want to sit on their local school board or go to a special advisory committee. We want to support the parents who are coming up to take our places. It is all about the relationship. Our relationships -- it is a really important for our parent enter relationship to understand the local systems and what services they provide to those families. We know we can't do it all. Families come from a wide variety. I am from Michigan, but I had my children in Ohio. When I came back to Ohio, there was a wonderful network of support we could not find a network of support or where the people were. We developed the alliance and we were happy to get the local support to families. We are funded by the Department of Michigan and the Department of Education. We are funded by the US Department of education. We are drawing funds from both the state and [indiscernible] to help us continue this work.

>> This is Jennifer again. I will tell you quickly a little bit about DB Central. As you can tell from the others that have already presented, each state is somewhat unique in the way they are set up and providing services to families. Here at DB Central, we provide support for families in Michigan. We have a child or student with a combined vision and hearing loss and we provide that support in a number of ways. The first one is training. Training can be general topics, specific training. This could be for professionals, it could be for families. It could include both. Additionally, we do some individual training that might be specific to a training -- child or student that would always include the family as well. We provide information dissemination which includes a lending library which is available at no cost to families and professionals. Another part of our information dissemination is our website, Facebook, and we also do conference presentations. The sharing on websites and Facebook, as others have mentioned, is definitely an area where we are sharing the PTI's information and they are doing the same for us. The next piece is family connections or family support. That is connecting families with the resources on statewide, national, within their local areas. This is another area of collaboration where we can tap into those local networks that Kelly has talked about. Also, the connecting families with each other the next piece for us is technical assistance. We promote evidence-based practices both for families and for service providers. There is another full-time employee on our project, which is the deaf-blind project. Her name is Beth Kennedy and she is our director and also our educational consultant. Beth and I always work closely together, especially in regards to technical assistance so that we have the family and service providers working together. We also have some system change initiatives as well. First, we have postsecondary transition. The next is intervenors, which maybe not everyone on the call is familiar with. That is a one-on-one support staff with specialized training in deaf-blindness. change initiative is family leadership. This is another major area where we have had a significant amount of collaboration with Michigan alliance for families over the years. We have really tapped into their training expertise to help support us in our training efforts with our family leaders. As you can tell, a lot of the states are set up very differently. Just to let you know, DB Central is a statewide project. We are housed at Central Michigan University. We are not housed within another program or center. We are not housed within our department of education. We are a standalone grant. We do have two full-time employees. We are not housed in a program or near the Michigan alliance for families in location. We are both statewide. Ultimately, we are serving the state together. As Kelly mentioned, we have the parents network staff that are statewide. That allows us to help our families to tap into resources at a local level. I will go ahead now and turn it over to Kelly so that she can give a brief history of how we got to where we are today. I will quickly share about areas where there are some overlap in our activities and where we do some work together.

- >> This is Robbin, we have gotten confirmation from the captioner that he or she can stay on. We do have some extra time, just to give you that heads up.
- >> Great, thank you. That is good to hear.
- >> One of the things that is unique around our family engagement collaboration is that we both came as we exist now at the same time. Other agencies had our grants and we both got our grants at the same time. We built trust as we build our own products and people and outreach. We have built that together. We have grown up together. We know what the other one has done. We have supported each other. We both are about building the relationships. We know we have to support families at the local level. It is so important. We have an all staff conference twice a year. Jennifer comes to those. She also is -- she also comes to the online staffing. All of our staff knows or. They know the resources they are able to send families to her. We don't try to duplicate each other's efforts. We want to support families. One one of our parent mentors get a family that might or is identified with deaf-blindness , they automatically call Jennifer and say we have a family. They automatically are in the best hands they possibly can be in. We hold on to what else they need. We support the families from that way. We have grown together. Our relationship has not been bumpy cause we have grown up together.
- >> I have to admit, I have greatly benefited from the history that was already in place that was forged before I came to DB Central, which I have been here six years now. It was very nice to me that there was already a relationship in place. It made it easy for me to maintain and look at ways to expand. When the current grant application came out in 2013, I was really excited to see that it specifically emphasize the collaboration with the parent training and information centers to provide training and support to families of children who are deaf-blind. I thought this was great because we already have a relationship. We have already done some work together. Anytime I have contacted Michigan alliance to say if they are able to help, they have always been so receptive. When I contact Kelly, she keeps me moving forward, thinking of bigger and Etter. When we have gotten that, I had contacted Kelly. We got together and had a brainstorming session. She really took it beyond what we have already done. That was pretty cool. As I mentioned before, one of the real basic things that we do, we share each other's information on websites and on our Facebook site. For instance, Michigan alliance has a very nice series on postsecondary transition. On our website under our postsecondary transition resources, we have a link to their post secondary transition webinar series. We also list their upcoming training and events in our event section on our website. I know they list our events and things as well and share those on Facebook. I have also come to their annual training to talk a little bit about DB Central services . They do have so many parent mentors. It is important that we make sure the information is out there. As new people are coming on board for Michigan alliance, that they know about the services that we provide. That has really helped with the next bullet there. That is

the referrals to DB Central from the Michigan alliance parent mentors that have come across families as they are doing their work, providing trainings and working individual with families in regards to special education. They then know about us and can refer them to us. Getting them that information has really helped to make sure that we are getting those referrals. All along, Michigan alliance, ever since I came here to DB Central and before that time, they have been providing training as a portion of our family leadership training specific to individualized education plans related to special education. That peace has continued. It has been very beneficial. More recently, one of Kelly's ideas was to not only get the information out to the parent mentors through our face-to-face training, but why not get the information out through our Michigan alliance for families webinar series? We were able to participate in that webinar series and they had a large following statewide on their lunch hour webinar series. That was a great opportunity for sharing.

>> Historically, in the early days, long before I was in this position, Michigan alliance provided training at the annual conference as a segment of that and I started things. We also have Kelly as a member of our advisory committee. Recently, another one of Kelly's brainstorms was getting things to the local level, which I really love that idea. We had a couple of our family leaders, which is not a paid position at DB Central. It is parents who have stepped up and said they would like -- they have wanted to take it to the next level and participate in a structured leadership training series. They have done some other activities as a result of that. They attended the region one parent mentor monthly meeting and shared information about DB Central along with me. That was pretty cool . It was neat to see what Kelly mentioned there about the local connection because one of the family leaders, as we walked in, she immediately recognized one of the parent mentors and it was neat. They had worked together in supporting some special education services for the family leaders daughter and it was cool to see a connection. Those are some of our activities working together.

- >> I know we are starting to run a little long. This is a quote that describes how things have gone along in our relationship working together. Coming together is a beginning, keeping together is progress, working together is success.
- >> Thank you, both of you, Kelly and Jennifer for sharing your relationship. It is really great. Donna and Cheri, can you still hear us?
- >> Donna is still here. I think Cheri is still with me.
- >> Sorry your WebCams are not working nicely.
- >> It must be something going on here.
- >> Your up.
- >> This is Donna. I hope everyone is hanging on. I know it is passed 4 PM. I just want to highlight a couple of things and give you a brief overview. I think that's a lot of what the previous projects talked about, North Carolina, New Jersey and Michigan, we are doing a lot of similar things. We try not to duplicate efforts. We share links and

resources. We tried to get families together. We are on each other's advisory board. We work closely together. We talk weekly. We are strong collaboration. I think it was brilliant that we came up with the idea that the deaf-blind project should work with the state PTI. It has taken the relationship to the next level. They made sure that the leadership training has been one that has been highlighted for us. We would have such a small group. It is so much better now having families network with each other. That has been our goal, to have families networking with other families around the state in the area. It is not just deaf-blindness, but parents of children who are visually impaired or hard of hearing. We are trying to get the families together around the state and get families together to meet each other, network with each other, see the commonalities. We have Spanish-speaking families. We try to cross all of the diverse cultural lines. Josie Thomas is the executive director of [indiscernible]. I do a lot of work with her. She has been like a mentor to me. Sherry Dowling has been a great colic and a great friend. We have known each other for 14 years. We really like working together. That is the most important thing. Because we share values and we have common respect, we value each other's work. I think that liking each other actually helps. I feel bad for states that don't have this kind of relationship with their parent training information center. I remember approaching Josie many years ago and just starting the conversation and trying to figure out what their needs were, how we can meet each other's needs, and I think that is the beginning of how to even develop a relationship. It is important for the deaf-blind projects that are out there that have not been able to establish a relationship. Maybe we can do some problem solving or some brainstorming on how to make it work. When you go into a school, we have to build a trusting relationship. We have to show them that we are in it. We have things that are very similar that we believe in. How to get that relationship started and build that trust, is something that is so important or states the cause we are on such a tight amount of money. How can we not tap into the parent training information center? The parents place of Maryland has been exceptional. Josie is known nationally for her skills in being an executive director of the PTI Maryland. We are fortunate that we are Marilyn's [indiscernible]. We have started relationship for advocates. That is different. We have had a lot of turnover. We are -- we know that we are here. We try to do collaborative efforts. We invite them to our advisory board. We keep that flow going. We keep the channel open. Some states still experience the struggle where you are trying to get the by Ian build a relationship and trust and get the commonality with each other. We experience both. Just so we let other states no, we hear you. We understand this is a challenge, but not mission impossible. If there is anything I can do to problem solve to help you establish the relationship with a PTI, let me know. I am always good for discussion and a few laughs.

>> That is great. Thank you so much, Donna. Take you for mushing it in at the end. Thank you for everyone for hanging on for 15 extra

minutes. I think what that means is there is a lot of good collaborative work going on amongst the two different organizations. That is really exciting that we are all able to hear and share. I think Robin is going to put up a polling question for those who are still with us to make sure that the information that was shared today was worthwhile for you and is going to help inform your work. While we are doing that, I want to sincerely thank everyone for their time today and sharing their unique relationships and experiences. It is vital for moving forward. Here are the polling questions. You guys can click on it and we will leave that there for a moment. >> This really was the infancy of describing the report highlighting the relationship among the state. We won't look forward to carrying more conversation about what Donna was referencing about what folks

the relationship among the state. We won't look forward to carrying more conversation about what Donna was referencing about what folks were referencing and what we can do more. Thanks again, everyone for your time today and we will look forward to carrying this conversation forward in the future.

>> I think everyone who would like to respond to the poll probably has by now. Thanks again. This will conclude the second webinar. Have a great West —— great rest of your day.

>> Thank you.

>> [Event Concluded]