

# Innovative Partnerships: Improving State Systems for Children and Youth with Autism Spectrum Disorders (ASD)

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DEIDRE WASHINGTON-JONES Good afternoon, everyone. And welcome to our webinar today, "Innovative Partnerships: Improving State Systems For Children and Youth with Autism Spectrum Disorders". I am lieutenant commander Deidre Washington-Jones and I'll be monitoring this webinar today. With this webinar today we have set up for you a panel of presenters, and from them you will hear about the various types of partnerships that they engage in across the country and how they really use these partnerships to improve the system of services for children and youth with autism spectrum disorders and these organizations that are represented today are from across the country so we're really excited to have them here to share their knowledge with us about their partnerships. Before we get into the actual webcast, I'm going to start off with going through some logistical issues. Please listen up. This will help you as we move through the webinar as far as some of the technical issues. First, the slides will appear in the central window and should advance automatically. The slide changes are synchronized with the speakers' presentations. You do not need to do anything to advance the slides. The second bullet is really, really important. You may need to adjust the timing of the slide changes to match the audio by using the slide delay control and that slide delay control is at the top of the

messaging window. We recommend that you change the slide settings to about 12 seconds. At least 12 seconds as that seems to work best for most people. Also, we encourage you to ask the presenters questions at any time during the presentation. You can simply type your question in the message window on the lower right of the interface, select question for speaker from the dropdown menu and hit send. Please don't forget to include your state and organization in the message so we know where you are participating from. The questions will be relayed to the speakers periodically throughout the broadcast but we'll have a question and answer period that we'll address those questions that you sent at the end of all the presentations. On the left of the interface is the video window. You can adjust the volume of the audio using the volume control slider, which you can access by clicking the loudspeaker icon. Also for those of you who selected accessibility features when you registered, you will see text captioning underneath the video window. And then finally, at the end of the broadcast, the interface will close automatically and you will have the opportunity to fill out an online evaluation. Please just take a couple minutes to do so at the end. Your responses do help us plan for future broadcasts and help us to improve how we design our future webinars. So now that we've got the logistical information out of the way I'll move into reading the bios and introducing the speakers. My first speaker I'll talk to you about is Diana Autin. The executive co-director of the Parent Advocacy Network the New Jersey parent and information center. Family to family health. Family Voices and federation of families and the statewide parent to parent program. Diana also co-directs the region I assistance center providing technical assistance to the federally funded parenting training and information centers and community parent Resource

Centers in the northeast United States. In that capacity she serves at the parent center facilitator of the inclusion community of practice and a member of the idea partnership creating agreement community of practice, and on the implementation of state evidence-based practices advisory committee. Diana is also the national field coordinator for the national Family Voices, which works to keep families at the center of children's healthcare. In addition to Diana Autin we also have another panel speaker have Sharon Fleischfresser, a pediatrician and the medical director of the Title V children and youth the special healthcare needs in the Wisconsin Division of Public Health and serves as principal investigators for Wisconsin's connections grant and the co-chair of the Wisconsin chapter American Academy of Pediatrics committee. She has been engaged in improving systems of care for children and youth with special healthcare needs in Wisconsin for over 15 years. Also, we have Anne Bradford Harris. She's the co-director, clinical services unit program center at the Waisman Center in the disability at the University of Wisconsin in Madison. She's an assistant clinical professor at the School of Medicine and Public Health Department of pediatrics and nursing. Also Anne Harris is the evaluator of the connections grant, Wisconsin's combating autism implementation grant and been involved in training and leadership for over 30 years. We also have Susan Olsen, the director of the services division at the Center for persons with disabilities Utah State University. One of the programs under her supervision is an individual with Disabilities Education Act Part C early intervention program. The program serves a three-county region of northern Utah with an average of 325 children. And finally, we have with us Gina Pola-Money, a proud mom of five wonderful children, two of which have passed away from a rare

degenerative disorder. She's the director of the Utah Family Voices, family to family health information center in partnership with the Utah parent's center. She also works with the Utah Bureau of children with special healthcare needs and the Utah leadership education and neurodevelopmental disabilities as a family leadership director charged with getting family involvement providing parent input to state and national level policies and programs, advocating for Utah's youth with special healthcare needs and helping families build the necessary skills to effectively navigate the complex system of care. As you can see, we have a very nice, very highly-qualified, exciting panel scheduled for you today. And so now I'll move on and turn the webinar over to our first speak, Diana Autin. Diana?

DIANA MTK AUTIN Hi, this is Diana, I'm thrilled to be presenting on this webinar. And I'm very excited to hear from the other presenters as well. Today I'm going to be talking about systems of supports and services for children and youth with special healthcare needs autism spectrum disorders and other developmental disabilities and families in New Jersey. Please go to the next slide. I think one of the most important things about what is happening in New Jersey is that it really is based on a wide array of collaborative partnerships that have been brought together under a community of care consortium for children and youth with special healthcare needs and their families. This statewide consortium includes parents and parent organizations, disability groups, advocacy groups, providers, pediatricians and family practitioners, state agencies, local community organizations and local communities. Some of the key partners that you see on the slide are the statewide Parent Advocacy Network and

as Deidre mentioned we house a lot of the New Jersey chapters of national projects like Family Voices and the Federal of families for children's mental health so we're a one stop for families in New Jersey. And the New Jersey pediatric council on research and education and the New Jersey hospital association, the New Jersey Association of children's and teaching hospitals, New Jersey family practitioners association, federally qualified health centers and their association. We also are in partnership with the clinical enhancement programs that I'll talk about a little later which are programs that have been funded by our governor's council on autism. Our New Jersey Department of Health and senior services which houses early intervention, Family Health Services, our Title V program for children with special healthcare needs. Our Department of human services which is where we have our Division of developmental disabilities as well as the new office on autism and that's where our Medicaid and children's health insurance program is housed. Our Department of children and families, which includes our Division of child behavioral health association and our Department of Labor, which is where our Division of vocational rehabilitation services is housed. We're partnering with the university center of excellence on developmental disabilities in New Jersey. The protection and add Virginia Cassie disability rights New Jersey and our council on environmental disabilities and other advocates and families. Centers for independent living and others and we have partners from the autism advocacy community including autism New Jersey, parents of autistic children, the autistic self-advocacy network and family support organizations, county-based family-led organizations that provide support to families and that includes a growing number of children and youth who have both mental health and developmental disabilities like autism spectrum disorders. So

go to the next slide, please. I tried to organize my presentation around the six core outcomes for children and youth and their families because one of the things that the community of care consortium is working on is making sure that we are engaging in activities that are going to improve New Jersey's performance in all six of the core outcomes for children and youth with a full range of special healthcare needs including children with autism and other disabilities. In addition to housing the ASD and other DD project, we also have a state implementation grant known as a D70 grant for all children in need of special healthcare needs and have both of those grants at the same time, which is really helping us do a lot more in depth work across all six core outcomes. So in terms of the families being engaged at all levels and satisfied with services we have our governor's autism council composed of parents of children, youth and adults with autism spectrum disorders. Clinicians, doctors, other healthcare professionals and state agencies and recommend policy changes to meet the needs of people with ASD and their families as well as they have funding that they can provide to support clinical and other activities that will help children and youth with ASD and their families. Go to the next slide. We're also excited that we have what we call span family resource specialists, trained parents' housed in each of the 21 special child health services case management units and right now we're actually hiring parents who are also going to be housed in the six clinical enhancement centers hiring parents of children with ASD. They can provide information, support and connection to resources for families. New Jersey is very lucky. Our Title V program for children and youth with special healthcare needs includes a county special child health services case management unit in every county. By having our trained parents there. Our

family resource specialists, we're able to be right in the place where parents of children with special healthcare needs including ASD and other developmental disabilities go for case management support. Of course, since we also house Family Voices and the family to family health information center and the parent to parent program, we're able to provide family support to families of children with ASDs. Next slide. We're also very privileged in New Jersey to have a range of family support organizations that provide a range of supports to families of children with ASDs and developmental disabilities and we partner with each of these organizations in our community of care consortium. Autism New Jersey, autism family services, parents of ought advertise particular children, the family support center which has information and support across all developmental disabilities and the family support planning councils which is where the family voice is to help determine how family support planning dollars are spent in their county. So all of these partners are part of our community of care consortium and we all work together so that we don't duplicate services and that we fill in service gaps for families. Go to the next slide. In terms of early and continuous screening to identify ASDs and other developmental disabilities in the last year the American Academy of Pediatrics, a core team member has been working to build the capacity of 30 practices in a pilot county in New Jersey to improve early and continuous screening, connection to resources and medical home for children with children with ASD and that experience over the past year is now going to be brought to bear on practices in all the other counties that we're going to be establishing medical homes in. The six clinical enhancement centers funded by the governor's council on autism have reduced waiting list for evaluation for children who are suspected of having ASDs and many of

these clinical enhancement centers can provide consultation to school districts and primary care practitioners to help them ensure that once identified and diagnosed that children receive appropriate services in terms of their pediatric practice and in terms of their education or early intervention. We also have as part of our Title V program a regional multidisciplinary evaluation centers, 11 of those that can assist in early and continuous screening. In early intervention we have targeted evaluation teams and we have policies that have been developed by our early intervention system around the identification and services for infants and toddlers who are suspected of having autism spectrum disorders and other developmental disabilities. Let's go to the next slide.

The American Academy of Pediatrics is also working on assuring better child development pilot here in New Jersey and we're part of that pilot providing the family perspective. And advocating for use of standard, routine screening tools that have demonstrated capacity to identify children with ASDs and other developmental disabilities and working to inform families and providers of screening resources like early intervention and early periodic screening, diagnose and Medicaid. Many families and even professionals are unaware of these screening resources here in New Jersey. Getting the resources exist, getting the information to them has made a big difference. Next slide. We do have and we've been involved in the development and review of these guidelines. We do have early identification of autism spectrum disorders guideline for healthcare professionals issued in New Jersey in April of 2009 by our Department of Health and senior services and assessment and service guidelines for children with autism spectrum disorders issued by our early intervention systems in February 2004. We have good information for professionals around early and

continuous screening and assessment that has made a big difference in our ability to try and identify children earlier and make sure that the assessments that are done are identifying both children's needs and the kinds of services and supports that might be appropriate. Go to the next slide. The governor's council of autism is working on a center of excellence in the planning stages. That center, once funded, will provide state-of-the-art di-- we're very excited about that opportunity that is going to be coming to New Jersey very soon. Next slide. Now we'll move to medical home. We've been doing a lot of work with our core team, our core partners to expand medical homes in Children's Hospitals, federally qualified health centers and community clinics, pediatric and family practices and because we are a parent-led organization the idea of parents as partners on those medical home teams is central to us. In addition to being able to provide support and training to parents from within those practices we've trained a cadre of 75 parents, including parents of children with ASDs who can go into medical practices and share information and resources on everything that is available in the community and in government agencies and in terms of the services we can provide to help practices be able to do a better job of screening and connect families to resources and provide a medical home. And one of the big focuses of both of our state implementation grants is expanding the use of medical home tools, including screening to identify children with ASDs and we've developed resources for practices, really tailored to the kinds of information they need. Let's go to the next slide. In New Jersey we're also very lucky. We have a network of 20 community health centers and federally qualified health centers that have multiple offices around the state to provide access to care on a slide fee scale. This is important in New Jersey because we have

a large population of undocumented immigrant families not eligible for government health insurance and who often can't afford health insurance on their own so these community health centers and federally qualified health centers are places where many of these undocumented immigrant families access their primary care for themselves and their children. In our medical home activities around children with autism spectrum disorders and other disabilities we are including federally qualified health centers in each county we're working to make sure we're meeting the needs of underserved families. I think it's really important to note there is a lot of information out there that shows that African-American and immigrant children are diagnosed as having ASDs much later than white children and middle class children and so it's really important to make sure that our activities are reaching out to those community providers that are serving those children to make sure that they are identified early and provided with appropriate services. So the next slide. In terms of community services organized for easy use by families. In New Jersey we've long had a birth defects registry now called the birth registry. It's been expanded so it includes an autism reporting system which records all report of all cases in ASDs in children and automatically connects those families to county special child services case management units and in our state we're instituting tracking to see if services were offered and what services were offered so make sure that families aren't just referred to services but families are accessing services with their children with ASDs. Next slide. Of course, when we talk about community services organized for easy use by families our existing network of county case management uses where we have the family resource specialists is a community-based resource for families of children with

ASDs and working with our family organizations and care management organizations to make sure they have the resources they need to serve those families and children who have -- who are diagnosed with both mental health and developmental disabilities. We know that's a growing population in our state. And we also have access for mobile response for crisis situations so that families don't have to call the emergency room or the police if there is a significant behavioral issue for their child at home. The next slide, please. We also have an inclusive childcare project that -- where we offer onsite training and technical assistance on red flags in child development and how to include children with challenging behavior including ASDs and almost all the calls we get from childcare centers about children that they are having difficulty including are children that have challenging behavior and often it's a child that has an undiagnosed disability such as ASD disorder. Through our new project we're working with parents of autistic children to do workshops for childcare centers on key strategies to identify the possible ASDs or other developmental disabilities in the children in their childcare center and screening and service resources. We also have an inclusive after-school champions project working to help multi-site after school programs in immigrant communities include immigrant use with ASDs and other developmental disabilities. Next slide.

Adequate public and private insurance and health financing. In our state insurers must pay for therapy must pay for that and we were involved in making the insurance legislation was expanded beyond ASDs. Our health insurance program covers children up to 325% of the poverty level and families can purchase insurance can purchase it at the state's cost. We have early intervention services at no cost to families up to 350% of the Federal poverty level and young adults in our state can

already state on their parents' health insurance up to age 31, actually. Up to age 31. This is really an important resource for families of children with ASDs. Next slide. We also have our catastrophic illness and children relief fund that reimburses families for uncovered medical debt. One of the things we've been working on is make sure that underserved families are aware of this resource and outreach materials are available in other languages and are on the sides of buses and other places where underserved families or more likely to see information and child health services in every county that serve children and youth with mental health or a dual diagnoses of mental health and ASD and other developmental disabilities. Next slide. Effective transition to adult systems of care. We have a project that is funded by our bar foundation where we have technical assistance specialist with expertise in autism and we have several resources that our state operates including a Division of Disability services which has an Office of information and assistance. We were involved with autism New Jersey in training our county voc rehab transition counselors who assist youth at IEP meetings and help young adults with ASDs and other developmental disabilities secure employment and we've also provided training to the network of county centers for independent living to help them be able to really support youth and young adults and the families around transition. Next slide. We also do a variety of county and web-based transition workshops. Many conferences for families and professionals. Our university center of excellence has done a wonderful transition to adult health guide not only available in hard copy in English and Spanish but available in an oral version in English and Spanish on the website and a series of resources for youth. An interactive CD. Transition resources for health practitioners. One pagers that doctors

with keep in a folder and pull out when they need it and a transition guide for parents. The last slide we've also been doing a lot of work around self-advocacy. We have a statewide youth advisory council that includes youth with ASDs. New Jersey was the home of ARI. Kneeman. On the national council on disability and started to self-advocacy network and there is a youth leadership project at the New Jersey council on developmental disabilities and so we're trying to work together to make sure that voices of youth and young adults with ASDs and other developmental disabilities really are part of the systems change as well as being part of the decision making in their own lives. So that is -- all of these activities are done, again, within that partnership through the activities and support of about 75 organizations and agencies and well over 150 people who participate in our community of care consortium. Thanks very much. And I'm really pleased to turn it over to Sharon Fleischfresser from Wisconsin.

SHARON FLEISCHFRESSER Through very much. Boy, that was a great presentation and I can't wait to talk to you about lots of great ideas and partnerships. Thank you. I'm Sharon Fleischfresser. The Wisconsin medical home autism spectrum disorder connections initiative is our state implementation grant for improving services for children and youth with autism spectrum disorder and other developmental disabilities. It is located in the Title V children and youth with special healthcare needs program in our Wisconsin Department of Health Services. Connections uses contracts with key partners including the University of Wisconsin-Madison Waisman Center to strengthen our state's infrastructure and support for families with children and youth with special healthcare needs. Today's webcast focus is on innovative partnerships

and Anne Harris and I have talked to about our partnership with the Title V program and the leadership education and neurodevelopmental and related disabilities or LEND program and our work together to enhance our system coordination and outcomes. Anne and I will talk about strategies we've utilized to strengthen and expand our statewide partnerships and the enhanced outcomes from our partnership in particular, us working together. Next slide, please. Our efforts to build partnerships really includes the creation of the state plan. We've capitalized on the opportunities of the regional medical home autism summits in both 2007 and then again in 2010. To bring together agencies, programs and parent groups at these regional meetings and then back at home to develop, revise, monitor Wisconsin's state plan with five goals that cut across agencies and sectors. In particular the overall systems coordination part of the plan works to assure that a broad stakeholder group has an infrastructure that functions to promote coordinated professional development, data collection and policy development and financing. Many of the same partners that we already heard about from New Jersey. Next slide, please. Our system coordination goals look to strengthen our statewide infrastructure by connecting initiatives under one umbrella. We want to be sure there is no wrong door for accessing services in the support system. We want to assure that everyone has access to information and resources. We want to improve our connections among services and then strengthen our local and regional partnerships for training and outreach. Connections builds on the infrastructure of our children and youth with special healthcare needs program. It is five regional centers that include the Waisman Center, a university center of excellence on developmental disabilities and home to the LEND program. It also

includes other partners in our collaborator's network like Family Voices of Wisconsin, parent to parent of Wisconsin, first step, our 24/7 hotline and interactive website. ABC for health. Our regional children and youth with special healthcare needs oral health consultants. Nutrition consultants and many others. Many of the same partners, I was struck, as we heard earlier. So really trying to build on the capacity of an existing network really does help to promote sustainability of our work beyond a grant. Next slide, please. Some of the collaborative strategies that we've used to promote these partnerships include the idea of state and regional communities of practice and shared work. I'll talk a bit more about that. Ways that we can include partners in new funding and developing initiatives. I think we saw a lot of how New Jersey, too, has built on existing initiatives. Including collaborating agencies in our management teams and advisory groups and then identify products and activities that meet our multiple program goals. The children and youth with special healthcare needs program and LEND have utilized each of these strategies in our connections work in particular. So, for example, when our program, the Title V program was considering responding to the combating autism the state implementation grants we worked together to envision the work of the grant. We wrote the grant together and our budget includes shared staffing. Anne and I will illustrate each of these strategies with examples from connections. Next slide, please. So one of these is our community of practice on autism spectrum disorder and other developmental disabilities. When we wanted to pull together the efforts that were underway in Wisconsin. The community practice represented such a strategy that would bring these diverse partners together and is really modeled after a model supported by the Office of special education. The

children and youth with special healthcare needs program, along with many of our partners, were already part of a statewide community of practice on transition that was an outgrowth from our healthy ready to work initiative and the Department of public instruction, our Department of education's work related to transition and we found it was a really effective way to bring diverse agencies, people at both the local, regional, state level together to partner. So we chose to replicate that structure. The community of practice in structure includes a steering team, the community of practice itself and its practice groups. So our Wisconsin community of practice on autism spectrum disorder and other developmental disabilities is led by a 27-member steering team. Again, I was struck by the -- some of the membership that we heard earlier about in New Jersey are very similar. So our Wisconsin Family Voices, our Department of public instruction, our professional primary care organizations, our Part C early intervention, etc. A very long list of folks who are part of our steering team. And again, they represent our close network of the Waisman Center and the LEND program, our regional centers and the Wisconsin surveillance of autism and other developmental disability system. Our steering team meets six times a year and gives input to the community of practice planning. Its improvement and most importantly sustainability. Our co-chairs include a parent of a child with autism spectrum disorder who is also the executive director of the autism and the children and youth with special healthcare needs program. The community of practice model promotes the creation of practice groups based on shared work. The idea is for the community of practice participants not to create new work but think about ways that we can coordinate and share our work. A practice group may come and go based on the needs and interest

of the community of practice. Our current practice groups include medical home and early identification. Many of the same partners, again, that we heard about in New Jersey. Parent supports and policy, community systems, professional development, school age and youth transition. Each meeting highlights the shared work of one of the practice groups. During each meeting emerging national best practices and/or research of national significance are highlighted and participants are given the opportunity to share existing state and local model practices. Some topics addressed so far are parent supports, professional development. We did a joint meeting with the Milwaukee autism urban summit so urban issues in particular, medical home and resources. Our most recent community of practice was a joint meeting focused on transition and youth with our statewide community of practice on transition. Each meeting provides face-to-face time for our practice groups supplemented with calls between the communities of practice meetings. At each of our meetings we've had over 80 individuals representing multiple organizations and agencies from education, health, early intervention, etc. Families and self-advocates. It's been very exciting for me because there have been a lot of new partners to our Title V world that I did not know about before and so it's been very helpful to expand our partnerships. We have a community of practice listserv that now includes well over 400 contacts and again, many are new to us. We've created a database called WISCU of these contacts utilized and maintained by Title V and LEND for outreach and evaluation. In addition connections supports five regional teams led by our children and youth with special healthcare needs regional centers that have been engaged in resource mapping at the community and regional level. Each center has created a core team and again that's a

cross sectional group including families, health, education to assist with the work. Over 500 new resources have been identified and submitted to our first step. The state's 24-7 hotline and the interactive website. In addition the regional teams provide -- identify issues that feeds into our community of practice and our practice groups.

Next slide, please. Other collaborative partnership strategies have included the creation of a medical home integrated management team that is supported jointly by Title V and LEND. Our work initially focused on the work we were doing related to the developmental screening and screening for autism spectrum disorder supported by connections but also then included our Title V support of primary care provider, train the trainers, developmental screening initiative and the Waisman Center's research topic of interest, project 3D, an initiative outreaching to family physicians in particular. It really provided for us a way to coordinate our efforts to avoid duplication. A joint work plan was created. Since we've expanded our group to include, as we've added new initiatives. For example, we have this year early identification that links developmental screening and screening using outreach to primary cares provider. Part C, Part C technical assistance, etc., has become part of our integrated management team. Some on an ad hoc bases, others as regular participants. We meet quarterly to review our work plan and our progress. From our collaborations in this partnership in particular we've created materials like the Wisconsin specific learn the signs act early. We've also, and I mentioned the community of practice database has been expanded. We call it WISCU to include information regarding our outreach efforts to primary care providers through all these vehicles including our regional centers. So that we have a sense of who are the primary care providers we've

reached and to what level are they engaged, etc. We can use that database to continue to think of our outreach strategies related to medical home, to track our progress, and really to try to continue to support our primary care champions. Next Anne will talk about how we've used our partnership related to training and professional development and again, the enhanced outcomes that have come from our partnership. Next slide, please. Anne.

ANNE HARRIS Great, thanks, Sharon. In my role as LEND director and evaluator for the statewide implementation grant called connections I'm able to really stay connected with the work both related to training and professional development which is the main purpose of the LEND program, as well as the broader work of the USED and looking at the outcomes statewide and that's what I'll be talking about. We've had some interesting both direct and indirect impact on training based on the share at work that we've been doing. We do have a shared staff person named Gail who has been a key person for both the statewide connections initiative as well as the LEND program. Making sure some of the materials and training strategies are shared between the community trainings that the connection is sponsoring as well as the LEND program. That has been a real advantage to having that person in that position. We also have had some direct impact on training because our LEND trainees are able to interface with connections and they've done an example of this we've had three long term LEND trainees who have completed their leadership project and other types of work, research "Working with Medical Professionals to Enhance and Support PATBI

Advocacy and Education Efforts--ing with the connections project and some of the outreach and also some of the policy work that they've done. We've also had lend faculty that have presented at the community of practice meeting and we've had people have the community our LEND staff and trainees attending the community of practice meeting. There have been some direct interactions between those activities. Indirectly we've also been gathering and sharing resources so that some of the products are available and information is accessible across programs to a wide variety of audiences. We've also used some distant learning techniques to do that. Two other pieces of -- projects, I should say, that are working at the Waisman Center or funded there is the national professional development center on autism spectrum disorders looking at evidence-based strategies for mainly school teachers and providing training on those strategies through mostly web-based means. And also some state consultation. So those materials are available both to the community of practice and the connections project as well as our LEND trainees. The CDC surveillance study looking at ASD and other developmental disabilities and they've been able to provide national and state estimates to both the community of practice and to our LEND program through a series of presentations. Having those resources available here at the Waisman Center and partnering with them in their outreach efforts as well as sharing the information and training methods has really been helpful. Next slide, please. I wanted to spend a little time on evaluation and outcomes for our project and this is in relation to the connections project but again it overlaps with the other work that we've been talking about. There are four areas on the next two slides. The first two are interagency collaboration and product and then we'll move on to systems

change and information and training. But some specific examples of interagency collaboration is that as Sharon stated in the community of practice we've been able to bring together a real diverse group of stakeholders and systems representatives that have really been able to talk in ways that didn't occur before. So that is one of the enhanced outcomes that we see as part of the connections statewide implementation grant. Also as Sharon mentioned we've had an integrated management team around developmental screening but we also have been participating more than ever before in advisory councils and committees, across agencies. You meet somebody at the community of practice I can see how your work relates to something else we're doing and people have been invited to participate in other types of advisory groups. In terms of products, there was another website that Sharon shared for the Wisconsin specific act early materials and we also have a series of webcasts that cover a variety of topics that are available on the website that is listed there. So we've really had through the collaborations a series of products that probably would not have been created with any one of these projects but because we were working together we were able to develop a wide variety of topics both on the oral webcast series as well as through some of our print materials. We also have some preliminary -- of community resources that we've been working on and a navigation guide to services and support with children and youth with special healthcare needs under development. Also on the slide in front of you now, the website, we have recorded video vignettes from our partners in this collaborative process. We used these videos at a presentation and they're now available at the web if you want to listen to more people telling their story. In terms of -

- Sharon mentioned the database. It has helped us both not to duplicate efforts but

also to know who we're reaching and maybe in different ways and we're looking at evaluating essentially response and looking at how many exposures, if you will, to some of these different training and meetings -- training activities and meeting to see how things like medical home activities and access to resources for children with special needs are -- how that is being improved through the state through these multiple efforts. Sharon again already mentioned that we have community of practice groups and those groups are actually assuming leadership in some of the different policy and systems changing within the state. The community of practice group on policy was able to advocate for access to educational data source for the WISED program. Accessing educational records is part of the study. It was an effort that came about as part of the community of practice group. In terms of information and training, we have, as Sharon mentioned, identified many new resources for the statewide information first step database and we also have done much more in terms of involving our trainees with both the statewide work as well as having the state connections project be able to access both trainees and graduates of the lend program for the work in terms of things like the navigation guide, etc., that they are working on. It's provided a resource and expansion of their work. Finally in terms of evaluation, we have had an evaluation team that's worked together to really plan and review progress and look at some of these outcomes and for our third year of connections grant we're really looking at ways to measure some of these enhanced outcomes from some of the unforeseen outcomes and looking more at qualitative data and we're hoping to share it in both ways including this webinar and some of the poster sessions we've had. We

have one coming up at AMCHP. I'll end there and hand it over to the Utah state program, Susan Olsen.

SUE OLSEN Thank you, Anne. As mentioned I'm located at the Center for persons with disabilities at Utah State University and I direct to up to three early intervention program which participated in Utah's ADS -- what I would like to share with you are some very simple strategies that we found that we could implement within our early intervention program to increase the early identification, access to appropriate services. Initially to address this objective we formed a child team consisting of early intervention providers, parents of children with ASD and child representatives. The committee was unfamiliar with the CDC materials and spent time reviewing them and identifying the best uses of the information and the team decided to disseminate them in community sites. We serve three counties in northern Utah that are a mix of urban and rural areas and so sometimes it's hard to get our information out there. And so we really kind of inundated our community sites. Our grocery stores, our faith-based organizations with the information. We also mailed or hand delivered packets of information to over 75 primary care physicians and healthcare agencies. And then we shared them at community child activities to increase the overall public awareness. I think that we really were able to ride the coattails of a lot of the media information that was going on about ASD and the increased incidence of ASD and families began to take notice of their child's development. Next slide, please. The second activity that we did involved a review of our early intervention programs intake process to determine whether parental concerns were fully identified at the time of referral. It was

found that doctors and parents making the referrals do not typically identify ASD as an initial concern. The parents on our committee indicated that they were never asked about their concerns related to autism but had we asked they would have identified them. They indicated that they had underlying concerns, which they had discussed with their child's primary care physician but felt that the physician had not listened to their fears. They believe that all parents should be asked at the time of referral if they have any concerns. So the child find committee proposed that all parents calling to make a referral for their child for developmental evaluation be asked if they had concerns related to autism. So the committee formed two questions. Have you or anyone who knows your child been concerned about autism? And does either parent have a family history of autism? And if the family answered yes to either one of these questions we also asked the parent if they could complete a social/emotional ages and stages questionnaire. And we're aware that the ASQST lacks a sensitivity to screen specifically for autism but it captures a broad view of children regarding self-regulation, compliance, communication, adaptive functioning, autonomy, affect and interactions with people. The ASQ was believed to be the most appropriate tool to use at this point in the process because of the way it casts a very broad net to social and emotional concerns. Then if the child's ASQ scores exceed the cut-off indicating concern the early intervention autism specialist reviews the screening to determine whether further testing or assessment is warranted. Next slide, please. Further activities include a training the up to three staff on red flags of autism and strategies to talk with parents about signs and symptoms of ASD. Early intervention staff had identified they were not prepared to discuss autism issues with parents and so we used some of the

materials from the CDC website to help give them strategies the talk with families. The impact of these activities increased identification of children with parental concerns of autism by 10% from the baseline year in 2008 and also decreased the time of our internal referrals for ASD assessments from 12 months to 3 months. Those are kids already in our program receiving services and then we began to see signs and symptoms and we needed to refer them to our autism specialist. So that's nine months of time that we really gained that is very significant for these children and families. Initially the implementation of the questions reduced the internal referrals. There were still a number of children throughout the implementation year who were referred for ASD assessment. Close to their third birthday they received little to no specialized service. To address this issue a second round of staff training on the signs and symptoms of ASD was completed as well as interdisciplinary team strategies to support decision making. Next slide, please. The impact of the campaign met many of the identified barriers to early identification and diagnoses to respond to parental concerns. The need to increase staff awareness and identification of signs and symptoms of ASD and increase staff skills and confidence to talk with parents about autism. Additionally evaluation for ASD concerns significantly earlier allowing for early referral for diagnostic evaluation. Decrease the time to more appropriate ASD services and a greater likelihood of increased developmental gain and a higher level of support and appropriate referral to school district. Thank you for the opportunity to share these simple but impactful ideas. Gina Pola-Money will be talking to you about the ABCs of autism.

GINA POLA-MONEY Thanks. I welcome this opportunity and I will get right to it because I know we're running out of time. This is the ABCs of autism and title this story of true collaboration as we go through. Next slide, please. So in the beginning when we're thinking and talking about information needs of families, our local Utah families for effective autism treatment and other families and providers attending some of the support group meetings started talking about how do we get information out to families and I think right now there was a matter of -- that there was almost too much information, and what was credible? Where should they go to find that information and such? They had an idea there was so much expertise in our state and how could we get them all together? These ideas spurred from the families themselves on what they either would have liked upon diagnosis or would still like and during that time a couple years ago we had Lorrie, she was in our Utah regional LEND program as a trainee and a speech/language pathologist doing a lot of work with families. She decided to start a leadership project for that year. Out of that came a 12-hour training which was really initially set up that it would be six week consecutive trainings, two hours apiece. They were live sessions with families that had RSVPs and came to every training. During this she had some extra support and was able to offer childcare so that these families could attend together both mom and dad, if that was what they were needing. As that went on, the first pilot went great. And the evaluations were wonderful. Parents really gained a lot of knowledge out of that. The problem, though, was that we have so many experts in the field speaking its how do we get all of these people back together? During this our Judith Holt at our Center for persons with visibilities thought let's videotape another life series to figure out how to get it out to other families, especially

in the rural and frontier areas of Utah. So we pulled off a second live series and it was videotaped verbatim. Through all of that, the Center for persons with disabilities took that and developed a facilitated training guide and developed a DVD. We have piloted that in one of our rural communities just recently and rather than doing a six-week series, it was piloted as a two-day conference for families. We had over 80 participants show up. We really anticipated that the majority of those would be families and the outcome was that it was about half and half. We had school professionals and health professionals also attending. During that, a lot of feedback was given and such that the professionals got just as much out of it as the families did. Through this, as I stated, the families really came up with the idea, and through some, of course, MCHB funding with our LEND program it was started as a leadership project and it was enhanced through all of this with our autism integrated services grant. And from there the family to family health information center, which is also an MCHB-funded grant, implemented in and we are looking at sustaining that with all of the partners and grants that we have. The -- each module, next slide, please -- which are the chapters, there are six. The first one building resilience, this includes healing after the diagnosis and the wise consumer. This module focuses on providing advocacy skills and identifying common reactions of family members to the news of the diagnosis and then the wise consumer part, it also talks about all of the pieces that you need, including a medical home and what that may be. The second one really deals with behavior management and it helps families to identify some of those basics of behavior problems. Understanding the trackers of the behavior problems. As well as helping to find tools and solutions to help with those behavior problems for families. The third chapter or

module is the introduction to autism and early intervention, preschool services and such which really goes over what an IFP is and then going into special education talking about what IBA, IAS and what an individualized education plan is as well. Fourth module is talking about the communication and integration issues that many of the children have and through that one they talk a lot about the components of communication and identify the common deficits in each of those components. They also help families to understand the intervention strategies for enhancing those communications. With sensory integration kind of the same lines is that they help families identify the sensory integration disorders and understand the full evaluation process. They also talk a lot about what the treatment options available for children with sensory integration issues are. In the fifth module we talk a lot about interventions and they do go over such things as ADA and other models such as search and go over complimentary alternative medicines and such talking about being a wise consumer and knowing about what those treatments are and how to objectively evaluate and measure those interventions. So that families can really have as much information as possible to make informed decisions. And then the last module, which is finding resources and organizing their record keeping but the end of that is also a parent panel. So in this last module they really have gone over the importance of keeping good records and how to understand the effective ways to store those records for all of the needs that may come, including applying for services and benefits. And also where to locate the credible resource information. We have in the last panel families or siblings and other caregivers that are on that panel that also talk about how they found resources and why it's important to find those resources. And also what in the

state agencies and such should they really be looking towards and finding to help their family members and their children. And then also again they talk about being a wise consumer. Many of these modules were presented, again, by the experts that we felt that we had in the field here in Utah, which encompassed many developmental pediatricians, family advocacy groups, individual families, as well as Ph.D.s and such that are really working hard in the field. Next slide, please. For this particular part, the authors or the partners that we had involved, there were many and I have to give a lot of credit to Lorrie that put all of this together because putting together two live series was a lot like the, quote, of herding cats and she did it twice successfully. When we videotaped the second series bring that expertise that is really in our urban corridor to be able to give that same knowledge and expertise to families and providers and professionals out in our rural communities. And as you can see, there is quite a list on our partners. And I just have to make one correction is that I have Utah's family for early autism treatment and it's actually Utah families for effective autism treatment. For this successful ending we felt this product that came about with many of the MCHB-funded programs and projects that we also brought in many of the community providers, autism, parent support groups as well as the larger disability support groups, community services and individual families. We wanted to really make sure that this tool that so much work and effort had gone into was able to be provided to everybody that needed it. So in our integrated services grant, we have five family navigators that are, of course, families of children with autism or have children on the autism spectrum that are the experts that we refer medical homes and such to when they're looking for resources. The navigators helped in putting together the parent training manual, as

well as the facilitator manual and are currently the ones providing the materials to the state. We have now had probably around 10 requests around the state to provide this training and so that it doesn't, because of resources being limited and such, we're really excited that this particular tool is one that can be taken from -- from us to anyone that it has step-by-step instructions on how to do that so really you only need a facilitator to provide this training anywhere in the state. The one thing we always ask is that they really customize it to their local community so that they bring in their own parent panel and we do provide a lot of resources, hard copy materials but that they look at those and make sure they're applicable to their local community and also add in. So it really became a user-friendly tool that I think everyone has ownership in regardless whether they were part of any of the grants or programs, because as I said, medical homes and families alike and support groups can use it. And really get the information out. And we are also looking at creative and flexible ways that if we don't particularly have somebody to facilitate it in a certain area, that we are looking to go web-based with it. So our next chapter includes evaluation of the different vehicles that we can provide the presentations. We want to get a lot more outreach throughout the state and there is currently the Spanish version being developed right now. Of course, we'll want to develop mechanisms for outreach for our Spanish speaking population. Our happily ever after will be if we can get enough information out and provided so that all of the families get the information and interventions as early as possible. And we're feeling like this is one of the projects out of -- I guess products out of all the projects and programs that we've been involved with that can help lead us in that way. So I will turn the time back over to Deidre.

DEIDRE WASHINGTON-JONES Well, we've heard from quite a few of the presenters, now about their innovative partnerships, some of the products that have been the results of partnership and who they've partnered with and hope that you've enjoyed this presentation. Now we do have a few minutes left for question and answers. So if you have a question, please submit it. I do have some questions that have already been submitted from the audience. So I'll just go down those. The first one is, I think this is directed towards Diana in New Jersey. It says, can you provide more detail about the ASD registry? For example, where is it housed and what provides data to the registry, how long has it been in existence?

DIANA MTK AUTIN Sure. The registry actually was added to our long-existing used to be known as the birth defects registry now known as the birth registry. Basically that had been a registry where children with special healthcare needs and disabilities were entered into the registry maintained by our Department of Health and senior services. It has been expanded to also about a registry for children with ASDs who are not typically born exhibiting the symptoms of ASDs. Whenever a child is identified as having ASD, they are registered in this online registry which is housed within our Department of Health and senior services and this has really been within the last couple of years that this has happened and now a new component that is being added to the registry is the follow-up so that the registry will be able to actually let us know whether or not the children who are registered and their families are being connected to the support services that they need.

DEIDRE WASHINGTON-JONES Okay. The next question I think this one is for you, too. It starts off with the passage of the higher education opportunity act. Do you think your transition services will have an increased function on transition to postsecondary education and has your state included higher education disability service providers in its work?

DIANA MTK AUTIN We do -- even before the passage of the act we had several colleges in New Jersey that were partnering with community colleges to implement post secondary opportunities for students with ASDs and other developmental disabilities and so we already had been working in collaboration with those colleges and community colleges to implement those programs and make sure that information got out to families so that they could take advantage of the programs. You know, the passage of that law has been pretty recent and so I don't think it's had a significant impact yet but one of the things that we do is we do have information already available for youth with disabilities on our interactive CD that talk about all the community colleges in New Jersey that offer targeted services for youth and young adults with a variety of disabilities to be able to take advantage of classes in community colleges and we've helped provide technical assistance to families who have youth with ASDs and other developmental disabilities to participate in classes at community colleges for credit with modification and support. So I do believe this will be an area we'll get more involved in. Our statewide youth council has a lot -- will have a lot to say about what

we do in this area and what kind of priority this should have. We really want our youth and young adult activities to be led by the youth and young adults.

DEIDRE WASHINGTON-JONES Two more for you directly. The first one is, is the transition to adult health autism specific?

DIANA MTK AUTIN No, it's not any type of disability specific. Focused on youth with developmental disabilities because it is the university center of excellence on developmental disabilities but it is a great guide and in particular because it is available both in hard copy and also on the web in written form but also on the web orally it's very accessible. Much more accessible to youth and young adults with disabilities than many other type of publications typically are. It's not just for youth with ASDs. In a lot of work we've been doing with youth in our state who have ASDs, one of the things that they really feel strongly about is that the types of resources that are available for all youth with disabilities and also for all youth really should be comprehensive enough to be useful to youth with ASDs and other developmental disabilities. So there are certain things that we're doing that really are targeting looking specifically at ASD because things like what are the appropriate screening tools, etc. A lot of the other work we're doing is create and support the creation of tools that will be useful for the full range of youth with special healthcare needs.

DEIDRE WASHINGTON-JONES One more for you directly then we'll get to the other questions. This one is can you provide more insight on your strategies for partnering with community health centers?

DIANA MTK AUTIN Our strategy for partnering with community health centers is very similar to our strategy with partnering with other community-based organizations that served underserved and immigrant families, which is that we don't go into the partnership with any particular expectation but instead say this is who we are, these are the kinds of things we have available. What makes sense to you? How can we be of help to you? How can the work that we're doing be useful to what you're already doing and how can we learn from each other. One of the things we've done, for example, is we have some of our CHIP or immigrant outreach and enrollment parents actually housed part-time at some of the federally qualified health centers to help them help enroll eligible children for our state Medicaid and children's health insurance program and by having our staff there, they are also sharing resources with families about all the other activities that we do and gradually over time there has developed a trusting relationship so we're now seeing the federally qualified health centers throughout the state as a valuable resource and partner in many activities, including our community of care consortium.

DEIDRE WASHINGTON-JONES Okay. The next question is for Wisconsin. Maybe you, Sharon, either one of you. I think this was more your presentation. The question is, could you give an example of a management team collaboration and how the

team's membership and objectives may be different from a practice group, regional team or community of practice?

SHARON FLEISCHFRESSER Sure. This is Sharon. Anne jumped in, too. Our management team really is started with a small group so it's not part of the community of practice in the practice group but there are members like myself, Anne and others who have roles in both. So it really focused on our initial work that was happening around developmental screening and outreach to primary care providers. Where, for example, the Waisman Center had a grant but focused only on family physicians as part of that grant activity to develop developmental screening. We were doing the train the trainer initiative modeled after what Illinois had done and so that activity was going on, plus we had outreach and education to primary care providers as part of our connections grant. So we really felt the need to kind of put our ducks in order about who is doing what to really assure that there was no duplication of effort but that we were actually building on the resources that each of us could do. I think it's -- from that discussion came this idea of an integrated work plan where we could take parts of what each of us were doing but kind of really so that across agencies the right-hand knew who the left-hand was doing. Anne, any other comments?

ANNE HARRIS Except we ended up -- we're still working on the database to help us track this. Because from my perspective Wisconsin is still a relatively small state but there are a lot of people talking to the same people and wanted to make sure that

that's the right-hand left-hand part. Not saying the same thing to the different person and they didn't see us from different places.

SHARON FLEISCHFRESSER We wanted to make sure all of our efforts were connected to our regional centers because there is the go-to resource people and we felt primary care practices needed to know about them and on their speed dial and wanted to make sure that all of those outreach efforts were connected to this idea of referral to early intervention or educational system as appropriate so that they were making those links and that we needed to help to make sure there was a common message.

DEIDRE WASHINGTON-JONES Okay. The next question is for Utah. This question is, is the DVD of ABC's of autism available online or for other states to review?

>> It is currently not online and we will get it online as soon as possible. Part of the issue that we're dealing with on getting it online is the DVD is straight verbatim of everybody talking and presenting, which can get, you know, it's not very interactive. We're still looking at that. It's available if you want to email and we can get you a copy out.

DEIDRE WASHINGTON-JONES That was the other question that they asked. Someone else asked about the DVD and wanted to know if they could have one sent to them. It sounds like they can.

>> Yes.

DEIDRE WASHINGTON-JONES Okay. Another question I have for -- that came in for Wisconsin is does Wisconsin have a template available to coordinate efforts to learn what other agencies are doing?

>> A template? Well, we use the community of practice as kind of the -- I don't know if I would call this a template but where at each of our community of practice and through its listserv communication, we have opportunity to share what others are doing. I'm not certain if I would call it a template.

>> When we started the integrated management team we used basically tables. Grids that showed which agency are group was working on what and sort of tried to combine those things. I wouldn't say -- it was an internal working document not a template. We are doing the same thing as a result of our early summit is going through to make sure we understand who is doing what.

>> The other piece at the beginning of the community of practice and with the creation of the steering team where the connections project outreach coordinator, Tim, did phone calls with key participants to say that we're participating -- what are you hoping to learn from this? What would you like to see happen? To get a sense of what were folks who we hadn't usually partnered with, what were they looking to get from the

partnership or participation to help inform our group as far as what do we need to provide? How can we keep people engaged? How can we continue to have people come to this, etc. So that was a series of questions through a phone call survey that Tim did.

DEIDRE WASHINGTON-JONES So we have one last question. And that one is any of you all can answer this question. But the question is, for a state that is really sort of just starting out to really work on their system of care on children and youth with ASDs and other developmental disabilities trying to bring people together in the infancy stages. What are the core collaborative partners they should try to target to get the bang for their buck in improving their system of care?

DIANA MTK AUTIN This is Diana. Obviously as being a family-led organization that houses both the state implementation grant and the autism grant. We think probably the most important key partnership are family-led organizations like your Family Voices, state affiliate organization and your family to family health information centers and parent training information center and parent to parent. If you're lucky to have a bunch housed at one family organization makes it a lot easier. Because our focus also is really looking at closing gaps for underserved families we would say it's critical to identify the community-based organizations and providers that serve underserved families not only with children with ASDs and developmental disabilities but all types of community organizations. We have -- the small immigrant organizations in New Jersey belong to and we've been able to get information and support out and also

information from immigrant families from all different backgrounds throughout the state by that partnership and they're very interested in helping all immigrant families including immigrant families that have children with ASDs and other developmental disabilities. I would say for us those are really two strong recommendations we would make.

DEIDRE WASHINGTON-JONES Wisconsin?

>> I would just suggest -- I don't know if the question came from a Title V program. But if not, I would say that your state Title V program can play an important facilitating role of bringing people together. So I would certainly partner with your Title V program. I think that's a key partner. Then I think, you know, family advocacy groups absolutely. But also I think you need to pull in those agencies that are at a state level also responsible for policy and service delivery so you're Department of education, your early intervention, etc. But Title V can play a critical role of being a neutral party to bring the pieces together and we get the information role that families play in all of this. So I think if not, that's the place I would start.

DEIDRE WASHINGTON-JONES Okay. Utah, did you have anything else to add? On that one?

>> I would just Ditto what everyone else has said. I think when we really started out, it was through our Title V and our children with special healthcare needs that we pulled

everyone together, whether it be education, healthcare providers and got everybody in one room to start really talking about all of the things that everyone have going on. There was so much wealth and information out there but really focusing on building, I guess, a vehicle that everybody could share and start working on doing and implementing statewide.

DEIDRE WASHINGTON-JONES Okay. And also as a moderator I would like to add to this question a little bit as I work with the state programs here at the Maternal and Child Health Bureau. I've seen to the extent you can also add your really include your physicians working through the American Academy of Pediatrics as well as education and Medicaid and some of your other policy folks, as well as definitely Ditto what everyone else has said, including the families and the community providers. And also sometimes reaching a little bit out of the box and being a little bit more innovative and creative and trying to reach out to the business communities, too. I've seen that work with some states, too. So those are the answers to those questions. I would like to thank, really thank our panel of presenters for sharing with us your wealth of information. I think this was a very, very good webinar and you shared a lot with us. Great ideas around partnerships, innovative partnerships and also you gave us information about the products and impacts that come out of the partnerships. That was great to hear and I want to thank you for that. This concludes our webinar today. Thank you so much, everyone.