

Division on Services for Children with Special Health Needs in collaboration with HRSA's Office of Rural Health Policy

DEIDRE WASHINGTON JONES: Welcome, everyone, to this collaborative webinar between HRSA's MCHB Division of special health needs and the Office of rural health see. I'm Deidre Washington Jones and will be serving as moderator along with Julia Bryan. The purpose of today's webinar is to provide some examples and a discussion about the unique needs of children with special healthcare needs in rural communities. With the focus on technology, research and state systems. First I'm going to go over some logistical issues and lieutenant commander Bryan will introduce the speakers. For the participants, please be aware that slides will appear at the central window and should advance automatically. The slide changes are synchronized with the speaker's presentations, you do not need to do anything to advance the slides. And please remember, you may need to adjust the timing of the slide changes to match the audio by using the slide delay control at the top of the messaging window. We recommend you change this setting to 12 seconds, as that seems to work best for most people. We encourage you also to ask the speakers questions at any time during the presentation. 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 remember to include your state or organization in the message so that we know where you're participating from. The questions will be relayed to the speakers periodically throughout the broadcast. However, we will have a question and answer period at the end of the presentation. So please keep in mind that that's when your

questions will be answered. Also on the left side 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 on the loudspeaker icon. And those of you who selected accessibility features when you registered will see text captioning underneath the video window. And 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 take a couple minutes to do so, as your response will help us plan future broadcast webinars I'll now turn it over to lieutenant commander Bryan who will introduce the speaker.

JULIA BRIAN: I'm Julia Brian. Our first speaker is Brent Askvig the director of the North Dakota center with persons for disabilities. He has been at the university for over 20 years. He's previously served as the center's associate director, the department chair in special education, and assistant to the dean of the university's graduate school. Dr. Askvig has degrees in education and a doctor's degree in education, a special education with a specialty in educational research from the University of Idaho. As executive director he oversees a program of 85 staff with approximately 7.5 million annual funding. Nearly all from grants or contracts. In his 20 years at the center Dr. Askvig has developed and run programs totaling nearly \$20 million. Our second presenter is Dr. Victoria Freeman. She is a research fellow at the shep Center for health services research at the University of North Carolina. Her research and evaluation experience includes multiple studies of healthcare services for children. As part of the center, she has led investigation on studies of aspects of rural healthcare including access to healthcare for children and Medicaid managed care

programs. Provision of intensive care services in small rural hospitals and critical issues facing EMS services in rural areas and the rural hospital emergency department preparedness for pediatric emergencies. She has worked with the Maternal and Child Health Bureau at HRSA and is looking at national performance measures. Detailed recommendations for change of we are form answer measures and analysis of the trends and priority needs and specific performance measures. Dr. Freeman worked previously as a pediatric oncology nurse at the University of New Mexico hospital and received her doctorate in public health degree in Maternal and Child Health from the University of North Carolina. Our final presenter for this afternoon is Amy Carlsen. She serves as the faculty for the University of Washington leadership education and neurodevelopmental disabilities or LEND where she supports parent leader trainees to develop leadership and advocacy skills and insures the family perspective is highlighted in all aspects of the LEND training program. She's also on staff with the state Title V funded Washington State medical home leadership network and involved in activities of the projects county base volunteer teams to improve family-centered care for children with specialties needs and on the advisory council for autism and advised in the mapping pilot project to improve early dentfication of children with autism. Amy has 19 years of experience as a registered nurse and is the parent of a 10-year-old son who has autism. Amy has a passion for helping the medical community better understand the unique challenges of families who have children with special needs. Now we'll turn it over to Dr. Askvig for his presentation.

BRENT ASKVIG: Good afternoon, Ladies and Gentlemen. If we could have the first slide. Technology based services in a rural state. Welcome from North Dakota. I need to tell you that we're wishing it was warmer in North Dakota and we are wishing that the sun was shining. But it's a great day for us here in North Dakota and it's a great opportunity for us to talk with you and with the other colleagues that you're going to hear from today about some things that we're doing in the rural areas in our state and about how we are approaching issues related to children with special healthcare needs. If we could go to the next slide, please. You're going to see a slide here that shows a little bit about North Dakota. We are a fairly large rural state. We have a very small population. In fact, we only have about 9.3 people per square mile. When you put that into context, other states that folks think about as being very, very rural such as Nebraska have about 24 people per square mile. Kansas 47 people per square mile. We're very, very sparsely populated. It is a great place to raise a family. But about 2/3 of our counties are what we call frontier counties and the U.S. census bureau defines a frontier county with 7 or fewer people per square miles. We have a lot more land than we have people if you put that into context. We have a lot of space between the people, and we have a lot of challenges. While we do like to wake up to beautiful mornings when you can look across the plains and see large sunflower fields, you can also see by our map while we're centrally located in North America, we're quite far distance from a lot of national and international service centers. Next slide, please. While growing up raising a family and having children in North Dakota is a great, wonderful event, it does present challenges particularly if you have a child with special healthcare needs or you have other family members who need services. We

have a long distance between our major service centers. While our geography is relatively flat you'll travel for miles, like today, through the snow, to try and access a professional who can assist you with -- or your child with the services that they need. Obviously weather is an issue. We try not to play that up too much. We do that at times in our grant proposals to get people thinking about what it must be like in North Dakota, but we will have at times lots of wind, lots of snow, very, very hot, humid summers and just a difficulty in getting around in our state. Many of our service sites for children with special healthcare needs are located in what are our more populous cities. For those of you in larger metropolitan areas, put it in the context of North Dakota. A populous community in North Dakota is 35,000 to 55,000 people. That's a very large community in North Dakota. We only have eight communities of 20,000 people or more in any one place. So a lack of service sites and having to travel a great distance to get to those service sites kind of complicates matters for our families and for our children. And particularly for children who have some significant healthcare needs and some immediate, at times life threatening situations. If you have children on ventilators and just imagine trying to access a professional for services 75 miles trip one way and having to take all of the equipment and hope nothing breaks down in that process. It is at times a very scary situation for families. And, in fact, we do have families moving often to those service sites. When they do get to those communities, one of the things they encounter oftentimes are lack of professionals. We have no pediatric psychiatrists in our state. We have very few pediatric specialty physicians in our state. Access to physical therapist and occupational therapist. It sounds like I'm painting a relatively bleak picture and for some families it actually is.

But for many of us, it's what we grew up with, what we were faced with, but now as a service provider, as someone who is involved in assuring quality services or access to quality services for families and youth with special healthcare needs, it's a very serious situation. Go on to the next slide, please. Our center on disabilities is a university center on disabilities funded through the administration on developmental disabilities at the U.S. Department of Health and Human Services. We are tasked with pre-service community education, research, community services and information dissemination for our state. And one of the things that we've done is take a look at what appear to paint as a relatively bleak picture. Some of our excellent features in our state that allows us to get the job done and get access to people with the kinds of services that they need and appropriate services, one of the things I need to tell you is because we have such a small population, most of us who are on state committees who are in state and local and regional offices actually have personal connections with folks which actually facilitates that. We also have a state that is highly connected. Our state has invested millions of dollars in state infrastructure for high-speed, particularly Internet connectivity so there are some folks living in communities of 20 to 30 people that have very high speed DSL and even higher access lines for data and communications interaction and that really helps us quite a bit. We try to maximize professional time when we're looking at families who are spread out or professionals who are spread out from families who need services. We try to maximize professional time. As a service provider, early in my career it was not unusual for me to travel two hours to a family to do a home visit, provide one hour of home visit time with the family, and the child, drive back two hours. So four hours for one -- four hours of travel for one hour time. You

only get one to possibly two hours worth of professional service in a workday. We're trying to maximize professional time using that technology. Our staff here have accessed the top technology kinds of hardware and software that have allowed us, through privacy, security, HIPAA compliant kinds of procedures to make connections with families. Families don't have to travel. Professionals don't have to travel and in our experience, the types of service that they receive have been at least as good as the kinds of service that they would receive face-to-face. Next slide, please. In about the last ten years our center on disabilities has really taken that approach of using connectivity and maximizing professional time, looking at top technology and making your it's appropriate and secure to do a number of different things. We have developed distance audiology screening procedures. We have the capability to screen adults, newborn children from a distance to see if they have any audiological difficulties. We just finished developing the national protocol for early childhood audiological diagnostic assessments. Our staff worked with audiologists and team members throughout the state and in the national HRSA office to develop a toolkit and a protocol that allows us and allows audiologists who are at a premium in North Dakota to be able to do diagnostic assessments for young children at a distance using existing Internet technology that is HIPAA compliant. Our staff have worked long and hard on that so they have a technical protocol, a diagnostic procedural protocol and a toolkit that goes with that. We worked for a number of years on realtime remote online captioning. This is a situation that many of you perhaps have seen at your schools, perhaps you've seen this at conferences that you've been at where the speaker's voice is translated into a text or captioning type of a presentation either on a slide or on a

screen next to the presenter. So that we have been able to hook up teachers, professionals who are doing a presentation, whose voice is transmitted to a captionist at some other distant spot in many cases outside of North Dakota who listen to that, who use a courtroom captioning machine, electronically hooked to the computer, that types in the data or excuse me, the voice that they are hearing and either in a note format or a verbatim word for word format and transmits that back to the transmitting site with approximately a three second delay. So, for example, a child who has a hearing impairment who is at a small school in North Dakota that can't afford a sign language interpreter, and the teacher says it's time to work on chapter 3, one, two, three, within those three seconds, the teacher's voice is now transmitted on a laptop and we're working on hand held devices now, so that it comes up on that child's laptop screen as the text captioning of what the teacher had just said. We're at the point right now where we are using our hardware and software as a host site and other captioning companies are now tapping into that. We've done online speech language therapy where we've had the speech language pathologist at a premium in North Dakota able to deliver speech language therapy services to children in very rural school districts. And so we've been able to make those connections and we've actually been able to do articulation therapy, which is usually a very precise type of therapy where you need to, as a therapist, be able to see very clearly and hear very clearly what the child is saying and how the child is saying it and our technology has advanced to be able to do that. We've done online health and wellness training for adults with intellectual disabilities and perhaps our most recent work in the work I'll talk about a little more here is our technology-based team diagnostic in autism spectrum disorders. We're working

through a program through the Maternal and Child Health Bureau on doing technology-based team diagnostics using interdisciplinary teams and distance technology in diagnosing young children with autism. Next slide, please. You should be looking at or shortly will be looking at a slide autism diagnostic clinic. We have video samples of these that we're unable to show today but we show you on this slide show you the kinds of things and some of the technologies that we use in actually being able to do diagnostics with autism and with the teams. You can see, for example, in the central slide there is an educational specialist working with a young child and that's actually a captured video clip. In the left side of the slide you'll see what the school psychologist who is sitting there with his back to you is seeing as the child is working on an activity. And on the right side you can see a couple of the professionals, the school psychologist and other educational specialists 100 miles from the site and they were completing the protocols. Next slide, please. We've captured a bit of a grainy slide here. This is the diagnostic negotiation and discussion slide. Here we have several of the professionals who actually were at the site, physician, therapist, educational specialist, diagnostic folks. The child and family members who are talking about and discussing the results of the actual diagnostic event. Again, those folks who are at a distance can view the actual discussion as it is going on in realtime. The folks that are at this site can look at a screen and view the distance participants who are interacting with them during this diagnostic procedure as they talk about the results and try to come to some discussion or some resolution as to whether or not the child has autism. Next slide, please. Finally, because our professionals are at a distance, the whole report writing, delivery type of a process requires us again to use technology. And not

just simple report writing where each person writes in their little piece and sent to a special place -- sent to this secretary who staples it together. We actually have the interdisciplinary team writing on each other as papers and reports through an accessible site called share point. A Microsoft based system that you may not be familiar with through your centers or through your schools. This share point allows document sharing and document access to team members. They set their deadlines. They are using technology now that type as you talk types of technology that transmits then their dictation to the word processing document. They can upload the word processing documents and the team can actually work on that type of a final document in a real interdisciplinary process again using technology because we all cannot be in the same place at the same time in many instances. That's a real brief, very quick description of some of the things that we're doing here in North Dakota. If you can take a look at the last slide, please, we would be happy at any point to answer questions later on or after this session there is a phone number and email for me. If you're really interested in all the hardware and software components, Steve Peterson in our office is the master guru at that and he can tell you about the T-1, T-2 lines. Bandwidth and all the things that sort of blow my mind on that. He can tell you about all of those specifics. He can help your I.T. folks talk about it. We have used not only these larger interactive video network systems through our state infrastructure but we've actually used point to point computer to computer realtime connections with very individual specific families. So it doesn't have to be large network types of systems, too, and Steve could help you out on that. I really appreciate the time and I am about at the end of my time. At this point I would like to turn it over to Victoria Freeman.

VICTORIA FREEMAN: Well, thank you very much for inviting us to talk about rural healthcare for children with special healthcare needs. I'm at the North Carolina Policy Analysis Center and I'm here to represent my former colleagues who did the work that I'm going to describe. Neither of them are here at the center. Some of you may know Becky in her new role at HRSA. I'm the designated hitter here. At the North Carolina Rural Health Research and Policy Analysis Center we focus on healthcare in rural areas across the spectrum of types of care in different populations so we often ask if it is more difficult for rural residents to get the care they need and what are the barriers and burdens and what are the possible solutions? Let me put a plug in here for the six federally funded rural health research centers. I missed a slide here and I'll give you one web address to write down if you want and if you're interested. The web address for the rural health research gateway. It is www.ruralhealthresearch.org. It is a searchable website. You can link it to, research reports and to link to reports and peer-reviewed articles on all things rural. One study just released is a study that the main rural health research center did on access to mental health services for rural children and their families. It is a great resource if you're interested in rural health. Next slide, please. The challenges for children with special healthcare needs and their families can be daunting no matter where you live. This list of potential services is meant to be illustrative and not exhaustive and it's to draw attention to the many points of need for families with children with special healthcare needs and probably every topic on this list has special challenges for rural families. So it's not just a matter of a specialist or a highly specialized therapy. There are often challenges for rural residents across the

spectrum of healthcare. Next slide, please. I want to focus today on a study conducted by Dr. Skinner as a starting place for considering the challenges placed by rural families to obtain healthcare. You can see a reference to the paper they wrote at the bottom of this slide. If you want to know all the details, I'll give you quite a few, that's the best place to go. They used data from the national survey of children with special healthcare needs to look at rural and urban differences and access to care and the burden of care. There are lots of ways to define rural. It was defined in residents in a non-metropolitan area. For those of you who work in rural areas, you know this is one of the more crude measures we have but nonetheless, it is what's available in these datasets. And this is a particularly well designed and national survey. We take it with its limits in terms of definition of rural. The analysis that Becky and Ashleigh did here compares rural children to urban children but more importantly uses statistical modeling to control for the effects of other things that contribute to healthcare use. I'm sure you've all read or heard of results of studies claiming one thing or another and you think isn't that because people have this problem more often in this area? So in this study they made an effort to control for those factors using statistical modeling. For those of you who want to see the numbers I've included the odds ratios indicated by the OR and the odds ratios that account for differences between the two groups indicated by the adjusted odds ratio. Next slide, please. First of all, how do rural respondents to this survey compare to urban ones? 19% are rural. It's a good sized survey to determine differences. Rural residence are more likely to be poor and a notable difference for those below 200% of poverty which may represent a bigger difference in the working poor. Lack of insurance is statistically significantly different

but not a large actual difference and finally rural students are more likely to be white and the mother's education is to be high school or less than high school. These are the differences we know exist in this sample in these two groups and these are the things that are important to take into account when we're looking at differences in access to care. Next slide, please. We'll start with access to a usual source of care. For all of the results slides I'll -- on the bottom line. Either literally or the bottom line in terms of the message. Not in the details. You have the slide so you can get the numbers if you're a statistics geek. They're there for you. But the important thing here is that there is no difference between rural and urban respondents in regard to having a usual source of care. Once you control for the other factors that are different between the two populations. So any differences that might have been observed and whether they had a source could not be attributed to rural residents but other factors such as income. The source of care did differ after considering personal characteristics and that's not surprising given the important role that rural health clinics, community health centers and health departments play in rural areas and the lack of pediatricians in rural areas. Next slide, please. Then when we move on to delay of care and the barriers that cause delay, there is a similar pattern here for parental report for delay of care. When you control for personal characteristics and research this there are differences in delay of care which doesn't mean that rural parents don't delay care. It is just they're not more likely than urban parents to delay care. Where they do differ is in the reasons for delaying care, some of which are intuitive and some of which are not. Being in a rural area is important in regard to barriers even if you consider other factors. The barriers are mainly barriers of availability. Care doesn't

exist or care is too expensive and therefore not available. For urban parents on the other hand their barriers are often more related to the structure of existing resources such as waiting too long at the doctor's office or communication problems with the provider. So that's a little bit about delaying care, which is care delayed by implies that maybe the care was received. Next slide, please. Next we go to unmet need for care and the authors of the paper, Becky and Ashleigh, divided these. I've divided them as well into two groups. Care for the child and care for the family. Care for the child. At the bottom of the slide you'll see there are no differences in unmet need for routine care, specialty care, prescriptions or mental healthcare. It doesn't mean there wasn't an unmet needs but rural residents were no more likely to report unmet need than urban -- for dental care it seems to be related socio-economic factors. Although lack of dental care in rural areas is a very well-known problem. Next slide, please. These are the barriers that led to unmet need as reported by rural parents. It's a busy slide but the important things to note are that availability of services and transportation are significant barriers and they remain a significant barrier significantly more important barriers after controlling for personal characteristics. These are the areas where parents report more problems. Rural parents. Next slide, please. This is the flip side. This is where rural parents are less likely than urban ones to report barriers. Again, after controlling for other factors known to affect healthcare utilization, rural parents aren't as likely to report specific factors related to existing services or resources like care not at -- a health plan problem or time. Next slide, please. The second category of unmet need for services was -- were services for families. These are services like respite care, genetic counseling and family mental health services. There were no

significant differences between rural and urban reports of unmet need for these services again. Want to emphasize it wasn't that there aren't problems it's just that urban and rural were not different. Next slide, please. For barriers again they were different. This is starting to sound kind of familiar, right? In these cases the barriers differed some from the barriers to traditional medical and ancillary services for children. Cost is a particularly large barrier for genetic counseling and this difference persists even after you control for poverty and insurance and the other differences between the two groups of respondents to this survey. Next slide, please. Again, here is all the details for those if you want them. The bottom line is if you look at the last two bullets for these differences, these are the areas where rural families are less likely to report barriers. And one was for the cost of respite care which really begs the question, is free respite care more available in a rural area where extended families exist and can provide support? Convenient appointments times are not a barrier. Availability is the main concern. Next slide, please. Finally, there are a number of questions in the survey that assess the burden of care for a child for the family with the child with special healthcare needs including the economic burden, the lost opportunity burden and the time burden. Even after controlling for personal characteristics, providing care at home is more likely to be reported by rural parents. One could argue that is this a burden or in terms of lost opportunity when there is no opportunity to work or is this just a fact of life in rural areas? Which I think probably in many cases it is. The bottom two suggest that it also is probably just a matter of fact of life in rural areas, rural parents are less likely to report cutting work hours or stopping work even after you control for other factors. Probably a big function of not having the employment opportunities in

rural areas. Next slide, please. So in summary for children with special healthcare needs and their families access to healthcare is limited both by personal characteristics and by healthcare system barriers. Both of these are extremely important areas to consider and that for programs to address but the solutions obviously are very different for each type of problem. Economic opportunity in rural area is a huge, huge issue these days. Probably has been for some time but poverty and under insurance are consistent barriers and they accounted for many of the differences that the authors observed in this paper. These are challenges that are likely to remain in these tough economic times and I can't even begin to make suggestions for how to improve economic opportunity in rural areas. There may be, though, I say hopefully given the rumblings in Congress, relief for other economic factors such as health insurance. With healthcare reform affordable insurance will become a reality for those without employer-based coverage including the working poor. Other aspects of the Affordable Care Act for those that do have insurance such as removal of lifetime limits, insurance portability and elimination of the pre-existing condition restrictions will be a tremendous boon for families with special healthcare needs who gain insurance through these changes. Healthcare system changes also remain a challenge in rural areas. The role of rural health clinics and other safety net providers is critical. Programs that support these primary care providers and link them to specialty providers and practice guidelines will be important in maintaining a medical home for rural children. Dr. Askvig's presentation was absolutely perfect for my next point which is the use of telemedicine provides exciting opportunities to bring previously unavailable care to rural areas. The technology is improving every day and

can make it feel as if all parties are in the room together. This offers tremendous promise to provide services for children in rural areas. And it addresses the probably most commonly reported access issue or barrier, which is transportation and availability of care. So hopefully some transportation issues can also be relieved when virtual care can come to the rural resident because transportation is a well-known barrier particularly for people with limited means. There is a renewed focus on home visiting in the healthcare reform bill and that offers promise as well to rural areas in terms of supporting demonstration projects for the types of support services needed for children with special healthcare needs. So I'll stop here and move on but I want to thank you all for the opportunity to highlight the work we do at the rural health and research centers and the work we're doing to try to make healthcare in rural areas better. And I will move on to the next person and turn it over to hear about the pilot project in Washington State.

VICTORIA FREEMAN: Hi, this is Amy Carlsen and I just want to say good afternoon or good morning. I'm calling from Seattle where it's still morning and very wet and dark. So I'm going to talk about community asset mapping in Washington State rural communities. Next slide, please. To just give you an idea of the increased prevalence of autism, 2009 Federal study indicated that one in 91 children will be diagnosed with autism. In our state, in September of 2008 the Washington State Department of Health, as well as the University of Washington LEND programs were awarded an autism implementation grant to help look at some of the needs for serving these children in our state. And through that grant we formed a combating autism advisory

council. One of the first needs that we identified and that we wanted to handle as a council was the long wait times and the bottlenecks that we have in our state in terms of getting assessment and diagnosis for children not only with autism, but also developmental delays. Currently the wait list for families to be seen in a diagnostic center in the State of Washington can be anywhere from two to eight months. As providers verified the current system wasn't working to help families get timely identification and diagnosis this community asset mapping pilot project was envisioned. This project is our approach that we have used in the State of Washington to include the system of healthcare for children with special needs, specifically in rural communities where it can be impossible to travel five or more hours to a diagnostic Center for an evaluation and where many of the recommended services that are -- that are talked about in the diagnostic evaluation don't even exist. So next slide, please.

This is kind of a busy slide but this is our tiers to diagnosis autism pyramid that we've developed as our template for our work in the pilot communities. If you're familiar with the kids toy WIDGETS we also use that. We take this template into the communities and facilitate discussions three to five hours in the communities about what is happening at each level and we have found that a lot is happening at the bottom two levels, the child development awareness and the general developmental screening that we can build upon to keep families closer to home. Next slide. So it serves as our framework in our communities. Next slide, please. The goals of this pilot, and we have been doing it -- we envisioned it about a year and a half ago, have been actively working at it for the last year and we have about another year left in our grant. So we want to make steps to autism diagnosis clear for families and providers within their

community. We want to reduce the long wait list and we also want to identify training and technical assistance that is needed in rural communities to improve this process. Next slide, please. So what have we done so far? We selected initially three pilot communities that met certain criteria and this criteria was based on diversity both geographically and ethnically, as well as could this community really commit to the process? Once we selected our three pilot sites, we had a community liaison who invited the key stakeholders from public schools, birth to three, parent to parent, pediatric medicine. E cap, Head Start to the table that was put on with technical assistance from the University of Washington LEND program and the Department of Health. And I serve two hats. I work with the University of Washington LEND program but I'm also a parent of a child with autism. And then through these discussions, each community identified next priority steps that they could link back to the combating autism advisory council for ongoing technical assistance. This shows the three pilot communities. As you know, the State of Washington is divided in half by the cascade mountains and so we look at our state as the east side and the west side and Seattle is here and that's where most of the -- that is where most of the diagnostic centers are. There is also one in Pierce County and there is one in Yakima and then there are some places scattered throughout the state that can see kids. But generally the bulk of it is in King County. Next slide, please. These are the other sites or counties, communities, that are doing -- using our pilot and using our materials to do things on their own and also getting support from the grant and from the technical support team. It's actually this project is just booming. We're very, very busy. So we mapped Walla Walla and Lewis county in February and island county in August and it was interesting

that while the communities were on -- next slide, please, summary of needs. While the communities are very different, their needs are very similar. And the one thing that they wanted was a roadmap for parents and providers. This roadmap would be something that would guide from the time that you identify that you have a concern about a child to getting a diagnosis. Some of the other needs were that there was a need to increase childcare provider awareness and knowledge of developmental red flags, often childcare providers are the first access to service or any service system that these families have. And other training the providers in how to talk to parents saying there is something wrong with your kid is not necessarily helpful. So we've done some training with childcare providers. The communities wanted to expand provider knowledge, skill and utilization of screening tools such as the M chat and others. Ultimately they want the diagnosis to occur within their community. So next slide, please. The lessons we've learned. And this -- I speak with two hats as a parent and also as a nurse and a provider and so the communities really like the pyramid. They think it's helpful. They -- it's been useful and we've used it a lot. As a parent, what I have learned with this program is that perception is not reality. And I live in King county and am thankful to have all the support that I have here and it was very sobering to me to see the lack of services and some of the support that we don't have out in the rural communities. And once you get into the communities and work with them you can really see that. The other thing that we've learned is that networking moves mountains. And literally we have moved mountains in our states. The communities are very hungry for the opportunity to have facilitated dialogues and they really appreciate the technical assistance that the council has provided. Next slide,

please. We've also learned that for communities to be successful in carrying out the next steps, that they need to have some sort of dedicated infrastructure in their communities, whether it's through the medical home, the children with special healthcare needs or through the FRCs. It's very important to include family members in the community discussions and to also -- and to help them to be able to participate in the discussions. And we learned that communities want to bring capacity in providing evidence-based intervention services and this is really the elephant in the room. Parents will drive anywhere to get a diagnosis but really getting the services in the community is really what is important ultimately and we hope that we are just touching the tip of the iceberg with this program and that we can -- eventually get services in communities that are rural. So right now the communities are developing their own roadmaps and they look very different from community to community. We have Walla Walla is very close to having their own diagnostic center and we've also had some -- I'm sorry, this is the next steps for communities slide. We also have directors from some of the diagnostic centers going out into the communities and doing talks and networking. It's been so exciting. So the benefits are that network -- I'm sorry, the next slide, which is benefits. The benefits are that the networking has moved mountains. We have connected local community medical providers to each other, to public health and to developmental pediatrics -- pediatricians at the diagnostic centers. We are bridging the educational system to the medical system both locally and statewide and they have really come up with a lot of creative ways to serve these children before they get a diagnosis, and like I said, the mountains are moving. Next slide. For outcome, projected outcome is hopefully that the building of this

infrastructure should increase the capacity to -- for children with developmental delays like autism to get appropriate early intervention and early identification in a coordinated, efficient and timely manner and the other outcome is that it will help this in-- this infrastructure will help families, schools, medical providers and community members to know how to access the services and resources for children with special needs in their community. So last slide. Why does it matter? Well, as a parent of a child with autism, it matters a lot to me because we have been the beneficiaries of so much support and services. And this is a picture of my son. He is 10 and has autism. I asked him if I could use this slide and his picture and he said sure, if it makes me famous. So hopefully he'll get famous. But I wanted to share a story in closing and why does it matter. One of Josh's strengths is that he is my personal GPS. He loves roadmaps, he loves maps, he loves -- he knows all the streets and he loves to wander around and figure out where things go. He rides a special ed. bus and ridden the same bus for years, taken the same route to school back and forth and he came home one day and he was very upset and I said what's the matter? And he said well, the bus took a different way home, but I wasn't afraid because I know the city. And this project is, as we work with communities and families, my hope is that while it's very overwhelming to have a child with a disability, to get a diagnosis, it's very overwhelming for families, but as we continue this project that we can say, that it doesn't have to be devastating. That we can say, don't worry, we know the city. So last slide. If you have any questions, you can contact both myself and Carol Miller, who is the person who is the autism implementation grant coordinator. Thank you so

much for your time and for the ability and the opportunity that I've had to share this exciting work and I'm going to turn this back over to Deidre.

>> Hello, everyone. Thank you for attending this event. Please don't forget to complete the evaluation directly following the webcast. Also, I just would like to take -- we're about to get into the question and answer period but I just would like to take a few minutes just to let you know that if you have any questions regarding funding opportunities or programs regarding children with special healthcare needs or the Office of Rural Health Policy programs, you can contact myself, Deidre Washington Jones at D Washington Jones at HRSA.gov for my colleague. JBRYAN@HRSA.gov.

DEIDRE WASHINGTON JONES: Okay. Now what we'll do is we'll start our question and answer period and some of you all have sent in questions. Please continue to do so. So the first question I have is, do you have -- this is for the presenter, I think this is for Brent, do you have GPS mapping on children with special needs to help with disaster planning and for interactions for EMS in your state?

BRENT ASKVIG: This is Brent. We currently do not. Our state emergency preparedness group has just begun a process of registration for adults with disabilities. It's a volunteer registration process. They focused on adults or adult families -- adults of family members who have disabilities related to their emergency planning. I don't believe they are doing anything with the GPS at this time. So we -- we're not doing that.

DEIDRE WASHINGTON JONES: Can any of the other presenters add anything to this question? Do you have it in your state, do you know? Okay. Well, let's move to the next question. This is also for Brent. Where is your state with health information exchange among healthcare systems and providers related to health information?

BRENT ASKVIG: That's a great question. We are just in the beginning stages of the health information exchange and I.T. technologies. Our state just received a grant from HRSA I think within this last year. The first year they've spent related to the planning, the connectivity. Looking at who does what in the healthcare system related to everything from electronic health records to exchange of information between their more centralized to their outreach rural clinics. That's being handled through our State Department of Health and our state I.T. department right now. Again, it's still basically in the planning stages. I do know that some provider organizations, some clinics and some hospital centers are doing some pieces with the electronic health records, electronic medical records and exchanges of information on that. But that's not a widespread cross system piece that's being used at this point. I would have to say as an entire state we're not there yet.

DEIDRE WASHINGTON JONES: Okay. Do any of the other speakers have anything to add to that question? You can go ahead now. Okay. The next question is -- I think this is for Brent. Is that toolkit related to early childhood diagnostic assessments available online for use by other states?

BRENT ASKVIG: We are -- we have just received permission from our project officer in HRSA to make one final minor change on I think a logo or a piece of information and that will be available. Let me give you the email for the gentleman who will be in the process of disseminating that. His name is Neil sharpy. His email address is neil.scharpe@MinotstateU.edu. I just got a note from him on Monday that he had received permission for dissemination and copying of that information. I don't know if it's -- I know it's not up and out electronically. He needed to make that last change but Neil would be able to get a copy of that to you either in print or electronic form.

DEIDRE WASHINGTON JONES: Okay. One more question. I think this one is for Brent. We do have some other questions but I think Brent this one may be the last one for you. We have to see. It says how do you address the issues of confidentiality between agencies relative to your electronic medical records? Do you have business associate agreements, memos of understanding? Is it the same for EMR?

BRENT ASKVIG: We're at the point right now where we're not exchanging electronic medical records. We're going through the traditional ways of consent to exchange information amongst agencies. We may send those files electronically in PDF form but it's on an agency by agency individual basis at this point. So, for example, if a family is considering going through our diagnostic clinic in autism, we'll ask for release of information on the traditional form and then send that -- sometimes electronically, sometimes through typical mail at this point, to the agency that holds those records. In some cases they're beginning to send those to us in PDF form which is a nice way of

handling and exchanging that information. There is always concern about, since its electronic where does it go and what is happening with it? Our folks have kept a pretty tight handle on this point through our traditional means of exchange of information within our team. But at this point it has not been any formal agency agreements. It's on a case by case, child by child basis.

VICTORIA FREEMAN: The next question we have is for Victoria and we may go over the 2:00 mark just to finish up with the question and answers. This one is for Victoria. What was the rural sample size from NDC--

>> Let's see, the rural sample size is 13,000. For the survey versus 25,000 for the non-rural. Now, this is a national survey so it's one of the reasons that our definition of rural is at the metropolitan versus non-metropolitan. For any given area if you get smaller you don't have enough people and there are confidentiality concerns. That represents a population of 1.8 million.

DEIDRE WASHINGTON JONES: Our next question is -- I think this can -- we'll start off with Amy but I think this can go to any of the presenters. I want to know about your thoughts about dental care delivery and how it can be improved with children for special healthcare needs in rural areas.

AMY CARLSEN: Wow. It's a hot topic. We at the University of Washington work with the dental school here to not only train the providers in what, you know, in working with children with special healthcare needs, but kind of giving them the parent perspective

also. And so I don't know. Our state is working on that. We have by no means accomplished it.

DEIDRE WASHINGTON JONES:

Okay. Are there any other thoughts? I think also this is directed towards maybe Victoria, too, or any of the presenters if you have thoughts about that, dental care.

VICTORIA FREEMAN: Dental access, Victoria. Dental care in rural areas as well as a lot of urban areas, is a real need and just for everyone. The more we can, I think, this is my personal opinion, the more we can do other types of programs through a pediatrician's office like sealants so we can take best advantage and use of our dentists and dental hygienists and dental providers in any way we can either through mobile clinics or, you know, this is one thing you can't do by telemedicine is provide direct services. It's a real challenge.

DEIDRE WASHINGTON JONES: Okay. And next question is for Victoria. What was -- we already answered that one. The rural sample size. Okay. I think those are all of our questions that the participants have submitted. If there are no other questions, we can take just a minute or two to see if anyone else has questions. If you have those, you can submit those now. Let's see. It doesn't look like anymore are coming in. With that I would like to thank each of our presenters. You have done a wonderful job. Hold on, there is one more question. I spoke too soon. Here it is. This one is for Brent. Have you published any formal studies on the diagnostic team for ASD?

VICTORIA FREEMAN: That's a great question. We have not. We're in the process of working with the University of Kansas who had received a Department of Defense grant to do comparisons of telehealth access and diagnostics versus face-to-face access. Their preliminary data suggests that there is no significant difference in the results or the outcomes of the diagnostic evaluation. We're in the process of trying to plan a study between the two states and increasing the population of the individuals within their studies. Again, it was just kind of a preliminary study on that. We don't have anything at this time. We're trying to gather anecdotal information as best we can. We're working with very small numbers. In two years we've probably done maybe 20 to 25 evaluations total and about 2/3 of them using any type of telehealth technology access. And so we're at the preliminary stages making sure that everything works. It does. And now we need to look at that impact. So the folks at the University of Kansas, I believe the name is Michael brawn, BRAUN, is working with a team there and that would probably be the best place to go for any preliminary information.

DEIDRE WASHINGTON JONES: We do have one last question that I'll answer and that is can you provide your email addresses again. Each presenter I think put their email addresses on the slide presentation and the slide presentation will be archived and available probably in I think about a week or so it should be ready. Upload it, mchcom.com so you can find the names and email addresses there. Also regarding if you're interested again in funding opportunities for children with special healthcare

needs or funding opportunities and about the different programs in children with special healthcare needs or the Office of Rural Health Policy contact myself, Deidre Washington DWashingtonJones@HRSA.gov. Or my colleague Julia Bryan. JBRYAN@HRSA.gov. So those are our email addresses. And now we are ending. I would really like to thank our presenters. They gave us some excellent information and some excellent examples. You heard today here about some of the unique issues of children with special healthcare needs in rural communities related to the technology issue, also you've heard about research and then finally you heard about state systems and how Washington as a state is approaching changing the state system and infrastructure in their state. We hope you have enjoyed this webinar. Thank you so much.