

MCHB/DRTE Webcast

Combating Autism Act Initiative (CAAI)

January 14, 2009

MADHAVI REDDY: Okay. Hi, and welcome to this mchcom.com webcast. This webcast is conducted by the Maternal and Child Health Bureau at the health resources and services administration. Supported by the Center for Advancement of Distance Education at the University of Illinois at Chicago.

This webcast today, we're going to be talking about the HRSA/MCHB initiative under the Combating Autism Act and the programs that are funded at MCHB through funding through the act. Also we'll have representatives from CDC to talk about the campaign later in the broadcast.

Just wanting to make sure that participants on this webcast know that the webcast will take place entirely through the Internet. You should be connected through mchcom.com.

If you have questions for the speakers as the presentations are ongoing, please use the feature on the web interface to type in your questions and label them questions for speaker and as we go through the webcast I'll be asking questions of the presenters. Also, if you have technical support questions that need to be addressed while you're viewing the webcast, please use the same web interface to type in your technical support question and the folks at CADE will answer your technical support questions so you can have a better view of the webcast.

At this time I will introduce the purpose of the webcast. As I mentioned, that this webcast we'll be talking about MCHB efforts, through the Combating Autism Act of 2006. There are representatives from the leadership education and neural developmental and other disabilities program. The developmental behavioral pediatric program. The Combating Autism Act research network, physical health and behavioral health and the state demonstration grant programs will be discussed during this webcast. Before we get into an in-depth discussion on the various programs that are supported under the Combating Autism Act we'll have an overview of the act from Laura Kavanaugh, a branch of the MCH Training Program here at MCHB. In addition, we'll also receive a presentation from representatives from the CDC about the campaign. It's to teach parents what the normal developmental milestones for their children are and when they should be occurring. By learning the signs, the program hopes that parents will be much better equipped to identify a problem such as autism spectrum disorders.

So at this point I will introduce the presenters for this webcast. As I said before my name is Madhavi Reddy. I'm the moderator and a project officer for the LEND MHC training program and I'll be doing the LEND presentation later in the webcast. I'm also joined by Miss Laura Kavanaugh, the Training Branch chief. She also spearheads, the internal autism workgroup community that we have here at MCHB to coordinate activities under the Combating Autism Act. She'll be giving you an overview of the Combating Autism Act and the initiatives that are supported here at HRSA. And briefly mention some of our coordinating activities with CDC. Following Laura, we'll have a presentations by Robyn and Hae Young. They'll be followed by Deidre Washington, the project officer for the state demonstration model grant and she'll give a presentation about that grant program, as well as discuss the evaluation, the national evaluation of the HRSA activities under the Combating Autism Act. Following Deidre we'll have a

presentation by Nanette Callahan. We have a lot of speakers today. Following Nanette I'll give a presentation on the LEND program and we'll finally have a presentation by Dr. Georgina Peacock and Katie Kilker Green. Following the research network presentations I will ask questions for Robyn and Hae Young. So if you have questions for the research presenters, please type in your questions during their presentation so that I can ask them questions immediately following their presentation. For the other presenters, I'll be taking questions for all of their presentations at the end of the webcast where we'll have about 15 to 20 minutes for a question and answer session. Without further adieu, I think at this time I will turn the webcast over to Laura Kavanaugh to give us an overview of the Combating Autism Act.

LAURA KAVANAUGH: Good afternoon. And good morning for some of you. It's a pleasure to be with you. I'm Laura Kavanaugh. I'm chief of the Training Branch at the Maternal and Child Health Bureau. Today I'll provide a brief overview of the Combating Autism Act itself to give you background about the legislation that started this whole initiative for us here at the Maternal and Child Health Bureau. It was enacted -- next slide, please. It was enacted as public law 109-416 in December of 2006 and it amends the existing Public Health Service Act to combat autism to research, screening, intervention and education.

Next slide, please. It funds activities in the national institutes of health and the Centers for Disease Control and prevention. You'll hear of those efforts by Dr. Peacock and Katie Kilker Green this afternoon. The area I'll emphasize is the activities that went to the health resources and services administration through the Maternal and Child Health Health Bureau is where it's administered. HRSA has a \$37 million effort. \$20 million of that was actually funded previously through the leadership education and

neurodevelopmental pediatrics program and a new \$17 million came to fund other activities and also the state demonstration grants. I'll talk about those more.

Next slide, please. I also wanted to talk about federally this legislation also reestablished a federal interagency autism coordinating committee. This is a federal committee that is headed by the national institutes of mental health but it includes agencies like HRSA, the Centers for Disease Control and Prevention, several of the national institutes at NIH, as well as Department of education and others. Many federal agencies that address the very complex issues around autism and autism spectrum disorder.

Next slide, please. The goal of the Combating Autism Act Initiative or CAAI as we refer to it at the bureau is to enable all children, infants at risk for developing autism spectrum disorders and other disabilities to reach their full potential. How to achieve the goal?

Next slide, please. We're going to be looking at screening children for early detection for possible ASD and other developmental disabilities and conducting early and interdisciplinary evaluations to either confirm or rule out that diagnosis. If a diagnosis is confirmed provide evidence-based early intervention.

Next slide, please. So we're going to increase awareness, hopefully we'll also be reducing barriers to the screening and diagnosis, we're supporting research through the two research networks that you'll hear a lot more about later on, they also will be active in promoting evidence-based guidelines development and then training professionals to use these valid screening tools to diagnose and provide evidence-based intervention. All of this within a system of care for children with special health needs that the Maternal

and Child Health Bureau has been supporting for many years. These are all pieces of a puzzle.

The next slide, please. So the CAAI within the Maternal and Child Health Bureau is centered around four areas, first training programs, these include 18 expansion of existing LEND programs and then we funded four new leadership education and neurodevelopmental disabilities. Interdisciplinary training grants that we'll talk about in greater detail and expansions to some of the developmental behavioral pediatric training program and an interdisciplinary Resource Center to coordinate the efforts with our other training investments as well.

Next slide, please. So the training aspect of this focuses on an interdisciplinary workforce. Many different health professionals trained together in an interdisciplinary nation. Not only are we providing graduate level training to the health professionals they're responsible for providing continuing education and technical assistance to other providers. That's another piece of sharing these evidence-based practices into the training curriculum very early. Also many of our training programs provide residency training and train many other health professionals in their field. All of this toward continuing to build toward a system of care for children with ASD and other developmental disabilities.

Next slide, please. The second part of it combating the initiative for the bureau is two research networks. One is focused on physical health and the investigators at Boston general but there are nodes throughout the country. Then there is also behavioral health network centered at the University of California at Los Angeles.

Next slide, please. The purpose of these networks is first to establish a network to establish this capacity for conducting the research but utilizing the networks to conduct their own research over time.

Next slide, please. So they'll look at evidence-based practices. They'll look at guidelines, development and the dissemination of those guidelines and also they'll disseminate this information very broadly over time.

Next slide, please. The third aspect of this CAAI initiative here is the state demonstration grant. We funded six states to look at developing state autism plans to improve systems of care for children with ASD and other developmental disabilities. We also have funded a state coordinating center, again to integrate the efforts between these only six states that we're funding currently with other states as well because there is so much activity going on currently within autism spectrum disorders and other developmental disabilities within the country.

Next slide, please. The fourth aspect of the CAAI is the national evaluation. We'll be evaluating the effect of implementation of these grants and also this will provide the data that will be used in the report to Congress at the end of this initiative as well. It is required in the act that we provide data in this report to Congress. One thing I'm particularly happy about with the Combating Autism Act is the coordination efforts that we've had. As I mentioned before, the federal agency level we're on the interagency autism coordinating committee. Dr. van Dyck at the bureau represents HRSA on that committee. We've had terrifically good partnership internally and with the Centers for Disease Control and Prevention.

Next slide, please. So with CDC and Georgina will be talking about some of these activities, we're jointly sponsoring the summit started by CDC and we're now helping to support some of these regional summits throughout the country. We hope to be conducting some joint site visits between some states have both HRSA and CDC-funded grants and we'd like to conduct some joint site visits and we've also used the HRSA infrastructure, many of you who are from states might have already participated on a regional call where we've introduced the learns the signs act early information from CDC in those calls.

Next slide, please. Also we're collaborating around some of our health professions education efforts, the evaluation components, the two evaluations for the two efforts are being coordinated as well and we've -- some of the early efforts a CDC staff member has gotten activities. It shows you a map that looks at some of the efforts that are underway both by CDC and HRSA.

Next slide. Thank you. This includes a lot of the activities that Georgina will be describing later on in the broadcast today.

Next slide, please. In addition to the team efforts within -- the collaborative efforts with CDC we have a terrific autism team within the bureau. We develop guidances together. Contributed to the development of the national evaluation. We have a standing autism committee. We've already conducted some joint site visits and linking project officers with the state demonstration grants with some of the other efforts here within the bureau as well.

Next slide, please. This is an organization chart of HRSA, which is just terrible and ridiculously busy. I wanted to just make a note we're also collaborating with other efforts within HRSA as well.

Next slide, please. So within our bureau, which is in HRSA, the efforts that are underway that you'll be hearing about today include efforts within the Division of Services for children with special health needs. That includes the state demonstration grants. Also efforts within the Division of State and Community Health through the public health coordinating center is in that division. Within the Division of research, training and education are the two research networks, the leadership education and neurodevelopmental disabilities and developmental and behavioral pediatrics program in that division.

Next slide, please. This is the complete autism team within the Maternal and Child Health Bureau from Dr. van Dyck, who is the head of the Maternal and Child Health Bureau to all the individual staff members within different divisions. It also includes our evaluation officer and others who might not be directly -- project officer for a grant but are contributing to this effort.

Next slide, please. You're going to be hearing from many of the folks that are outlined in these subsequent slides.

Next slide, please. This is the Division of research training and education. Dr. Stella heads the research efforts and I'm the Training Branch chief and you'll be hearing today from Nanette pepper Callahan, Madhavi Reddy, and Hae Young Park from this division. Another division that's part of this effort is the Division of Services for children with

special health needs. Bonnie Strickland is the division director and you'll be hearing today from Deidre Washington Division of State and Community Health houses the MCH Block Grant but also the state public health coordinating Center for the Combating Autism Act Initiative. They're one of the two Resource Centers that I mentioned earlier.

Next slide, please. Then we'll skip actually to the next one. That's just a little -- we do have an autism website that is now up and available to you. The URL is here on this web -- slide in case you cannot read it. It's www.msch.hrsa.gov. You can find links to some of the CDC activities and the interagency committee which has a national strategic plan that I hope they're finalizing today. They're meeting today to try to finalize it and other activities we'll post them there as we receive that information. If you'd like to contact me after this presentation I'd be happy to take your -- take any questions that we're not able to answer today during this webcast. This is my contact information. Thank you very much. Now I'm very happy to turn it over to Robyn who will talk about the first of the two research networks.

>> Hi, again my name is Robyn, I work with the LEND program but I'll talk about one of my other areas of focus, one of the research networks. So under the Combating Autism Act MCHB has funded two research networks, the first we call the autism intervention resource and the other is the autism, AIR-P. Hae Young will talk about that.

Next slide, please. The purpose of the networks, Laura touched upon these but basically they're to establish a research platform from which to conduct research on evidence-based interventions. And the broader goal, of course, is to improve the lives of children and adolescents with ought advertise particular spectrum disorder and other developmental disabilities.

Next slide, please. The specific goals of the AIR-B are really to conduct research on practices to improve the behavioral, mental, social and health and well-being of those with ASD. And also to develop evidence-based guidelines and validate tools for interventions. And, of course, more overarching goal is to disseminate information on the research findings, the guidelines that we develop, the tools that are validated and that really is to reach professionals, parents, the public, federal agencies, anyone, individuals impacted by ASD and their families and developmental and others with developmental disabilities really to spread the word on the research we're finding and the tools and to really disseminate what we're learning here.

Next slide, please. So the sites involved in the AIR-B are UCLA. Los Angeles is the primary recipient of the grant. They're also a research site. Then there are several collaborating research entities, four others, Florida state university, Kennedy institute. University of Michigan and University of Washington And UCLA has partnered with the RAND Corporation for help with the guideline development that I'll talk more about in a bit. And that is the southern California evidence-based practice center or EPS center.

Next slide, please. So just to give you an idea of some of the research that will be going on in the AIR-B, I have -- I will outline the two concepts that have kind of gone far along in the pipeline and there will be others coming down the road. The first is a caregiver mediated joint engagement intervention. The objective of that is to study and test the efficacy of a caregiver training model of joint attention, joint engagement. We hope to determine if improvements can be made in the speech and language abilities of children with severe impairments in communication using this particular approach.

Next slide, please. So the target population for this caregiver mediated joint engagement intervention are pre-school children ages 2-5 diagnosed with ASD and we hope to enroll 200 preschool children over the 2 1/2 years we have left and that would be about 40 children per site including UCLA and the four other collaborating research entities. The inclusion criteria for the study, the child has to meet the diagnostic criteria for autism and have fewer than ten spoken words functionally and the caregiver oftentimes the parent, it can be a caregiver, is available for the intervention. The child has to be between the ages of 2-5 as I mentioned. And the child has to come from an underserved or underrepresented population. That will vary across the different collaborating research entities. We're still fleshing that out as to what it means in different parts of the country at different sites.

Next slide, please. So again this caregiver mediated joint engagement intervention. What is it? Well, the children will be randomized to either a joint attention, joint engagement intervention which is mediated through the caregiver and a therapist, or just given a caregiver education intervention, which is really information about autism and different techniques. Information received. In the intervention the children will be seen in the home once a week for one hour of one-to-one intervention for 12 sessions. And they will have a trained interventionist with them and use a manualized treatment. The intervention will be conducted across three routines in the home. Chores, caregiving and play.

Next slide, please. That was sort of an overview of the first study which we hope to have started in approximately in March after IRB approval and other pilots have been conducted. The second concept that is in the works for the AIR-B is social skills intervention for school-age children with ASD. The objective of that study is to test the

effectiveness of two social skills interventions and to see how they impact child social interaction. One is experimental and one is more common practice, you would say. We want to determine the generalization of targeted social behaviors to children's peer interactions at school. We're hoping the skills that are learned are generalized to their daily lives.

Next slide, please. So the target population for this particular social skills study are elementary school-aged children 5 to 7 years old. And again, we hope to enroll over the 2 1/2 years 200 school-age children. Roughly 40 per site of the five sites and the inclusion criteria for this study is that children have to be high functioning ASD and have to be fully included in schools. In other words, they have to be in a regular classroom with peers, with non-disabled peers and they have to have an IQ greater than 70 and they have to be verbal to participate.

Next slide, please. So what is the intervention for this? Well, children will be randomized and assigned to either an off campus social skills group that follows a typical social skills curriculum. That's the general practice and what you often see with kids with high functioning ASD they go to off campus social skills groups or a peer mediated intervention conducted at the child's school with other children from his or her classroom. In other words, the intervention would be with the children with high functioning ASD in conjunction with their typical non-disabled classmates. So each intervention will be conducted for eight sessions one time per week.

Next slide, please. Again, the hope is that that study would also hopefully begin in March. There are some other ideas that we're mulling around, that the group is mulling about. Some pilot research studies being considered that have not been fleshed out yet.

One is a peer mentoring model for adolescents in high school. Another is a psycho pharmacology trial and another is developing some training modules for distance families and professionals both for treatment and dissemination purposes. Next slide, please. So some other activities of the AIR-B. You've heard us touch about guideline development and again the RAND Corporation has begun identifying experts to begin the iterative process for getting guidelines for parents and professionals. Tool development. AIR-B is responsible for tools and measures currently in the pilot stages in conjunction with research protocols. One tool, for instance, is a quick rating measure of engagement between the parent and child in the home across the various home routines. That goes nicely in conjunction with that first study that I mentioned with the pre-school children, working on joint engagement and joint attention. There is a tool that's being piloted there. Lastly, the AIR-B is responsible, a large part of their funds need to go to dissemination, getting the word out, as I mentioned, to the public, to professionals, to parents, to those with ASD and so one activity, a major activity that UCLA as the primary grantee has decided to pursue is to develop an autism -- it will developed to share tools, research findings and other relevant information on ASD. That's an overview of the AIR-B, the purpose, the activities, the two studies that are close to being underway and the other ideas that we have coming down the pike. So with that, I would like to turn it over to my colleague, Hae Young Park, project officer for the AIR-P network.

>> Hello, my name is Hae Young Park, I'm the MCH project officer for the second autism research network, the Autism Intervention Research network on physical health. AIR-P. As you can see the AIR-P, the purpose of the AIR-P is quite similar or pretty much identical to the AIR-B network to establish a research network to conduct

research on evidence-based intervention and more overall to improve the lives of children and adolescents with ASD and other disabilities.

Next slide, please. The goals also are very similar to the AIR-B network. The main goal being primarily to conduct research on evidence-based practices to improve the physical health and well-being of the adolescents with ASD and other developmental disabilities and develop evidence-based guidelines and develop tools for intervention. For the AIR-P network it has been determined they'll begin with some consensus-based guidelines to initiate this part of their project and then as more evidence is being developed in the field they'll be able to transition to development of evidence-based guidelines. The third goal of the AIR-P network is to disseminate the information on their research findings, develop guidelines and validate to the larger community, the health professionals, public and families that are impacted by ASD and other developmental disorders.

Next slide, please. There are many components to the AIR-P network. The primary cooperative agreement was awarded to the Massachusetts general hospital MGH which is located in Boston, Massachusetts. MGH has subcontracts with 15 collaborative research entities that will be involved in the conduct of all of the activities of the network. Of the 15 sites, seven of these will be involved in the actual conduct of protocol research and these sites are Arkansas, Cincinnati, Colorado, Pittsburgh, Rochester, Toronto, and Vanderbilt. These seven sites of the 15 collaborating research entities will be involved in the actual conduct of the research studies of the ASD network.

Next slide, please. In addition to the actual conduct of the research studies, the overall, the entire group, the 15 collaborating research entities will be involved in the other

activities, including guideline development and dissemination efforts. And these are -- this provides a list of all of the different sites. Just a brief background about these sites, these 15 sites are part of an existing research network that was established by the organization called autism speaks. They are referred to as the autism treatment network or ATN. So they are up and running network of sites that are involved in autism research and they are part of the AIR-P network.

Next slide, please. In addition to the conduct of the research, there are also other players in the AIR-P network. The national initiative for children's healthcare quality, also located in Boston, will provide the support and primarily head up the efforts for the development of guidelines and evidence-based guidelines. Autism speaks is also a subcontract organization of the autism speaks will primarily be providing program it I can support and the Ennis corporation located in Maryland will be the coordinating center that will pull all the research data from the research studies conducted by the AIR-P network.

Next slide, please. There were two research concept proposals included in the original application for the AIR-P network. I wanted to give you an idea of the interest of this network and what they identified as a lead for research in the field. The first concept that was included is to evaluate the efficacy of a brief versus extended sleep education program with parents of children for ASD for improving sleep and behavioral outcomes. The lead site in implementing this study is Vanderbilt University and they'll work with the other six sites to ensure that this study is conducted.

Next slide, please. The second concept research concept is to evaluate the nutritional intake and diet patterns of children and adolescents with ASD and develop evaluation

tools and guidelines to practitioners that can be disseminated to the community of the University of Rochester Medical Center will take on the lead for this research study. Currently these two proposals are pretty much in final format. Before they're to be reviewed internally by the AIR-P scientific review committee, it's my understanding that the scientific review committee will receive the proposal shortly and then it is planned that in February, next month sometime, there will be a meeting in order to discuss the proposals and to review and rate the proposals for consideration and ultimate conduct the research conduct by the AIR-P network. Also they expect that after this process these two proposals will be initiated in March of this year.

Next slide, please. Other possible studies for the AIR-P network that they're considering include the following. Etiology and treatment of chronic diarrhea with ASD. And hormonal regulation in adolescent girls. It's expected that either through funding support through the AIR-P network or through the Combating Autism Act. Funds that support the AIR-P network or these projects will hopefully leverage additional sources of support when they are ready to be implemented.

Next slide, please. This last slide we wanted to give you some contact information for the research program. Dr. Stella is the chief of the research and demonstration grant and she oversees both networks, AIR-B and AIR-P, you heard from Robyn, the project officer for the AIR-B network and my contact information is also included. Thank you. I'm going to turn it back over to Madhavi Reddy.

MADHAVI REDDY: Thank you. Hae Young. At this time I will I think take a few questions or ask a few questions of Hae Young and Robyn. We've received a couple of questions. Before I get to those I wanted to remind you that if you do have a question

for any of our speakers, please type those questions into your block at the right-hand corner of your page and label it question for speaker so when I ask the questions, I will know that you are directing a question towards one of the speakers. Just wanted to mention that during the webcast you may notice that approximately five of the web slides have some problems or issues with them. If you would like to download a clean copy of the slides, please go to mchcom.com, click on links for this webcast and click on download slides and you'll be able to print out a clean copy of the slides because as I mentioned, about five of the slides that you'll see today have problems with them. Hopefully they will be corrected for the archive which will be posted in about a week's time at mchcom.com. So at that time you'll be able to see with the webcast archive and download the slides. Let me ask a couple questions we've gotten so far. I believe this question may be for Robyn. The participant is asking--

>> In my limited understanding of technology, the interactive web-based site to share tools, research findings and other relevant information on ASD. Beyond that I can't really explain more than that. They did give us a demonstration of a similar one they had for another scientific grant that they have when we visited UCLA. It was very impressive but it hasn't been developed yet so it's hard for me to give the specifics other than to say it's an interactive sharing mechanism for dissemination, for interaction, for research findings and so forth.

>> This question is also for Robyn. The question is -- is Dr. -- from the University of Wisconsin involved in any way.

>> He's not familiar to me but that doesn't mean he's not involved in some capacity. We'd have to check on that.

>> I think this question also might be for Robyn I'm but not quite sure. It could be for both Hae Young and Robyn. The question is, it's one thing for people, who do not speak, though Jamie has been working from speech but communicate by typing independently. Your requirement for speech may be leaving out children who should be included. I site these two people because they've been -- [inaudible]

>> We'd be happy to share that.

>> We can share that. I think if they're talking about the research study, the concept number one possibly in the AIR-B, the purpose is really to develop speech. That's really the whole outcome. So I think we just have to think about this further with your comments and we'll take them back to the network but --

>> I have one more question for Robyn, are there plans to research social skills of so-called low functioning school-age children? Is all the research going to be at the university?

>> Right now that's not in the pipeline of discussion for the AIR-B. We can certainly bring that up as a point of interest that the group has raised. You know, there are limited opportunities for the research because we expect a large sample size and the group has to have the expertise in the area that is being researched. So as of now there are not plans for that particular research as part of the AIR-B.

>> What was the second part?

>> The second part and is all this research -- [inaudible].

>> All the universities, they are all universities in the AIR-B but all very community-based universities that have a very strong community connection, work in the community, clinics in the community, reach out to the community. They are doing a lot of amazing things within each of the communities. For instance, in Florida there is a very rural population so they do a lot of home visits and a lot of things that really reach out to different populations. UCLA is more of an inner city population and they have different strategies and so I think it's very community-based research, actually, just led by these research teams at the various universities.

>> I have another question. When the research is completed, how will the recommended treatments be funded when insurance companies are limited, Medicaid is limited, and most families with a child with ASD do not live near the research?

>> That's a very broad question that I don't think can be, unfortunately, answered on this call.

>> I think that's part of the reason why as part of this initiative we try to link the training programs and research so that the research is not being conducted in isolation. The financing issues, the reimbursement issues, all of these complex issues will not be resolved solely through the Combating Autism Act Initiative certainly. You'll hear as we talk about the state demonstration grants and the other collaborative activities underway, one of the activities that I mentioned earlier is our collaborative activity with the Centers for Disease Control and Prevention is looking at regional summits. Regionally within a state how can you look at collaboration between payors, part B, other folks within the education community, as well as health to

address these issues. ASD is such a complex issue in terms of the different types of folks who are on the spectrum as well as trying to come up with reimbursement mechanisms. We're trying to address those issues. I don't think individually the research networks are going to be able to solve the financing issues that come along with the guidelines that will come out of the research network. A terrific and a terribly important question.

>> I want to mention again for folks who are having trouble viewing their slides or reviewing the slides on the webcast, like I mentioned we were having difficulty with about five of the slides, presentations about slides are available at mchcom.com. If you go do that website and click to this webcast, click on the link to the webcast and navigate to download slides for this webcast link you should be able to download a clean copy of the slides for this webcast if you're having trouble viewing them on the webcast. I believe we have another question. Will there be a charge to families whose children take advantage of this?

>> Will there be a charge? I don't know.

>> In our study as far as I know it's -- families will often get reimbursed and given an incentive to participate in some cases. So no, not as far as I know. They are given this service as part of the study and oftentimes will receive some sort of compensation or incentive for being part of the study but it varies.

>> It's true for the AIR-P as well there would be no cost.

>> I have a couple more questions from -- this question, I notice that you frequently include references to children with other DBs in addition to children with ASD. Could you clarify the relationship between these different populations?

>> I can take that. The legislation for the Combating Autism Act talks about children with autism spectrum disorders but children with other developmental disabilities. What we're interested in is looking at a system of services for children with special healthcare needs much more broadly. What happens when you screen a child for ASD and it turns out they have another developmental disability but not autism. They won't be left out of this system of care. That's why we're talking about this much more broadly, even though it's funded under the initiative called the Combating Autism Act Initiative. We don't want to set up a whole separate system of services only for children with autism spectrum disorder.

>> I think this is a comment from a previous answer to a question that Laura may have given. The participant says given the number of children with IQs less than 70 they really should not be left out.

>> I think it's one of the criteria of the study.

>> That's just one particular study and that was just criteria for that particular study. I don't think the intention is to leave out children in any, you know, any functioning level. That's just the criteria. Every study has to have inclusion criteria so you have a commonality across the target population. That's the particular group that was selected for that particular study.

>> I just want to clarify, too, as you're hearing us describe today these initiatives you're hearing very preliminary work because all of these activities were funded September 1st of 2007. This is a brand-new -- excuse me, 2008, I apologize. September of 2008. I'm skipping a year. So they are just underway just several months ago so it's important to us to share with you very early on in this process what the thinking was behind these initiatives. I think particularly with the research networks you'll hear about a lot more activity that is going to be coming out of these networks over time. These are just the early formulations of the early study and we appreciate your feedback in helping us to inform these studies as they're under development. Thank you.

>> Thank you, Laura. Another question says I'm particularly interested in one of the collaborative universities, University of Michigan. Maybe it's -- Robyn, is it one of your--

>> No, it's not.

>> It's maybe the -- maybe if she wants to get in touch with Robyn to ask more questions about the participation about the University of Michigan in the behavioral health research network, please feel free to contact her at the email address she's provided or her phone number. Okay. Let's see if we have -- we have another question. How will your studies control for other services children may be receiving such as early intervention or special education?

>> Well, the -- that hasn't been fleshed out yet. That will be a factor. A lot of these children, though, are as we said underserved and underrepresented children that are not in any intervention currently. So that will be control for us if we find that children are receiving other services. As I said, what we have so far is a research template for each

of these concepts that, you know, goes as far as to discuss the purpose of the study, the type of -- the targeted population, but there are a lot of factors that still have yet to be worked out, which is why it's still in the pilot phase and has yet to be implemented. But these are very -- these researchers are all very aware of the compounding factors that can be present and we'll certainly control for those. I'll bring it to their attention to make sure that was not overlooked. Thank you.

>> Thank you. Next question, how will the research networks share their information with this project?

>> Those states working on state plans have access to information so they can include their research and guidelines in a timely manner to include this if needed in state plans.

>> That is a very good question and our hope is that since we are autism team at the Maternal and Child Health Health Bureau. As guidelines and information come out from the research networks we'll be working together and I'll be getting those from the research networks project officers and feeding those into the states.

>> Plus we have our annual program meetings where we get all of the participants together. We just hosted that in December in Washington, D.C. here, actually in Bethesda, Maryland and where all the parties are involved and it's sort of an ongoing collaboration, I would say. It's a big part of the charge of the group here in MCHB.

>> We're absolutely committed to making that happen. With any entity we're funding. The research network or state demonstration grants it's our job to make sure anything we're finding in any of those areas are shared with all the others. What we're learning in

the state demonstration grants is informing what we're doing in training and the research networks as well as what we're learning in the research networks going out to the other two parties. It's vitally important to us.

>> I think this one question, Robyn may have already addressed. This is asking whether the University of Michigan, the behavioral health network, whether or not they'll be cost or if they'll be charging for children's participation in the research project.

>> Again, as far as I know there is no cost to the services and oftentimes there are incentives. I'd have to look. It hasn't been fleshed out that far within each site who is going to be involved and the recruitment. A lot of these things are really in the infancy stages so we'd have to -- please contact me and we'll get you in touch with the appropriate people at the University of Michigan to find out. Be great if we had more pipeline of children to enroll in the study and we're always looking for collaboration.

>> I think this question is for Deidre. Will the information also be available for states who have not received funding as well?

>> Yes, and as I think Laura talked about in her overview presentation, we do have AMCHP, our state policy coordinating center and they have in addition to providing technical assistance to the states and information to the states that are participating in this initiative they also have a broader mission to make sure that the information that comes out of the states gets distributed to the broader public health.

>> Okay. Since we're kind of running a little late on time here I'm going to just take one more question for Robyn and Hae Young and if we get anymore questions about the

research network, I will hold them and forward them to Hae Young and Robyn after the webcast and ask them to get in touch with you via email. So I'm going to take one more question. How much is this information being communicated to national healthcare provider organizations such as the American Academy of pediatrics?

>> It's our hope that the information will be disseminated broadly. I think the goal really about collaborating with different organizations primarily for the AIR-P in terms of evidence-based guidelines it is a partnership that needs to be established and I think that would be something that the AIR-P will be working in order to ensure some collaboration with national organizations.

>> Thank you, Robyn and Hae Young for staying and taking questions and we have many questions. If I -- as I mentioned if I receive any more questions I'll direct them towards Robyn and Hae Young. Or if you haven't asked a question already and you'd like to ask them, please feel free to email Robyn and Hae Young. Now I will turn the webcast over to Deidre Washington who will give us a presentation on state model grant program and also she'll talk about the national evaluation. Thank you.

DEIDRE WASHINGTON: Good afternoon, I'm Lieutenant Deidre Washington and I'll be talking with you this afternoon about the state implementation grants for improving services for children with autism spectrum disorder and other developmental disabilities.

Next slide, please. The purpose of this program is to improve access to comprehensive coordinated healthcare and related services for children and youth with ASD and other developmental disabilities. When we put out the guidance for this program, we asked the organizations to implement and improve or expand existing state plans and also to

improve the system of services for children with youth who had ASD and other developmental disabilities and that's the piece that is key to this particular program and it's a bit different from the training programs as well as the research program is that we really are looking at the states to improve the system of care.

Next slide, please. In thinking about the system of care and how you improve that, we asked grantees to address what we think of at MCHB ASCII components to system of care improvement. These components are partnerships between professionals and families of children with youth -- children and youth with ASD, access to a culturally competent family-centered medical home which coordinates care with pediatric subspecialties and community based services. Access to adequate health insurance and financing of services, early and continuous screening of ASD and other developmental disabilities. Community -- addressing community services and making sure they're organized and easy to use for families. And finally, the transition to adulthood. We've had -- we've seen in the United States such a surge of children and adolescents that are diagnosed with ASD and now you know we have to realize these youth grow up. So now what happens? How do we facilitate that process and the transition to adulthood?

Next slide, please. Before I get into talking sort of specifically about the states I would like to emphasize another key component, and that is the partnership building. With the states, this is so important. We ask the states to really, as they're building their partnerships, to really expand and to leverage resources. The states and agencies participating in this particular program, we have six. Alaska Department of Health and social services, the University of Missouri at Columbia, the Thompson center. The Wisconsin Department of Health and family services, the Washington Department of

Health, the Utah Department of Health and the hope school in Illinois. The funding for this particular program, each organization has received about \$300,000 per year and the total project period is three years starting, as Laura just indicated, September 2008 through September 2011.

Next slide, please. Now the next several -- with the next several slides what I'm going to do is highlight for you some of the activities that the states are engaged in. Starting with Alaska. Alaska has what I think of as a sort of really unique piece of their project. It's what they're calling the rapid responder team working in rural areas to complete in-home assessments of young children suspected of having ASD or other developmental disabilities. As you know, in Alaska it's very rural, it's very expansive and also very frontier. So having that ability for in-home assessments is important to them and a unique part of their project. Next, multidisciplinary training provided to increase capacity of identifying ASD to a variety of professionals both physical and mental, in the physical and mental health fields. This is the trainers will be both on-site and through distance education. You'll see as we move on training of providers is one of the key pieces in all of the state's programs. Finally professional and public outreach campaigns.

Next slide, please. The University of Missouri Thompson center. They have family specialists that are participating in the development of plans for youth transition to adulthood and providing information to families on transition skills. Here is that -- one of the components I talked about before. What do we do and how do we address the issue of the youth, the children and youth that are now growing up? This is the transition piece. Families and professionals implementing a family resource services program at the Missouri autism centers for excellence and these are -- the Missouri autism centers for excellent are centers. They're having them implement the center on-site. I think it's

something that's very needed. Training initiatives focused on developing parent and youth leadership skills. In Missouri they also have a cadre of regional specialists in the state. These regional specialists will be helping to facilitate their program once again training of providers, you saw this with Alaska, and finally resources and training for families on short and long-term financial planning. This is something that is unique with Missouri. And because we know when you have children with ASD and other developmental disabilities depending upon the insurance and even with insurance it can be very costly to parents and to their families.

Next slide. The Wisconsin Department of Health and family services, some of the highlights of things that they're doing include the formation of a state-wide community of practice on ASD. What this community of practice is -- let me take a step back for a minute. Wisconsin just like other states several other states, is fortunate enough to have several different autism initiatives going on in the state. However, they were really needing to work on a method or a strategy for bringing sort of all of these initiatives together and making sure the organizations that were participating in these different initiatives were aware of everything that was going on in the state. And so really this community of practice is a mechanism for doing that. You will have various organizations involved that are engaging in autism spectrum disorder activities and they will be actually working in separate practice groups to tackle specific issues in Missouri. -- I'm sorry, in Wisconsin, okay? Also, in Wisconsin they have the developmental regional centers, the regional component you heard me talk about before as a strategy for implementing programs like this in the state. Also an outreach campaign. Training the family practice and pediatric providers, community, parent and youth training. You've heard before this -- you'll hear some of this stuff over again as some of the states are engaging in common activities. Resident training. This is something that is

unique in Wisconsin that they are providing training to their residents around medical home concepts. And electronic repository of ASD information and resources and a medical home implementation program in which they're trying to strengthen local and regional partnerships and also identify gaps in sort of their current resources around the medical home.

Next slide. Washington Department of Health. Some of the highlights with what they're doing is they're convening an autism advisory council. They have a medical home leadership network. The medical home leadership network training summit which will be including youth discussions. They do plan to have youth involved in this and what this medical home leadership network is, it's 21 medical sort of home teams across the state which includes primary care physicians, nurses and families where they're working together to talk about these autism issues, as well as engaging in training. Washington Department of Health will also be providing training for parents, providers and care coordinators. They are developing autism website and finally, they will be really focusing on reviewing the state policies that affect the youth and families with ASD and thinking about what they can do to improve or change those.

Next slide, please. Utah Department of Health, some of the highlights of their project are training for family medicine and pediatric practices. You've heard this before including in-office and the peer mentor approach. Distance technology training and technical assistance for rural providers, Utah and Alaska really have a focus on this in their programs. Expanding ASD and developmental disabilities. Evidence-based information available to families and healthcare providers through the medical home portal. Also they have an outreach campaign and training for families. And this is just to note that -- I think Illinois also will have a campaign, too. But most of the states that are -- many of

the states that are engaging in outreach campaigns are using the CDC's Learn the Signs Act early campaign materials in their program and you'll hear more about this when you hear from the CDC later on.

Next slide, please. The hope school in Illinois. Some of the highlights of their program are they have a family advisory training program. They'll be training parents, they'll have outreach and training of providers, they'll also have town hall meetings to really try to look at some of the policy issues that are going on. Also this is unique to hope school is that they're engaging in providing assistance for health centers. Finally they're looking at statewide community planning for transition services. Here is that -- one of those core components coming up again that I talked about earlier. The transition piece. What are we going to do? How are we addressing this issue as they children and youth grow up to be adults? Next slide, please. Some of the other activities that the states will be engaged in, I talked a bit about this earlier during the question and answer period but they'll be working with the state -- our state public health coordinating center AMCHP, the association of Maternal and Child Health programs. They also have a broader mission, AMCHP has a broader mission with this particular project to provide technical assistance and resources broadly to other agencies. Public health agencies outside of the states participating. Next, states as well as all the programs that you'll be hearing about today will be engaging in the national evaluation. And also another activity that the states were engaged is with all the other programs is autism program meaning we most recently had in December of 2008 and the plan is that we will have these similar types of program meetings every year throughout the next two years.

Next slide. Now I'm going to switch gears a bit and I'm going to talk about the national MCHB Combating Autism Act Initiative evaluation. In addition to being the project officer

for the state public health -- for the state implementation program, autism implementation program I'm also the project officer for the national evaluation. Now the purpose of this evaluation is to assess the success of MCHB in addressing the national growing need to improve the health and well-being of children and adolescents with an autism spectrum disorder and other developmental disabilities.

Next slide, please. We are working with two contractors to both design and implement this evaluation and these are inside policy research and also Mathematica.

Next slide, please. This evaluation will be inclusive of all of MCHB's Combating Autism Act Initiative program. All four. The research networks that you just recently heard about, the developmental behavioral pediatrics program that you'll hear about next. The LEND program as well as the state autism implementation grants.

Next slide, please. Now what I have these slides up here and what I would like to do now so you get a sense of how we're starting to think about this evaluation for each of the four programs, what I've included here is sort of what objectives we're looking at for each of the programs to address. Please keep in mind that we're still in the process of editing our research questions and so all this information really is draft form but I would like for you to get an idea of what we're thinking. With the research networks, we're looking at them addressing what we call in our evaluation objective one, increase in public and provider awareness, objective two, reducing barriers to screening and diagnosis and objective three, research and evidence-based interventions, and objective four, promoting the development of evidence-based guidelines for intervention. So at this point, this is what we're thinking about the research networks and how they're feeding into the evaluation on a broader scale.

Next slide. Objective one increasing provider awareness, also reducing barriers to screening and diagnosis and finally, training professionals. We're looking at them addressing those three objectives. The states, mainly feeding into objective one and two. Increasing public and provider awareness and reducing barriers to screening and diagnosis.

The next slide, please. Under the evaluation we're developing research questions and logic models for the entire initiative as well as each individual program. The autism team here, as well as our evaluation contractors are looking at developing a data inventory which looks at all of the data that's out there, especially nationally, around autism and how that can feed into this evaluation. As Laura talked about earlier the evaluation is a requirement of the Combating Autism Act of 2006 and the most importantly the evaluation will be reported to HHS -- will be part of HHS secretary's report to Congress.

Next slide, please. The report to Congress will, in addition -- will comprise efforts by all of the participating DHHS agency not just HRSA and MCHB and also regarding this report and the entire evaluation as Laura talked a bit about earlier, MCHB and we've begun to collaborate with other agencies with CDC especially around the evaluation.

Next slide, please. Finally, this is my contact information. If you have specific questions about what is going on in the states, if you'd like to talk with some of the states PIs about what they're doing, there is my contact information for the state program as well as the national evaluation.

MODHAVI REDDY: Thank you, Deidre, great job. I'll turn the webcast over to Captain Nanette Callahan who will be talking about the developmental behavioral pediatrics MCH Training Program.

NANETTE CALLAHAN: Good afternoon and thank you for coming to our mchcom.com. I'm the project officer for the developmental behavior PED program. These programs began in MCH in 1986. The programs are funded for a five-year grant and they began July 1st, 2008 through June 31st, 2013. So they have a little bit different time lines as some of the other programs that you've heard about today. All our programs are funded -- are ACGME credited. What that means, they're accredited by the council for medical education. These accrediting programs started in 2002 is when they started accrediting these programs and there was the first board for certification for the developmental behavioral pediatricians started in 2002 also for the medical subspecialty. The fellowships are comprised of experience in patient care, the development of teaching skills, program development, research and child advocacy.

Next slide, please. The goals of the DVPs as we call them under CA8 is provide professionals with training opportunities to increase diagnosis or rule out individuals with ASD, provide continuing education and technical assistance to other providers, which we all feel is a very important component. Increase awareness of ASD, evidence-based interventions and screenings, and contributing to building systems of care for individuals with ASD.

Next slide, please. We have ten developmental behavioral pediatrics programs. There are more DPBs in the country but we support ten. And six of these programs were given money specifically to support extra autism programs.

Next slide, please. I've listed the ten programs. We're very happy to say our programs are throughout the country and we have them both all the way from the east coast to the west coast and in the middle of the country. They are Albert Einstein College of Medicine in New York, Boston University in Boston, case Western Reserve in Cleveland, Ohio, Children's Hospital also in Boston, Massachusetts. The University of Pennsylvania in Philadelphia. Yale University and those are the six that received extra funding under the autism act. Stanford University in Palo Alto, California, Rhode Island hospital in Providence, Rhode Island. The University of Arkansas in Little Rock and the University of Oklahoma in Oklahoma City.

Next slide, please. Next slide, please. I'd like to tell you just about one of the programs, since there are ten and I've decided just to tell you about one because of time. The Boston Medical Center has many fellowships and that's how they're using their money under this autism act. And this is a really exciting program because they're able to take two -- they've got two individuals, one is a parent of an as burger's child who is a primary care provider who works in the community. No special training in pediatrics but it allows to her to do didactic as well as training to increase her knowledge base to take care of her patients in her respective practice. The other is a nurse practitioner and this person is going to be working also in a community-based program and will be able to test children, as well as rule out children that have been sent there because of a positive reading and she can further test them. Then if she feels they need to go on to a developmental behavioral pediatrician she'll be able to refer them on. So both of these people have community-based programs and they will be able to help with the numbers of children that have been diagnosed now with different types of ASD. I'm going to cut this because we have so much more to do.

The next slide, please, is my information. If you have any questions or would like to talk to me or have anything I'd be happy to talk to you about developmental behavior pediatrics. It is now my pleasure to introduce Madhavi Reddy who will talk about the LEND program.

MADHAVI REDDY: Thank you. I will take questions for Nanette and Deidre after I finish my presentation and Georgina and Katie from CDC finish their presentations. We should have a few minutes for questions at the end of all of our presentations. Now I'll be talking about the leadership education and neurodevelopmental and other related disabilities program. It's called the LEND program. When we look at the LEND program in reference to the MCH Training Program and the Combating Autism Act I want to mention that all 38 LEND programs are under the Combating Autism Act but new funding under the Combating Autism Act for ASD and other developmental disabilities went to 18 LEND grants as expansion money and money went to fund four new LEND programs.

Next slide, please. The goals of the LEND training program under the Combating Autism Act are to provide interdisciplinary health professional such as neurodevelopmental pediatricians, psychologists, psychiatrists, social workers, nutritionists, nurses, etc., etc., to train the professionals with training opportunities to increase diagnosis of or rule out individuals with autism spectrum disorder. The next goal is to provide continuing education, technical assistance to other providers. In this instance we want to increase awareness of ASD. Evidence-based interventions and also screening tools for ASD. We want to increase awareness of all of these issues

here. The third goal is to combat -- excuse me, contribute to the buildings of systems of cares for individuals with ASD.

Next slide, please. The hope is that training the LEND training programs under the Combating Autism Act will receive an appropriate balance of academic, clinical and community opportunities through their training. The hope is that all types of training, didactic, clinical and community based are culturally competent and ethnically diverse. We hope the trainees through the training have the ability to demonstrate a capacity to evaluate, diagnose and rule out and provided evidence-based treatment for ASD and other developmental disabilities and that they demonstrate an ability to use cultural competence in a family-centered approach when they provide care to individuals with ASD and other developmental disabilities.

Next slide. As I mentioned, I haven't included all 38 LEND programs on these next couple of slides but I have included the programs, 18 existing and four new that received additional funds through the Combating Autism Act. The ones that are starred are new programs. They are the University of Arkansas for medical sciences, the University of Connecticut health center, University of Illinois at Chicago and the University of Colorado. These are the four new LEND programs that we were able to fund with additional funds for the Combating Autism Act.

Next slide. These are the remaining LEND programs that received expansion dollars through the Combating Autism Act.

Next slide. Next slide. As Nanette mentioned similar with the developmental behavioral pediatrics training program the LEND program has 38 programs that are spread

throughout the country with geographic representation in all sections of the country. So what are LEND programs doing this far under the Combating Autism Act? I've taken a snapshot of about four programs in the LEND training program and I'm giving you kind of just the highlights of what they're doing thus far. At the children's national Medical Center in Washington, D.C. trainees attend didactic training sessions one day a week. These sessions include practice discussions, journal, book and movie activities and they have the ability or the opportunity to listen to guest speakers. During these didactic training sessions trainees meet with their supervisor before the session, have a team meeting after the session and after -- in the afternoon they discuss a team case with fellow trainees and staff, team cases are based on information that they received during the training sessions and these training sessions are all day from about 8:00 to 4:30 I believe. Trainees attend a developmental pediatric session and I believe this is one day a week for four weeks.

>> Next I want to mention some of the activities going on at the University of Kansas. They have created four new master's level OT and speech students. Recruited two post doctors in psychology. They also have the permission from their department or their school of -- their continuing medical education to recruit for behavioral and developmental pediatric fellow. Hopefully that will take place sometime soon. They've developed an in-house database to track the age of when parents are first concerned about their children. The age of screening and the age of diagnosis for children that they see through their clinics. They've already trained physicians in Topeka and western Kansas on treating and validating practices. Also the University of Kansas, they are -- they've developed a survey for physicians and childcare personnel on what they know about red flags and screening for autism and they've also surveying through the referral sources for diagnosis and treatment. The LEND program has found a parent Resource

Center and ordering materials for the parent Resource Center and trainees will help with training at the Resource Center. The program is also conducting an interdisciplinary workers on high functioning autism in Kansas City. They're planning a conference in Wichita on autism with a track on early intervention and transitioning adolescents. And they've trained five school teams to work with collaborating physicians on screening and diagnosing autism.

Next slide, please. Indiana university, they're collaborating with the Indiana autism society to develop community-based field activities for the LEND trainees that they have in their program who will be on that ASD track. They're participating in Indiana's autism coordinating council and also involved in the Indiana family leadership initiative. The family leadership initiative includes family members representing a variety of family-based organizations. This initiative is establishing outcomes and a vision for family leadership in Indiana and identifying leadership competencies and learning resources for supporting families in a pursuit of helping families achieve individualized learning goals in the area of leadership.

Next slide, please. Just a couple more things. Indiana university they're also sponsoring a national conference on high functioning autism and as Berger's disorder. Developing a session on special education law. They'll be attending an annual conference on law an disability and they are planning to development a workshop for nurses and nursing students.

Next slide, please. Finally, a couple more things that Indiana is doing. They're developing a telemedicine autism clinic and working on research projects. Early feeding

patterns of children with suspected autism, sibling -- they're working I guess to research siblings of children with autism and social therapy in children with autism.

Next slide, please. One more thing from Indiana is that they're creating a new elective specific the autism diagnosis and treatment for medical residents, junior and senior medical residents.

Next slide, please. This is one of our new programs, University of Connecticut. It's a new LEND program. They're coordinating and collaborating on training with the Connecticut birth to three system and this system includes the Connecticut Department of Health, the state Title V and medical home initiative in Connecticut and also the Connecticut Department of education.

Next slide, please. The coordinator of these activities is planning to start new initiatives within the first year of their grants. They're planning to provide stipends to families for training which is exciting for a new LEND program to take up in their first year of funding. Next slide, please. And I just wanted to conclude by saying that if you have any further questions about combating autism activities under the LEND program you can feel free to contact one of the three project officers. Myself, my information is here and also Denise and Robyn. Our contact information is here. And you can find out or get more information about the LEND program at the website that I've listed here. Thank you and now we're going to turn the webcast over to Georgina Peacock and Katie Kilker Green at the CDC.

KATIE KILKER GREEN: Good afternoon, I'm Katie Kilker Green, a health communications specialist with CDC and work on the act early campaign which we're

excited to tell you all about this afternoon. We want to thank Maternal and Child Health Bureau for inviting us to participate in this webinar.

GEORGE GINA PEACOCK: I'm George Gina Peacock. A pediatricians working on developmental disabilities on the CDC's on the Learn the Signs early campaign and presenting the second half of the presentation.

>> To jump right in with the first half I would like to tell you a little bit about the campaign which was launched in 2004.

If you go to the next slide, you'll see that our mission is to -- that every child reaches his or her full potential.

We aim to do that -- moving to the next slide, by working towards four primary campaign objectives. That's to increase awareness of developmental milestones and early warning signs of ASDs and other developmental disabilities, to increase knowledge and the benefits of early action and early intervention. To increase parent and provider dialogue on the topic of developmental milestones and disorders. Not necessarily something that parents and providers talk about regularly as much as they do some physical aspects of development. But getting them talking about all developmental milestones as they should be occurring and increase early action on childhood developmental disorders.

Next slide. Through our campaign we target three main audiences. The first audience that we launch to in 2004 was to healthcare professionals. Really pediatricians, family physicians, physician assistants and others, other healthcare professionals who work

with young children, children age 4 and younger and their families. Also parents of young children was our next audience. We wanted to equip our healthcare professionals to be able to meet the needs and the informational needs of the parents of young children that we'd be targeting next and interested in parents of children ages 4 and younger. Finally, early educators, those including pre-school teachers, daycare providers and others who work with young children on a daily basis. So moving on, you know, naturally in the last year or so we've really seen that the campaign is pretty well described, the activities of the campaign are pretty well described by the title of the campaign. Since 2004 we've spent a lot of time helping those three audiences to learn the signs, to learn the signs of healthy development and warning signs of potential developmental issues. We also as of late have become much more active in the early part of the campaign which is really building the infrastructure to meet the needs of parents and professionals who know that acting early is important and who do so to help children.

Next slide, equipping healthcare providers. When we launched in 2004 we launched a resource kit. And these materials, the primary audience really is the parents but it is a kit that we put together to give to healthcare professionals, materials that they could have available in their waiting rooms, in their offices and places where parents could see them, could use them and could use them with their doctors that they were going to see. So we have informational cards, how to talk to your doctor, questions to ask about development. We have a series of fact sheets on developmental milestones as early as three months of age through five years of age. Materials for waiting rooms and exam rooms including posters and all different types of things. To really increase the dialogue between parents and providers. And all of these materials are available for free on our website. We hope that you've seen them. We hope you've ordered them and we hope

you use them in your communities. Speaking of our website, we have a number of resources for healthcare providers on our website. Under resources for healthcare providers we include CDC screening guidelines, coding information, as well as links to how to get the AAP autism screening toolkit and lots more. I would definitely recommend you visit the website and check out the additional resources.

Next slide. The campaign also works to educate parents and, of course, we've put together a resource kit just for parents. We have a website with interactive tools so you can actually go onto the website, click on interactive milestone checklist, you can fill out the checklist for your child. You can share it with a friend. Ask them to do the same thing. You can email it to your doctor. So there are lots of tools and information about development on our website for parents as well. In the hard copy resource kit we have the fact sheets about development. The little information card that we also provide in the healthcare provider kit about questions to ask your doctor about development. And a really fun and highly popular growth chart. On one side it has, you know, child's height you can add pictures of your child and then on the right side it has different milestones that your child should be reaching at different ages. We have a number of Spanish language resources, all of our materials on one side are in English and the other side are Spanish. We also have the ability to answer public inquiries through our 1-800. We have the ability to answer questions in Spanish and also offer Spanish website. We have a number of public service announcements for TV, radio and print. And finally, we have another resource kit for early educators. This kit also includes the very popular growth chart, posters that early educators might be able to post in their childcare center to get the conversation started with parents about development. Flyers that educators can put in a child's backpack when they go home so the parent, you know, can get the flyer and get the information for ordering a parent kit if they're interested in learning

more. And we have a CD-rom that we like to send out that, you know, early educators can print the materials, make copies of the materials, and share them with parents. Those are of our fact sheets that give information about developmental milestones at different ages and some very introductory information on different developmental disabilities. Another thing we heard from early educators is that they had concerns when they had concerns about children, they were very stressed out about the idea of approaching parents with their concerns. So one other piece that we included in that kit were tips for talking with parents about developmental concerns. And we also have a number of online resources for early educators as well. Of course, that interactive milestones checklist could be something that could be done in early education setting, daycare setting, and shared with parents as well. Definitely go online and check out some of those educational resources. Now Georgina will talk with you more about some of our recent activity along the act early line.

>> Thank you, Katie. So as Katie mentioned, we can really divide our campaign into two different phases and while we are -- there are always new parents to educate and there are always new providers out there seeing children who need to be identified with concerns that they may have in autism spectrum disorder or related disability, we have added a focus to this act early part of the message and the main part of this is a project that we have been doing where we are bringing together key stakeholders to come together in act early regional summits to really look at some of the issues around acting early for young children who are exhibiting delays. What's exciting about this initiative is that we, in cooperation with the association of university centers on disabilities, we're able to collaborate with the Maternal and Child Health Bureau and this has made this activity very rich because we are able to partner at a federal level to really link the projects that we're doing around the areas of autism and developmental disabilities and

those areas through HRSA's Maternal and Child Health Bureau. So as I said, our act early regional summits are meant to convene key stakeholders to facilitate communication and coordination for improving early identification and access into early intervention. What these summits do is bring together key stakeholders in the different areas, including education, healthcare, advocacy, parents, state agencies, and other people that are interested in this area of early intervention, bringing them together to talk about the issues that are unique to their local area. Or to their states. Because we know that on a -- nationally they're very different landscapes in different areas of the country so it really is our role just to bring people together and for them to look at the things that are going on in their states, the needs, the things that are going well, the things that are having challenges with and through a logic model process come up with some activities and also figure out what their intended impact is. So they go through a two-day process where they go through this process and then come out with some goals or some action items that they're going to follow up on. I think a number of you probably in the audience have participated in these summits or are going to participate in these summits. In 2007 and 2008 there were three summits. The first was hosted by the Maternal and Child Health Bureau in conjunction with the national medical autism medical home initiative at the Waisman Center in Wisconsin. Built on this meeting held in December of 2007 in Chicago, we hosted in cooperation with the association of university centers on disabilities two summits, one in Kansas City, Missouri for region seven and in Albuquerque, New Mexico for region six and we have not yet updated this slide because we just had a summit last week that was completed for region 4A in Nashville. And all of these summits have had sort of different flavors to them, but they all have been energizing, I believe, for the stakeholders that participated because they were able to really spend time talking about the issues in their states and also think about where they were going to go next. And so this opportunity to meet people that

they may never have met before that were only living a couple miles away, we had a couple comments where people said oh, I went 400 miles to meet someone that's in the same city I'm in working on the same issues. So really that was -- that is really what we hoped would happen is that people would come together energized around this issue of early identification and getting children into services as soon as possible and work on the issues that were local to them.

Next slide. So we will -- I'm on slide 13, sorry, I haven't been saying that. There are two more summits that are scheduled to be held in 2009. Region 8 will be in Salt Lake City in Utah in March. March 5th and 6th and then in region 2 in the Bronx in New York at the end of March. And our intention will be to have summits throughout the United States so that everybody gets this opportunity to meet together and come up with some plans to move forward in their states. As a way to continue the work that is done in these summits we've been able to offer some mini grants. These are small amounts of money that are meant to build on that momentum that is present in the summits. People have chosen to use these mini grants to continue meeting either through in-person meetings or also on the phone and also they have -- some of them have used this money to create or modify our materials to make them local to their states so that then they can be used in a dissemination of materials. Because we all know that we go to meetings a lot of times and then there is no follow-up to that. We wanted to really ensure that if we were going to have these meetings occur, that people felt that momentum that was started during those two days would continue. The association of university centers on disabilities or AUCD is also supporting this act early summit project so they're giving continuing technical assistance and providing technical assistance calls on various issues that states have asked for and will continue to follow will state teams following the summits at six-month intervals. Just to give you an update

on a couple other projects that are going on, there are two projects being done as research topics of interest. One in Oklahoma and one is Wisconsin. They are really looking at how family practitioners do screening in their practices and ways to help this population do screening better and identify children earlier and identify more children. We know there is a difference between family physicians and pediatricians and a need for a different focus in maybe the way we change behaviors among family practitioners to identify children earlier. And finally there are some collaborative research awards that are also looking at some of our act early issues. One is looking at some positive parenting materials and how we can incorporate developmental milestones and early warning signs of delay into those materials. The second is really looking at what role does a health -- an allied health professional play in helping parents navigate the early intervention system to a diagnosis of autism. As many of you know when a child enters the early intervention system often they may end up having autism but they may enter with a diagnosis or symptom of speech delay and with that first point of entry, that person is often a therapist, that therapist is a great support to parents and also could be a great help in helping parents to navigate this system. So both of those projects are going to occur over the next year and we hope to have some more materials and information that can help inform what you all are doing in your states around these issues. In addition through our cooperative with agreement AUC

>> Regardless of whether it passed or failed and look at that legislation for all of 2008 they'll continue to add the information for 2009. And so I encourage you to look at that. We've found that people are interested in what legislation is going on in different states and finding out what things have worked and what things have not worked with their legislation.

The next slide, slide 18, provides information for you on a different -- on the website, both English and Spanish. Also our autism information center which provides more information about some of the other autism activities going on at the CDC and finally the AUCD website which provides information on the act early summits as well as the legislation date I spoke about. We'd be happy to take any questions on either now on the phone or through our email. Thank you for having us today. We really appreciate this collaboration with HRSA's Maternal and Child Health Bureau. Thank you.

>> Thank you, Georgina and Katie. I do have questions for you. If you could hang on the webcast and I will get to your questions as soon as I get through a few others for Deidre. So let me quickly go through questions for Deidre. Will there be additional information available for the states?

>> We are unsure about that. We are unsure about the funding. This is any grant program. That sort of depends on funding that's available.

>> Thank you, Deidre. Let's see. There is just a comment about one of the participants says it's nice to see the component of the state implementation grants addresses six national performance measures for children with special healthcare needs. One more question. Who are members on the Alaska team and determining educational eligibility?

>> The rapid response team in Alaska have provided as part of that but -- I'm thinking they also have families, too. I'm not quite sure about that. I can't remember the specifics around who is a part of that entire team but I will tell you that as a requirement for all of these particular programs that are participating in this initiative we've asked them to partner with their -- not Title V agencies, family voices, also with the LEND program so

you'll find that one thing that's really, really unique about the states is that there are a variety of partners, including education and Medicaid in some of the states.

>> This question is for Nanette. The person wants to know who is the contact or administrator, project director for the case western program? I guess we can provide that.

>> It's Nancy ROSIEN in Cleveland. But I'll get your email address from Madhavi and I can send it to you.

>> It's also available on the website that Nanette referenced in her training program. Their email and phone number there.

>> Great, thanks. There is a fairly long comment directed towards Deidre, I believe. Let me see if I can ask it quickly. This person wants to just clarify that by medical home you mean physician care. I ask because it appears you are involving literal home away from home care. Is residential care a consideration of any research? She says I hope not in parentheses.

>> I'm not quite sure. I think she's wanting you to maybe just go back and say what you mean by medical home reference.

>> Okay. Most of our states that talk about addressing medical home in their programs are talking about not only the -- incorporating the physicians, the primary care physician, but also inclusive of that, not just the clinical care but also working with the family to link

them to other social services and other resources and so entire comprehensive view of a medical home.

>> Thank you, Deidre. I think you already mentioned this including adolescent transitioning to adult care are included in some of the planning for your grant.

>> Yes, definitely.

>> Thank you. This question is referenced to are any of the LEND programs developing state plans to address systems of care for autism? I wanted to say the LEND programs are actively involved in the regional autism summits. The act early regional summits that Georgina and Katie mentioned and they're developed in reference to other developmental disabilities and ASD. The LEND programs at the summits are actively involved in working with the states in the government of these action plans. Also in states where state autism implementation grants exist the LEND programs are actively working with those state autism implementation grant programs on their plans for systems of care in their states. So I think Deidre probably mentioned the involvement of the LEND programs with the states.

>> Right, definitely. The states are -- that's one thing unique about the state programs is the various partnerships that they have for the LEND programs in the state, connected with the LEND, the family to family, DBPs there and as well as with some of MCHB's other programs. The state integration programs that we have, we've asked they connect with those programs also. Just to name a few.

>> I think the remaining questions are for Georgina and Katie. Are you ladies still on?

>> We are.

>> Okay. Great. Thank you. The first question is do you have a toolkit for elementary schools?

>> We don't. This campaign really targets parents of children under the age of 4. However, our fact sheets do discuss disabilities obviously that affect the life span and do give some information about symptoms of disability in older children. So the fact sheets could be applicable to elementary-aged children.

>> Fact sheets are available to download and view or to print right off the website. Whomever is interested might want to go to the website, [CDC.gov/act early](http://CDC.gov/act_early) and take a look at what we have and see if it meets needs.

>> Next question, this person wants to know do you have PSAs recorded for purchase or download through your website?

>> Yes, we do. We have television PSAs and radio PSAs, the radio are in English and Spanish. And they are available for free and you just download them off of our website.

>> The other thing that might be of interest also is if the listener wanted to go to the main CDC website WWW.CDC.gov and go to CDC TV on the home page. You can see a video that's entitled, baby steps. It's about a four-minute video that gives the same information of our campaign that's a bit longer and sometimes people use that in teaching opportunities so not a PSA but something that's a bit longer that provides information about getting children identified and into services.

>> That, too, can be downloaded and saved for your own use.

>> Right.

>> Great. Let's see. The next question is will the summits, are they open or will they be open to community members? This particular person is in Michigan and wanted to know if she could be involved with the summit in Michigan.

>> The summit was Michigan was held in Chicago sponsored by the National Medical Home Autism Initiative and MCHB. It is possible that at the end of the summits there will be something that includes that region again because that region had a slightly different model than the act early summit. But we could put the person who has the question in contact with that team in Michigan so they can find out what that team has done since, you know, if they're meeting still and what they have done with their logic model activities.

>> Okay. Great. I will, I get that person's email address to you so you can contact her or vice versa. Next question, this question, which states receive the mini grants.

>> I don't have a list of those right now but most of the states who were in those first three summit -- the first three regional summits received funding through the mini grants and the mini grants will become available to other states once they've had a regional meeting.

>> Okay.

>> I can provide a list to Madhavi so she has that. But it was almost all of the states that participated did receive an act early mini grant.

>> Thank you, Georgina. We have two more questions and then after that I'm going to probably have to take your questions off line and forward them to the appropriate presenters. This one is more -- I'm not sure if it's more of a comment. Act early in too many situations means too act in a developmentally inappropriate way that exacerbates things like speech, interference with caretaker/child relationships and can be traumatic. What quality controls are being considered, our self-advocates included in summits and similar activities?

>> When we use the term act early what we're really talking about is mobilization of services. So we're talking about getting all the key stakeholders together so that children can -- children and families can be supported when their child is not reaching the milestones that are expected. So we're not talking about any specific treatment or any specific way that you would help a child, most early intervention -- all early intervention systems including Part C and section 619 have as a component to that family support and really one of our big messages is if we can identify children that are having developmental problems or developmental issues, that if we can get them into some of these systems that care for children and that support families, that children will be supported in reaching their full potential. So that is what we really mean by this act early is just noticing when things are not going as we expect and then getting children to people that can really help them and help their families as soon as possible.

>> Okay. Thank you, Georgina. The final question I think is probably for all of us in the room and at CDC. How will the allocation of federal funding to state public health organizations reach not for profit organizations to support and expand their work?

>> I think non-profit organizations, some of them are already part of the state implementation grants. The partners involved there. Georgina can speak to the regional summit.

>> They're represented as stakeholders at these regional meetings as well.

>> Right.

>> Okay. For folks who still have questions for Georgina and for Katie, please refer to your slides I believe on the last page of their handout. There is contact information for Georgina and Katie. Please feel free to email them or to contact them by phone. At this time I just want to say thank you for attending this webcast. We've had multiple questions, many questions, great questions and we've in our short amount of time we've been able to ask all of the questions but if you have further questions, please feel free to contact the presenters that you're interested in connecting with. Their information are in their slides. Please complete the evaluation form that will follow directly after this webcast. Archives of the event and many more MCHB webcasts archives are available at mchcom.com. Thank you once again for your participation and we hope to see you soon. Thanks. Bye-bye.