

## **2011 AMCHP and Family Voices National Conference: Roles for State Title V Programs in Building Systems of Care for Children and Youth with ASD and DD**

**02/15/2011 Omni Shoreham, Washington, D.C.**

GEORGIANA PEACOCK: Okay, alright, and I'm Georgiana Peacock from the CDC down at Atlanta and it's my job to sort of talk about -- we've had a lot of stories about collaboration of partnership and what I get to talk about is a wonderful partnership and collaboration with our federal agency partner, the Maternal Child Health Bureau, HRSA. And then I'm going to give you some examples of this collaboration that we've had. The Combating Autism Act has given us this opportunity to work together on a really important issue, autism, and really with our partners blend our programs, blend our funding so that we can really hopefully help support all of you in the work that you do for children and families with autism spectrum disorders and those who are maybe awaiting a diagnosis either of an autism spectrum disorder or another developmental disability. And then I'm then going to talk about some of the next activities that we have.

So the collaboration efforts really started with a trip by the Maternal Child Health Bureau, a bunch of people from the agency, Bonnie, and a lot of other people came down and said we just got all of this funding from the Combating Autism Act and we need to learn really quickly about what's going on in federal agencies with autism. And so they came down to Atlanta, we had a lovely day of activity that started with breakfast and started with lots of information sharing about the things that we were doing and the things that we hoped to do to support this work in states. And what that has resulted in is a number of activities where we blended our activities. We have an MCHB or HRSA CDC autism work group that meets quarterly, sort of in quotes. We meet when

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we need to meet but we definitely keep each other abreast of what's going on.

I'm going to talk a little about the ACT curriculum which has been an example of something that we have worked together to create and will be launched soon. I'm going to talk about the Combating Autism state demonstration supplements which a number of you I think have and then the Act Early Initiative.

So very briefly, the Act case, the study curriculum is a curriculum that has been designed for physicians in training. The way we have created this curriculum is really through the work of over 50 people. So these 50 people are people from the Maternal Child Health Funded Developmental Behavioral Fellowship programs, they're both fellows and faculty who are in developmental behavioral pediatrics as well as people at the CDC and one of our contractors, \*\*\*\*, and we put together a case curriculum to teach residents about autism in three different categories: in early identification and screening, in diagnosis, and caring for children with autism spectrum disorders, and these are the different cases where there's a story told about a child and a family and we lead the learners through a facilitated curriculum where they tell this story, there's prompted questions, there's videos, and then, you know, there's also a pre and a post test and this will be launched at the Maternal Child Health Development Behavioral Peds Fellowship program in March in Oklahoma. So that is something soon to come. What also I will hope you all need to know is that we are also starting now that the content is created, we are starting

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to put this into an online version which will be a continuing education version of the curriculum.

As a number of you I think probably have these grants, we were able to add a supplement to some of the HRSA state demonstration projects in Missouri, Alaska, Utah and Washington with the purpose of doing an evaluation of a targeted implementation of the Learn the Signs of Act Early Health Education Campaign. And those were awarded in October last year and are underway. Again, we were able to take some of our funding through the Combating Autism Act and funding that had already been given out through HRSA from the same act and blend those together so we can hopefully really improve things and gain benefit from being able to blend this funding.

And then the Act Early Initiative, which I think was stated at the beginning, was really what I had spent a lot of time on over the last couple years, which was really a model that we started to look at a collaboration for systems change. What we were trying to do was to help improve system collaboration by bringing key stakeholders together in early identification of children with autism spectrum disorders and developmental disabilities. And for some reason I actually had CDC, MCHB, and AUCD labeled on these circles but those have disappeared. So this actually started with the Maternal Child Health Bureau before the Combating Autism Act actually was there. And what happened is we came together with Georgia Winston and under an MCH funded project called the Autism Medical Home Project in Wisconsin, the first summit was held

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where key stakeholders came together from a number of different states and this was held in Chicago and they worked through some issues, they created a state plan and some activities they were going to do to move forward in the early identification of children with autism spectrum disorders and developmental disabilities. We took that model, we massaged it a little bit and we found a partner in the Association of University Centers and Disabilities which I think many of you know about and may be part of and we've now been able to convene Act Early regional summits in all 10 of the HSS regions with the last one finishing in September in Indianapolis.

So what we've now been able to do through this joint collaboration is have summits, regional summits in all different regions, 55 teams have met with 800 plus attendees. I hope and think that probably many of you attended one of these summits. We now are, as Bonnie mentioned, going through an evaluation process looking at the progress of these Act Early teams and where they are. What we found is that we've got 45 active teams that are still continuing to meet. They're still continuing activities that they talked about on their state plan. And we're trying to sustain this interest through a number of different processes. Some of you may have had a UCD mini-grant. Some of you may now currently have an MCHIP to Act Early systems grant. We also have an Act Early forum and if you're not part of that, this is a listserv of where things are posted and there's an opportunity to get information from people who are working in the area of acting early. And I

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will talk in a minute about what we're planning on doing to sustain this interest.

So just a little more information about what states have been working with these MCHIP and UCD Act Early grants. Disseminating and customized Learn the Signs Act Early materials. I'll show you a great example that has been done in Wisconsin in a minute. Continued collaboration through meeting of these Act Early state teams. Some states are developing resource guides and autism guidelines. As we heard about there's a special time when those things should be done and we've got to make sure we have the right thinkers in the room as well as the will of the community for creating those guidelines and creating them at the right time. Training clinicians and community providers, developmental and autism screening and community and medical settings and then creating roadmap for families and also roadmaps for professionals.

So some of the more concrete things we've been told by states as we're doing this evaluation, what did you do as a result of coming together. Florida created a flowchart to help professionals navigate that system in their state. Kansas has been able to reduce their waiting list for diagnostic assessments by creating regional teams. Their goal at the summit was to get those waiting times down to six weeks and they say that they have made really great progress in getting to that. Oklahoma in their early intervention program and their Part C program screens every child in the program at 18 months with an MCHAT. And in New Hampshire they'd done

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some MCHAT training for providers that reach out to homeless children and children living in poverty. In New Mexico, a common theme, we've got a navigation wheel for parents to understand different systems and how to access them and they've also customized some CDC materials. New York took a different approach and they have partnered with us to use some of the public service announcements that the CDC has and we've been able to work with them to use that in a public service announcement campaign. They also have customized some of the materials and are distributing those. South Carolina has set up a master clinician training and is also creating a roadmap, and then Wisconsin has created a customizable tri-fold brochure that actually has become quite popular and we have some other states that are now also putting their logos on this and are distributing it. This is sort of in a Candy Land format where you can see different milestones. It's in Spanish and English and here you can see the logos of the Wisconsin organizations in early identification and then you can't see on this, but there's local numbers so that people can call the number in Wisconsin.

Just briefly, we as part of the evaluation, we've been talking to some of the team leaders from the Act Early teams and most state teams do have or are developing their state plan or have moved forward from that state plan and are continuing to do the things that they set out to meet. Coordination of state efforts has improved and states are engaged in activities focused on awareness, education, training, and policy change. And the use of campaign materials has increased in many of these states and that's

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what really we hope that will happen because we're creating these for you. It doesn't help us if they sit in a warehouse. It helps us if they're useful to you and you are able to use them and then not have to use your resources necessarily to make these types of materials but we can help customize them and get them out to your constituents. And the majority of state team leaders have said that the summits were helpful in improving early identification, strengthening partners and establishing new partners.

So what are we doing to hopefully sustain this Act Early interest and initiative? We do have this Act Early forum listserv that if you're not a member of I hope that you will become a member of and also post it to because the idea of it is that people will post things that are working in their states and things that are happening. There is an opportunity to have a share point site for your team and AUCD, The Association of University Centers for Disabilities, will help set that up and help you through the system of using that share point site. As you know, a number of you have the Act Early grants through MCHIP and then there's the HRSA state demonstration programs.

I wanted to take this opportunity to talk about a few new things, and this is our attempt to tell those stories. So these are those stories about learning the signs and acting early and I will have some flyers out at the end but we're asking people or giving people an opportunity to tell their story of a person who helped their child and the family to act early, to learn the signs and act early. So I'll have some flyers out about that and those stories will be stories

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that we will use and that you all can use to talk about the importance of learning the signs and acting early.

We also plan on moving into a new phase which is to create some Act Early ambassadors and we're looking for people who will be a point person for Learn the Signs Act Early Consultation in the state. They'll be able to provide professional education about learning the signs and acting early and we are in the final stages of deciding exactly what that will look like and we will be asking for applications in March. And we'll be sure to post that to the forum as well as send that through other partners.

So in conclusion, I think the Act Early summit provided a forum to improve system collaboration but also collaboration on a federal level. I think that it's been a tremendous experience to work with our federal partner, HRSA, with MCHB to work together to hopefully support the activities that you all are doing in states. And these Act Early summits have improved future directions for the CDC's awareness campaign and future Act Early activities. This initiative has been strengthened with the network of professionals of you all who have been part of our Act Early teams and are continuing to do this work. And again, that synergy or that opportunity for collaboration between HRSA and CDC has been absolutely wonderful.

So I'm going to stop with that and would be happy to answer any questions along with the rest of our panel and thanks for coming.