

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.

Speaker 1: Questions any one of Georgia, Holly, Harper, and Georgina?

Speaker 2: For the Act Early **** and the Act Early materials, how do we access that?

GEORGIANA PEACOCK: Sure. So there was a question about accessing the Learn the Signs Act Early materials so you can go to the CDC website, www.CDC.gov/ActEarly. If you want information on the regional summits you can go to the AUCD website to get information on the regional summits and there's an Act Early page on there or you can e-mail me if you have a specific question, GPeacock@CDC.gov, so.

Speaker 1: Other questions?

Speaker 4: I was just wondering where there might be more information about the ambassador thing?

Speaker 1: More information about the ambassadors.

Georgina: It's not there yet because it's about to be launched. We will be sure to put that out through MCHIP, also through the Act Early forum and it will be on our website and we'll put it on the AUCD website. Or again e-mail me and I can send you information.

Speaker 1: I was sitting on the front so how many of you haven't participated in a summit, one of the regional summits?

Speaker 5: Have or have not?

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Speaker 1: Have. So a good many of you. One of the things that you should know about the state implementation grant supported by HRSA, is early on it was a requirement now it's a strongly encourage feature is that you have a state plan. If you don't already have one of those grants, and you're thinking about apply for one, find out who in your state -- if you don't where the state plan is because most of you have a state plan that was developed during one of these summits, find out where it is and build on it when you submit one of the state implementation grants or I think even any of the other collaborative efforts that we have with CDC. It will greatly enhance the likelihood of funding. So there's another question in the back.

Speaker 6: Are there other states that are integrating their early childhood systems programs with the Act Early programs?

Speaker 1: Are there other, are there other autism grants that are integrating with the early childhood systems grant?

Speaker 6: Yes.

Georgina: I don't have any examples. I do know that there were some early childhood systems grants people who came to some of the summits and I can actually maybe go back through or if people have examples to share right now that would be great. I know there were some participation but I don't have the exact answer for you.

Speaker 6: [INAUDIBLE] and providing families [INAUDIBLE].

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GEORGIA WINSON: We haven't actually integrated at the grant level but we have a strong collaboration both with early intervention and early childhood and so both are state grant and this HRSA grant both provide a lot of training and support to both early intervention, early childhood. The other great collaboration that we're just now beginning to tap into, you know, more strongly is Head Start and early Head Start. especially in the city of Chicago, early Head Start is opening up their doors and giving us space, we're doing ongoing training, and I think all of this really does begin to establish standards across multiple systems which we found is a big problem where and it's just jarring for families to be part of one system where, you know, here's what you do in this system and then, you know, you go to a new system and it's a whole different set up. So I think if you can have an organization that begins to really provide transition across the system is really helpful.

Speaker 1: Linda?

Linda: Hi Linda **** from the Maternal Child Health Bureau. As a follow up to that [INAUDIBLE] Holly, Harper maybe you can address this, that we have a companion program working on state implementation for all children with special health care needs and I was wondering if you can talk about the work you did with that grant **** with this grant and vice versa how the work you do now is also benefiting all children who need special health care needs.

Speaker 1: So the question is how did the original, we call the D70 grant, so broad state implementation grants for children with special health care needs in general, how did your experience with that grant influence your

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work with the autism specific grant, autism and other developmental disabilities grant and vice versa.

Speaker 7: I think we have, we had both grants and I believe the systems grant we originally had worked a lot on medical homes and we worked with UPIQ and established some of those relationships to develop the modules and flesh out the medical home website. And UPIQ is Utah Partnership to Improve Qualities, is the short, it's got a lot of different words in it but that's through the University of Utah. They provide training not just one what we give them money for but also asthma and a lot of other conditions for physicians and working a lot with medical homes and giving Medical Home 101 training and those kinds of things and quality improvement. So a lot of those things for Utah came about with the first integrated services grant.

And also as a follow up to the other question about combing the early childhood programs, we actually had a reorganization this year where we put, we had early intervention, home visitation was under children with special health care needs, they pulled those out and put them with child care licensing and now the people who are over the ECCS grant, not sex, anyway over the ECCS grant, and over that grant are now in a great big bureau of child development. So it's kind of exciting and it's kind of a new activity we're doing but there's been a lot of germination of thoughts and ideas from that bringing together of people.

Linda: And if you could, can you address if you're working with Illinois on because I think a lot of synergy that should happen because obviously you

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develop, let's say, work on medical homes it should cover all children.

Speaker 1: Same question for Georgia.

GEORGIA WINSON Yeah, definitely, actually that's been one of the most interesting areas I think that we've worked on in terms of making sure that this current interest in autism spreads out to children with other disabilities and other health care needs. One of the things that we've done in Illinois, we have the opportunity to get a waiver and the autism of Illinois took a really strong stand we want to be all disabilities not just autism. And that was kind of unusual prospective for us to take but we think it's really important. We also feel like the work we're doing under medical home, under this HRSA grant, and working with our Title V organization is advancing the medical home at a more general level. So we actually have the ***** pavilion. We have a variety of agencies; dental, pediatric, pediatric psyche, mental health center, an eye clinic and an autism clinic all co-located and we're actually developing a medical home model in conjunction with that. We've also been working with our lend coordinator and I think that collaboration has really been very important in terms of broadening the focus away from autism and looking at all children with special health care needs, strictly neuro-developmental disorders. We really believe firmly that's the way to go, you know, is to focus more broadly on children with a variety of different health care needs. And, you know, I think the autism community is lucky we're in the limelight now as an autism community and we need to really take that opportunity to raise the

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level of the votes for people with autism and raise everybody's vote. So that's.

Speaker 1: Well said.

Speaker 8: This question just makes me think we have noticed in our state too, in Washington State, that recently there does seem to be more funding that is condition specific; the epilepsy grants, the autism grants, and it just gets me to thinking I wonder if the thought that there is, I guess I wonder what are the benefits of using the condition specific grants versus you know former decades we thought oh, we need to come together for children's special health care needs because everybody needs the same thing. So. I guess the question is what are the benefits of having the condition specific fund.

GEORGIA WINSON You know, honestly I'm a hard one to present those benefits because I'm really on the other end of the spectrum on this. Oh, yeah, the question is what are the benefits in seeking disorder or disease specific funding versus working more generally for children with special health care needs? It's hard for me to kind of do a good job of arguing that perspective. In fact, what I really do believe happens, I believe that that movement is really kind of based on a scarcity mentality. I think people are concerned that the pie is shrinking and so people are really focusing in on let's get a piece of the pie for my particular disorder. I think the problem with that is that that is not going to put us in a position to ever get the pie to the size it needs to be and so we've really been very forceful in Illinois in arguing, you know, let's not buy into that.

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Yeah, resources are scarce and what we need to say is resources are scarce for everyone; they need to increase the resources. So I think the push behind it is scarcity and I think what it's going to do is it's going to give, you know, public policy makers and legislators kind of a pass and it will make them feel less guilty about not enlarging the pie; if that answers your question. I think it's a real problem.

Speaker 8: Yeah, thank you.

HARPER RANDALL: Although I do think there's benefit when because there's passion or an awareness that this is an increasing prevalence, autism, people, legislators can understand that and they can support that and they can't support integrated services medical home. They don't, can't wrap their hands around that, so if we can take passion and create a system that benefits everyone and okay, label it as autism, but everyone's going to end up benefiting by the work that's done through that process. So I can understand why there's a hesitation to support it. I mean oh, my gosh, if that's how we can get it funded then let's work that way. So.

GEORGIA WINSON I think, I definitely, I definitely agree with that Harper that, you know, I think it's more compelling. So I think that might be one of the reasons. Yeah, it gives it a face. But you know, one of the things I've learned, I've learned a lot about Maternal Child Health Bureau through this grant that I really have to say, I feel embarrassed to say, but I was pretty ignorant about before we received this grant. When I came out here a couple of months ago and they had the 75th anniversary, I mean there were amazing

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stories and they passed out this book that was about like 1935 about how to care for your baby and, yeah,

Speaker 1: I was there.

Speaker 9: Yeah, you were not.

Speaker 1: I mean at the conference. No I was not there in 1935.

GEORGIA WINSON But you know when I actually took that book, they gave that away and I got it sitting on my bookcase and I'm really proud of being part of an organization that has such a rich history. And so I think beginning, you know, to continue to take it away from, to say to people what does system development really mean, well it means that people, young moms and other people learn how to take care of their babies. It means lots of really exciting things. So.

Speaker 1: Excellent. Okay, very back and then right.

Speaker 10: My question is actually in line with [INAUDIBLE] collaboration with other initiatives. It just seems that some of the states are working on getting MCHAT, the routine screening of MCHAT integrated into systems, it seems like such a nice opportunity to work with ABCD, Infants in New York State and I'm sure some states are already doing this but I think once you get that system and get providers **** integrating the use standardized development screening tools, using **** or whatever it's much easier build upon that and get that MCHAT into practices is a much easier sell I guess. So I was

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just wondering if you had experiences with states building and partnering specifically with ABCD.

Speaker 1: Any states have an opportunity or experience partner with ABCD. But it's a very, very good point because there are multiple efforts going on now working in primary care and pediatric practices to implement AAP guidelines around screening, one developmental screening and autism specific screening. So I had exactly the same thought when I saw screening with the MCHAT never in pediatric practice. I mean that's pretty compelling. That's kind of an outcome of, so very, very good point. Oh, right.

Speaker 11: Just real quick, being a parent of a child that experiences autism, and having a child that's medically ***** from having a seizure condition, one thing and I was on both the grants for the state of Washington, is that sometimes it really drills into very specific problems around that condition. My son Christian, you know, we have the medical coverage. ***** who experienced autism did not and so that awareness and with our state now partnering with the Insurance Commissioner's Office with autism, now we have bills going forward because they get it. And with the epilepsy grant, we were targeting on a Hispanic population that was not doing a follow up checks with the medication and the youth were embarrassed. And so a specific focus so I just wanted to share that sometimes it is quite helpful to do that.

Speaker 1: The point there being that sometimes it's very helpful to be able to use a condition specific example to help move the entire system forward and we've sort of experienced that too. In fact, we do get

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categorical conditions specific money directly from Congress. You know, we don't have a lot of control over that but one of the decisions we made early on was that we would superimpose a system's framework on that and that whether you were talking about traumatic brain injury, hemophilia, sickle cell, epilepsy, autism, that we would have to talk about the issues that are generic, even though they play out differently for different conditions, that we need to talk about partnerships with families. We need to talk about medical home. We need to talk about early and continuous screening, adequate financing. How can families get services at the community level whatever the condition is and we need to be concerned about growing up and being healthy regardless of what the condition is. And then we, you know, we certainly implement what Congress tells us to implement. But and those issues play out differently at the clinical level for sure. But I agree with you and I think one of the things I think we do have to do is not to get in one camp or the other, you know, I'm systems or I'm condition specific because they really just as your example, they really do play back and forth and in today's economy I think we really got to leverage any opportunity, wherever it comes from, to help build the entire system for everybody.

So any other questions, comments? It's lunch time. We are right on time. Help me thank this panel again. Great information.