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

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BONNIE STRICKLAND: There are plenty of seats up front. So those of you that are coming in --one, two, three, four, five, six, seven seats. Just don't sit on the red folder. Okay.

Welcome everybody. Were all of you in the last session, the storytelling session? So, probably our story could be there are a lot of kids with ASDs, families are struggling, systems are struggling, we have to do something. Thanks. I thought that was a terrific session, didn't you? Well, we're going to get to some stories here today. So this presentation is entitled, "Roles for State Title V Programs in Building Systems of Care for Children and Youth with ASDs." Its session ID is H7, which is a workshop and AMCHP only session.

This session is accredited for continuing education. Immediately following the conference, a link to the CDC Training and Continuing Education online system will be posted on the AMCHP website. In order to receive continuing education you have to complete the online CDC Continuing Education evaluation form by Monday, March 21, 2011, so you've got some time. Be sure to keep track of the sessions you attend throughout the conference as you will be required to enter this in the online system and a tracking sheet is provided in your conference bag. Further continuing education information can be found on page 10 of your program. Also, a conference evaluation survey will be posted online immediately following the conference. A link to the survey will be e-mailed to all attendees. AMCHP will use this feedback to help plan future conferences. Your input is very important and greatly appreciated. Also, don't forget to fill out the evaluation

sheet that should be on the seat that you're sitting on. It's either under you or it's in your lap and be sure to turn it in at the end of the session. Turn your cell phones to a silent mode please and now it's my pleasure to move on into introducing this session.

Holly Williams is the Director for -- let me start with the first presenter, Georgia Winson. Georgia is Chief of the Autism Program of Illinois. It's headquartered at the Hope Institute for Children and Families. TAP is a statewide network advancing a system of care for individuals with autism in their families. Ms. Winson has led state and national initiative to support consensus resulting in a comprehensive model engaging a network of 27 agencies and universities. Wow. TAP's model has demonstrated success in sustaining services during significant deficits in state and private funding. The model has been replicated to create intersects for ability, a network of 10 Chicago-based agencies serving thousands of individuals with developmental disabilities in the Chicago area. The network approach has demonstrated efficiencies, adoption of uniform standards, and a market reduction in agency isolation. That's quite a story. Winson received her Master's degree in Psychology from Illinois State University. She is a clinical focus in the field of autism and developmental disabilities. Georgia will be representing Illinois, sharing that story.

Then next we'll have Holly Williams, who is the Director for the Children with Special Healthcare Needs Bureau in Utah, The Department of Health. She has over 30 years experience as a public health nurse and has a Master's degree in Community

Health Nursing Administration. She's worked for the Bureau of Children with Special Healthcare Needs for over 25 years in numerous capacities and has overseen numerous grants, projects; including most recently the Medical Home Grant, the ASD Developmental Disability Systems Development Grant, and the Utah Newborn Screening Clinical Health Exchange.

With her is Dr. Harper Randall. She is a pediatrician and the Medical Director for the Division of Family and Health Preparedness at the Utah Department of Health. Dr. Randall is the Chair of the Utah Autism Iniatiative, a multi-agency committee whose task is to review all state autism spectrum disorder services and programs. She sits on the Autism Treatment Fund Committee, the ASD State Plan Workgroup, and she has help draft an ASD waiver proposal for the Utah legislature. In addition to her interest in ASD, Dr. Randall supervises the clinical services offered in nine children with healthcare needs locations throughout Utah. She also provides consultation to the other CSHCN and MCH programs. So, it will be Holly and Harper representing Utah and telling their story.

Finally, and certainly not least, Dr. Georgina Peacock, all of you know her, is a Medical Officer at the CDC. She works as a content expert on the Learn the Signs Act Early campaign. In this role, she has been the CDC lead on the Act Early Regional Summit project, which brings together key stakeholders, many of you have been a part of that, in states who work in the area of early identification and referral for children with developmental delay. State teams in those summits work in a collaborative way to build up the system

in their respective states to improve access to care for children with developmental delays. Currently she is working on an evaluation of the regional summits.

And I am Bonnie Strickland. I'm the Director of the Division of Services for Children with Special Healthcare Needs at the Maternal and Child Health Bureau and I will be moderating this session.

So just a brief intro here. The increasing -- I guess we really could tell this story the way I started before. A lot of kids have autism. They're getting more; we're all struggling, families are struggling, systems are struggling. But this increased prevalence and diagnosis does pose major challenges to state Maternal and Child Health programs as they try to pull together services to meet the diverse needs of the children and families. In fact, I think we say it all the time, but in no area is it more obvious that in this area no one state agency can affect the system's change needed to adequately meet the needs of these children and families. And that's why we at HRSA are funding the Combating Autism Act Initiative. You think I'd know, CAAI. And because of the difficulty in affecting systems change, we're working across agencies as with our work with CDC and we're working on issues of critical importance to children and families on the spectrum and other developmental disabilities; adequate insurance, family professional partnership, early and continuous screening, services easy to use at the community level and ultimately transition to adulthood. Those cross-cutting critical issues.

And then third, we're working different aspects of the system, including research, training, and services and demonstrations infrastructure kinds of grants and that's where we're going to focus today is on that services, states systems infrastructure.

So today's session is a product of the work generated by AMCHP's State Public Health Autism Resource Center, which you probably know better as SPHARC. I think you have a handout on your seat, a fact sheet about SPHARC. SPHARC is funded by MCH and also now the CDC through the Combating Autism Act. Specifically, all of us on the panel, all of us here are members of SPHARC. It's a group of federal and state public health leaders working on autism issues, as well as representatives from key partner organizations. We've been charged with helping SPHARC **** identify and develop strategies and approaches to help state Title V programs build their systems of services for children on the spectrum and with other developmental disabilities.

Since the group first convened in September of 2010, SPARCH has developed the draft policy framework identifying key roles for state Title V programs and other state programs. Again, we said this can't be done by one agency. So, key roles for Title V and for other state programs working on the system related to children and youth with autism. SPARCH has collected a variety of state examples that show how states, particularly those funded with the grant funds that we provide, how states and communities are meeting the challenges presented by children on the spectrum. And they've also identified strategies on how states have managed

to strengthen inner agency and inner organizational coordination and partnerships.

The representatives here with us today are speaking on their – from their leadership perspective on their insights and their experiences and trying to address the multitude of needs, not only for children with autism but for developmental disabilities in general. So they're going to be talking about the roles for state programs as well as federal leadership roles to help Title V programs and all-state programs that work on autism issues, build systems of care for children and youth with ASD.

So at this point I'm going to turn the session over to Georgia and she will be talking with you about Illinois role in building the system of services for children and youth with autism.

GEORGIA WINSON: Thanks, Bonnie. Well to kind of go with the storytelling mode, everybody's kind of abuzz about the last presentation to talk to you about storytelling. I think system development is kind of akin to a Russian novel. Multiple players, a lot of intrigue and also most of the players in a Russian novel have multiple names, if you haven't noticed. And names with very few vowels and we have that. HRSA, AMCHP, MCHB. So my job is to kind of simplify system development. So I'm going to spend some time really talking about some basic tenets of system development and the role of Title V as it's been played out in Illinois and in the other states. Holly is going to actually drill down and talk about Utah's specific initiatives. Holly and Harper, Dr. Randall, and then Georgina is

going to talk about the interface with the federal government, which I think all of us have benefited from.

A couple things about system development and, again, this is very boiled down from the big Russian novel that system development is, but system development is really based on a combination of solid system interventions. And by solid system interventions I mean those interventions that are consensus driven, interventions that actually utilize common language and framework. So when you think about how do you intervene with a system, you need to talk the same language and you really need to look at common frameworks. You also need to look at interventions that have built in sustainability because system development is something that's going to happen over the long haul. It takes a lot of patience.

But we also need to make sure we employ those interventions through a flexible system of links and partnerships and that we engage those partnerships at the appropriate points in the lifespan of a system. In a few minutes I'll talk a little bit about maybe some mistakes that we made early on in Illinois where we actually employed what might be a really great intervention but we employed it at the wrong time in our systems development. So I think those are some important things to keep in mind.

When we think about system stages, I've actually identified four system stages and these stages have really been distilled from our work in Illinois. They're not discrete, so that we see these kind of stages overlapping as a system develops and we also know that these can be happening at both the state and the community level.

So where the overall state system may be at level three here serving and evaluating, there may be individual communities within the state that are still focused on the engage and aware part of the system. So I think that's something to really think about. This framework I hope can help you – when you think about your communities and when you think about your overall state.

Engaged and aware. The Autism Program of Illinois, we began in 2003 and our major appropriation was a state appropriation. That appropriation was brought into bear because there was a significant grassroots effort. That initial state appropriation came about by families and a few providers who were making the state aware of the dire circumstances that their families were facing and finding appropriate diagnosis and treatment.

So at this level of development we see a lot of grassroots outreach. There are some initial engagement of pivotal community partners. So in Illinois those partnerships where the Illinois General Assembly and several of our key universities. At that point it was University of Chicago and SIU School of Medicine. So we had a buzz going. We had identified a need; although, we hadn't articulated it clearly and we had some people coming to the table.

Some things you often see happening, in terms of appropriate interventions when a system is at this stage, our comprehensive needs assessment, some resource mapping, getting information out there, and beginning to develop some more organized awareness campaigns. So back in 2003, these are some of the initial things that we began doing to build the system. And if you think about it

your partnerships really are dependent in some ways on which level that you're in. I would say, and I think I'm going to make a pretty forceful argument, that family engagement is important across all levels of system development, but certainly family engagement at this level was really critical to our development. In fact, family engagement was the catalyst for the entire development of our system in Illinois.

The second level, kind of been titled Empowered and Equipped, and some of the characteristics of a system at this level are emerging standards of care. There are some based financial support. We're beginning to see inadequate workforce. There's a real commitment of pivotal partners and some of those that we've identified and experienced in Illinois are our Title V organization, which in Illinois it's the Division of Specialized Care for Children, education, Department of Human Services, various advocacy organizations, like Autism in the Society of Illinois. We've worked Autism Speaks at the state level and different trade associations, like the American Academy of Pediatrics and the Association of Family Practitioners. Some of these trade organizations have been really important and play a key role during this time.

Some of the interventions, when a system is kind of engaged in this part of its development we'd be some systematic training, published standards, insurance mandates so that we begin to build the system both bringing people into the workforce and also getting some money into the system so that workers really have a way to be reimbursed for their services.

Medicaid restructuring, sliding fee scales and looking for additional grant funding. So at this stage the system is really beginning to be up and running. One of the things I'll bring up in terms of a mistake that we made, I mentioned that the engaged and aware stage is where we started in Illinois, well we had a number of university partners that were part of our planning committee and those partners came to the table really smart people and I was one of the folks that was right on board with them on this and we said, "You know what? We need to publish some standards of care for Illinois. We're going to public best practice standards right now and we're going to convene a group and we're going to start working on that." You know the problem with that was that our constituent groups, our parents, the people that we really needed to make this system roll were much more interested in getting some very basic services out there. They were interested in us doing a real catalog of what the need was and so there was very little energy at that point around developing standards of care.

So we actually kind of had a bit of a premature focus on that. Now we didn't take it off the board and I'm really glad we didn't because if you get a system rolling too quickly and you get services in place and there are no standards of care, if you get money coming into a system and there are no standards of care, you'd have a completely different problem. So I hope you can kind of see what I mean in terms of really staggering your interventions with where the system is.

Serving and evaluating. I mean, I would say it's not where it needs to be completely but Illinois I think is kind of edging up on this level: serving and evaluating. We actually are – we have emerging service across multiple disciplines and I think this grant through the Combating Autism Act has been very helpful in that. I think the Medical Home is a great vehicle for this because it really talks about coordinated care. We are doing an increased access to services and we have a stronger focus on care coordination. One of the things that we've done in Illinois through this grant is we've developed a medical service protocol and all of the autism programs centered have a protocol that allows them to interface appropriately with primary care physicians, with education, and others.

So I think care coordination is really a hallmark of this level of development. Also Resource and Referral. So you're getting tangible things into people's hands and you're evaluating how those services and how those resources are affecting families. I would say for the autism program right now our evaluation we're moving towards outcome level. I would say that we're still a little bit stuck on outputs and I would love to see us – and we're going to be working to kind of ramp up and do even more in terms of documenting clinical outcomes, but we have a good system for looking at what we're doing and we're beginning to look much more closely at how that's affecting our families from a clinical perspective.

And in the final level, which I think is probably where it's a never-ending process, is expanding and refining. So at this I would say

that a system would have a very balance – a very strong balance between the need and available service. Any of you who know Illinois know that we're not at this point. New things need to happen; we need more money, we need insurance mandates, we need additional support for practice parameters. So I don't want to send the message that once you leave one of these stages you don't ever revisit them, because you do. It's a constant moving back and forth. I mean, we have an insurance mandate in Illinois. So you can say, "Oh, we accomplished that. Wonderful." But our insurance mandate doesn't cover any families that are with self-insured plans. So that's a series deficit and it's something we're going to have to revisit.

I want to talk a little bit about the really fantastic infusion of energy and resources and ideas that this HRSA grant has provided to Illinois and particularly our interface with our Title V organization. If you look at the state implementation grants there's a myriad of grantees represented in that grant program. There are universities, there are public health departments, there are family advocacy groups, there are non-profits, like our grant The Hope Institute, there are Title V organizations, but I think that I can demonstrate that Title V has really been an integral part of our development even though our Title V organization was not the recipient of this particular grant.

And I'm going to do this by going back to some of the HRSA MCHB six-priority areas, partnerships between professionals and families. You know, when I was talking about our early years, when we were in the first stage of development, our Title V

organization had already done a significant amount of work in parent partnerships and this is even before the HRSA grant to us. Our Title V organization came in and trained me and trained all of our staff on developing family advisors and solid family partnerships. This was really a tremendous support to us and I think it got us over some significant hurdles in our early development.

Access to Medical Home. The Title V's focus on Medical Home is incredibly important when you think about a system of care. If you have a Medical Home focus right away you're bringing everybody to the table. Now people come to the table, some of them reluctantly. People come to the table at different levels and degrees, but the whole concept suggests that we're going to bring all the important players to the table and our Title V organization in Illinois has emphasized this for the beginning and it's been a major part of our planning for our autism program.

Access to adequate insurance. The insurance mandate in Illinois I can tell you that representatives from our Title V organization that they actually were a part of reviewing the legislation in Illinois, they made very strong edits and provided support for this legislation and that's been incredibly helpful.

Early and continuous screening. Our Title V group has utilized ASD specific training that was developed with us in conjunction with our AAP chapter to really get additional information out there to providers. Additionally, Title V I think across the country has a very strong focus on developmental screening and they've been

very responsive to actually looking at more autism specific screening as autism has become a prominent feature in terms of our public health care awareness.

Organized community services. Our Title V organization currently, under this grant, but even at the very beginning, did a lot to link the autism program as we were growing to both state and national resources. Some of you might even know Dr. Charles Onufer, he was in charge of our Title V organization when our program started and it actually was my first month on the job. I had an appointment Dr. Onufer and I went in to say, "Dr. Onufer, I'm Georgia Winson and we had this major state grant and we're really excited about building autism services and how can you help us." And we're talking along and all the sudden he got up from his desk, walked back into an inner office and came back with an 8x10 and said this is grandson and he was just diagnosed with autism. And he said, "I'm really interested in what you're doing." He said, "Our Title V organization doesn't serve kids with autism. That that's not one of our service parameters where it's a primary of autism," but he said, "We're going to help you in whatever we can." And boy did he.

He introduced me to the people at RAAP organization, he introduced me to all the trade organizations for physicians, he was very, very helpful.

And obviously transition services. Title V is doing a lot to disseminate information for us.

Finally, I want to talk a little bit just about system partner's roles and responsibilities. The Autism Program of Illinois is actually the lead partner for this particular grant and when you look at the system of care and what a lead partner needs to do as the system develops. Initially, we focused very heavily on advocacy. At our second stage, I would say it was advocacy plus training, workforce development, and looking more for multiple funders, at serving and evaluating advocacy plus training plus funders plus a strong clinical focus in gauging clinicians around the state. And then here, expanding and refining advocacy, training, funders, clinics, and universities to really support that piece of it.

A lead partner and I would say the Autism Program because of our state funding is a lead program initiative in Illinois but I think Title V is one of the programs that fit all of these criteria. Established creditability, stable human and money resources, broad appeal to all facets of the system, and ability to support the system across the stages, knowledge of the system, the current status and future needs, a long term commitment, strong alignment between the organizational goals of Title V and the system life stage and system needs and a knowledge of fundamental system building blocks. What I have learned about the building blocks available at the federal and state level through this grant is really going to help our program go forward in a major way in the future and I wouldn't have had that without our relationship with Title V and without this ongoing HRSA funding and a system support partner.

For us, Title V I think is serving this function and that means they walk along with us every step of the way. That they are walking in

parallel with us. They've made a long-term commitment to autism in Illinois. They have an ability to work in a support capacity. One of the things I've valued about our Title V organization that is – can't be really quantified but it's because of the people that are involved is it's a pretty humble group. I mean, this is a major program funded by the federal government that's been there forever and they said, "You know, the autism program got the state funding, we're going to work with." And they have been incredibly helpful; they're non-competitive, they're collaborative in almost every way imaginable.

And then we have some partners that are more system developed – program development partners. Some of those would include law enforcement of Illinois. We've worked with law enforcement to develop first responder training. Our Family-to-Family worked closely with us to develop a discrete program to train families. So some programs fit into that and then some are linkage partners. So our healthcare and family services, our public aid, gave us access to their database and they've linked us to docs who provide Medicaid services around the state. So their primary role has been linkage but they've been important nonetheless.

So I hope that this kind of gives you a quick overview about just in general how a system can work and about Title V in Illinois and Title V's benefits. And Holly's going to give us more of the specifics in Utah.