

## **AMCHP Annual Conference, 2010**

### **Moving Ahead Together:**

#### **Celebrating the Legacy, Shaping the Future of Maternal and Child Health**

#### **The Nuts and Bolts of Building Community-Based Service Systems for CYSHCN**

March 6-10, 2010

UNKNOWN SPEAKER: Good morning. Good morning, everyone. Hi, we're wide awake, right? It's Sunday morning and a full day yesterday. And I was telling people I was here from 8:30 until 9:30 last night, but I'm here and I had to drive from home so...welcome. We're really delighted to see you this morning. We welcome you to this fantastic skills building session around the nuts and bolts of building community-based service systems for children and youth with special health care needs and their families. And we will be hearing about some state and family experiences about building these systems of services at the community level and we'll also be hearing about how you can help back home. But why are these service systems important? Why are they important to you, to families, and to the bureau? Well the reasons why we think they're important is why families and providers think they're important. Number one, having systems...service systems that are coordinated, integrated, working well for families at the community level is basic for having a really great system of services for children and youth with special health care needs and their families. I mean that's where the rubber hits the road so to speak. If it doesn't work well for families it's not working. And then how can we at the federal level assist our state programs to assist their communities in terms of building and sustaining those service systems. How can you help those

community-based systems look at continuous quality improvement mechanisms and processes? What data can you get to then go back and work with those communities around improving those service systems and how can you monitor those? So we'll be looking at all of those kinds of things and we hope that our emphasis on a community-based system one of the core components of a service system for children and youth with special health care needs is as important to you as it is to us. I'd like to introduce our speakers and she only gave me five minutes. She knows I'm a former teacher. I take a long time. But at like our speakers will be Diane Behl and she is a Senior Researcher at Utah State University and near and dear to my heart because she is...yes you are...she is a co-PI for Champions for Inclusive Communities, one of our national centers that really helps all of our programs look at community-based service systems and they have a great track record. They've had other grants with us, Champions for Progress, measuring and monitoring community-based systems, opening doors and they've done a lot of work around continuous quality improvement and care coordination. So they really have the expertise there and moreover they reach out to states and families as teams to work with them.

Anna Cyr is a mother of two daughters ages 24 and 16 who have a chronic condition called microvillus inclusion disease. And she and her husband have been working for many years to make sure that their daughters have a quality life. She is the Family Consultant to the Children's Special Health Care Needs program in Maine. She works with another program dear to my heart; she works with the Maine Family to Family Health Information Center and the Maine Parent Federation. She's also a family mentor

here with AMCHP and we appreciate that and she's worked as on the legislative committee of her state wide family organization coalition as well as immigrant and refugee families in her community.

Eileen Forlenza, another nationally known family leader serves as the Director of the Colorado Medical Home Initiative with the Department of Public Health and Environment. She's worked with many of our national centers, Family Voices, National Center for Family Professional Partnerships, The National Center for Cultural Competence, she's on many committee's the National Initiative for Child Health Quality and been around and she's worked a lot in her state and nationally even on things that you might not imagine working with siblings in foster care, domestic abuse victims, she has a wonderful voice. She sings beautifully and she's developed a song really in honor of her daughter and it's really heart felt.

Harper Randall is a pediatrician. She's the Medical Director for the Bureau of Children with Special Health Care Needs at the Utah Department of Health. She has been practicing pediatrics for about 16 years. And her work is tough. All of our state directors know that you wear many hats. She oversees the clinical services in eight CSHCN locations throughout Utah. She provides consultation to all the other CSH programs in her state. It's mind boggling. Early intervention, medical home and transition, fostering healthy children, newborn screening, newborn hearing screening so you do a lot.

And Toni Wall, last but not least, is the Director of Maine's Children with Special Health Care Needs program. She also started in public health working on the oral health program and was really instrumental in helping communities look at what's in their well water already before you put more fluorine in it. She has served as the Director of Children with Special Health Care Needs since 1999. She is the co-PI for Healthy and Ready to Work National Center, working with looking at transition from pediatric care to adult health care as well as how you get youth involved in advocacy and being their own advocates. So I'm going to turn this over to Diane and you'll have a different kind of interaction here. A lot of small groups, large groups, so Diane...

DIANE BEHL: Good morning everyone. I see a lot of familiar faces as well as some new ones so that's great. Just to quickly reiterate the session objectives here to make sure that you're in the right room. You're not supposed to be Annapolis 3. What we'd like to do is be talking about the definition of community-based service systems, understanding the systems change process that our learning community went through and what a developmental process this is emphasizing the value of this learning community model. I'm going to tell you what that is in a minute and give you an opportunity to see how you could potentially apply this process to your own state.

Let me start by getting kind of a sense of what brought you to this session so if someone could just offer up why they decided to come into this one so we have a sense of your priorities perhaps?

SUSAN: It's 2010, amazingly, and the system of care that we sort of thought ten years ago was going to be in place isn't. So is the remaining work to do (inaudible)...

DIANE BEHL:       Anyone else? Any challenges facing, yes...

UNKNOWN SPEAKER: Well in Iowa we decided to have a performance measure that is all around (Inaudible)... implemented. So I thought it would be impressive to see how this session might relate to my...

DIANE BEHL:...your state performance measure, good. Okay so please ask a lot of questions during this session. Okay any other thoughts? Anyone going through some financial challenges, yes? No?

UNKNOWN SPEAKER: (Inaudible)... guest of the B.C. Government (Inaudible)... sort of a go between in understanding how the systems work (Inaudible)... so in order for me to understand what I'm doing I need to understand how the system is supposed to work so (Inaudible)...

DIANE BEHL: And we need you here, good, thank you. All right, Steve?

STEVE: For mine it's kind of the (Inaudible)...

DIANE BEHL: Okay and how to work through that at lightening speed. All right, super. Let me see a show of hands who do we have in terms of family or youth leaders here? Oh great, that's wonderful because you're really critical of this process. What about state, CSHCN or MCH leaders? Super. Any community level providers? Okay, good. We're counting on that community voice through all of this, too. All right, great. Thank you. That gives us a sense in terms of your issues. And so our format as Diana said we want it to be interactive even though we're sitting up here at this table. We're going to want to just really get some dialogue going. We're going to have some small group hands on discussion group activities. We want this to be a time when you're sharing the successes but also the challenges you know so because I think we learn so much from that and to give you some action plan ideas that you can take home. So I'm going to start with this definition of what is a learning community because there are different terms. Some people talk about learning collaboratives, etc. We'll use the term learning community that was by Sange and Sharmer that talks about it being a diverse group of people working together, families, state people, community people, state national centers with the purpose to nurture and sustain a knowledge creating system. We're learning from one another valuing research, capacity building and practice on the ground work that will result in new ways of doing things in that practical know-how. And so are learning community that we're going to be sharing with you involved Colorado as our kind of guide state or mentor state and Utah and Maine as the partner states. Champions for Inclusive Communities has served as a facilitator of this effort with technical assistance with AMCHP as a very important resource partner as well as consultant. Grace Williams, who's in the back has been participating in round two

learning community we've been holding. And what brought us together was kind of this a common shared goal to say we've got to find a new way of looking at doing business and also meeting those states specific needs.

And so the other quick definition here, there is a lot on this slide is well what do you we mean by a community-based system of services? I don't know about you but this has been one of the hardest things sometimes for people to get their hands on. And one way that we've been thinking of it is it means well those services are organized so families can use them easily. They need to be provided in communities in a way that fits those family routines. Community-based services strengthen that community capacity. So when you think of those six outcomes it means what are you doing to insure there are medical homes collaborating with those other services that you've got maybe some creative financing strategies going on at the community level to fill those gaps. Care coordination at a family level as well as things like inter-agency applications that can help families quickly apply for services is part of this. Coordinating your screening efforts so families again know where to go if they're concerned about their child and that we've got community-based resources to support transition which I think is one of the big needs there. The other thing about community-based services is that it's closely related to that MCH pyramid and supports those core public health functions. You know we're talking about how do you develop those resources. Get...do good outreach so families know where to go for services that there is technical assistance and training available for our community providers to help families organize services and to mobilize those community partnerships. And so here's just a quick slide that I

stole from cast five that essentially defines, you know shows the MCH pyramid those sections and those essential public health services. And so it's been one of the things I think that Colorado really helped us keep our head around in terms of we're doing the work of public health remember.

So we're going to be going through the systems change process with you and you've got the six steps here. We're going to be talking about inspiring a shared vision, engaging strategic partners, assuring your communities...assessing your communities in infrastructure. Developing a plan in budgeting, implementing that plan and how do you measure those outcomes? And so as we go through this with you, one of the things to keep in mind is systems change takes a long time and it takes a lot of time. And as you'll hear from my friends and colleagues this is something that is continuing to be working on as we all speak. And so at this point I'm going to turn it over to Harper Randall who is going to talk about Utah's reasons for getting involved. I'll stay here and flip for you, okay.

HARPER RANDALL: So the overriding reason that our bureau wanted to move forward with this is we're really top heavy on that pyramid. A lot of clinical services and not as much infrastructure so that was sort of the overriding reason. But as others have already mentioned financial was really the...it shoved us into it. We've had dramatic state funding cuts. Two thirds of our state funding, actually three fourths of our state funding has been cut over the last two years. And as we all know that federal funding. And then our Aurora clinics because of the geography of Utah are very remote, require

air transport to get to them and they need us to continue to help them. So we needed to justify why we were spending the kind of money we were for these clinics and also how then we could better...we could assure that they would be sustainable regardless of what sort of cuts were ahead of us. There were no other opportunities for these rural communities to have multi-specialty diagnostic clinics. And so we really needed to figure out how we can keep these going, how we can justify the expense. So our timeline, Diane mentioned how long it's taken. We were fortunate enough to start working with Colorado and Maine in the spring of 2008. In the fall of that year, we got our stakeholder group within the bureau together, we revised our vision and mission statements, we developed a strategic plan. That following winter we started to develop some surveys to get more information from these communities, we distributed those both to providers and also to family members who used our clinics. And that summer we had some remote focus groups, that fall we said great, we summarized all our findings, we're going to develop this great restructuring plan and then this winter we presented that plan and were told we couldn't do it because it affected the Speaker of the House's area too much and we didn't want to upset him. So we had to go back and regroup which again has been frustrating and yet it also says there isn't only one plan that's going to work. We can look at other areas and so now we're redeveloping a plan, we're continuing relationships that we've already been able to build through this process with our rural communities and we're also continuing to identify for the community resources.

DIANA: Okay thanks Harper, Toni do you want to talk about why...your reasons for getting involved.

TONI WALL: Well first I'd like to take the opportunity to really to thank Diane and Harper and Cathy Watters who couldn't be with us today. She's the CHSM Director in Colorado. Eileen is here also to talk about the wonderful job that the three of us have really created a wonderful opportunity to work together to learn from each other and really to go beyond a really direct service type of component to really looking at an array of community-based services for the population that we serve. Maine also had declining revenues starting back in 2005. We recognize that we are spending a lot of money on just the direct service component for a small number of children and really when Maine started cutting services, we actually started to cut services back in 2005 to many of our clinics, excuse me, and then continue to cut those with more declining revenue. I'd like Diana to talk about...Well let me just talk about my budget first. Our budget is actually only \$795,000 to serve kids with special health needs. We are overspending our budget by 1.5 million dollars. 60% of that went to serving kids...it was just medical prescriptions and medical equipment. It's a lot of money for serving about 2000 kids. And it was really hard for me to justify that in recognizing that we had to pull up our suspenders and become more accountable for the money that we were spending. It took us three to four years to get down to that \$795,000 mark because we did not cut our kids off the program immediately. We moved them off very slowly. Anna do you want to talk about...?

ANNA CYR: When Toni invited me to go to Colorado and work with this learning community when I started to realize what it was all about I was very excited. Mostly because I...my dream is to have a global access point for families of kids with special health needs not based on any condition specific or financially specific criteria. I called it the club which my family was never a member of. So I was excited that it was going to be more inclusive and I have heard from families over the last 24 years that I have been a parent of a child with special needs that they want an access point out. That they can consistently use to enter the system and an access point that is consistent, that is knowledgeable about what the resources are, that sort of a one stop shop. I know we've all heard that expression that parents are looking for just because their focus needs to be on the care of their child or children, in my case. One thing I like to say is that...and I think I'm stealing someone else's idea here. We have an arena in our state called the Augusta Civic Center and the number of children with special health care needs in Maine would fill the Augusta Civic Center seven times. The number of children served by the previous system Children with Special Health Care Needs System would fill one tenth of the arena. So I'm hoping that we can fill that arena seven times.

TONI WALL: And there was also a desire for us to move to a more public health model where we incorporate assessment quality assurance and policy development. Our timeline as I said took a long time. In July of '05, I think you flipped to that...we eliminated specialty clinics and those included our metabolism, hemophilia, cancer, spina bifida, all of those clinics that we had actually sponsored through the hospital for

about 25 years. We found the hospitals were really oh my gosh, how are we going to support this? And low and behold those clinics are still taking place although hospitals now are experiencing a drastic cut in funding, too, but those clinics still do go on. We merged with a genetics program that brought in newborn hearing, birth defects, paranatal care and it was a whole new realm of public health programs that we had never worked with before. We had worked with them but we were merged together and it created serious problems with us. We all had different mission statements, different vision statements, which way are we going. It was very difficult. We closed our program in July '07 to new applicants. As I said we were overspending our budget. Then we had main care member services the EPS the T arm of main care, our Medicaid agency join us in '07 so that was...we went from a group of about four to about 18 people in a matter of two years. And then we actually started prioritizing our clients on a scale of one, two, three. One being the kids who had insurance and/or main care, and slowly move those kids off of our program and we still keep our level three kids on there the most intensive kids and they still require funding for particular conditions that they have. We've created a new vision, our new mission statement. We are within our budget this year. We created our new Partners in Care Coordination so we can expand and provide care coordination to a multitude of families not just condition specific. And this year I had to eliminate our DEC's, cerebral palsy and we just really completed our care coordination brochure with Anna's help and we're all set. And I'm ready to move onto Colorado.

UNKNOWN SPEAKER: Before we move on are there any questions? I thought Maine would have one or two...but...okay.

DIANA: As questions come up please raise your hand. And I also want to point out there are handouts in the back that I'd like you to get. There are folders as well as some other individual hand outs. Okay great. All right. Eileen. I think so. Well we're going to check with Jack.

EILEEN FORLENZA: I just...when I talk about this...I just...I can't sit so I can't help it. Sorry. Primarily because coming in as a parent of a child with special health care needs I felt so frustrated. And I echoed the sentiment that Anna expressed and that was why can't I find what I need? And moreover why do I keep hearing this from all these families? So as a parent and then joining one of our local health departments and that was my role as a...I lived in the county and worked at the local county health department. There was this buzz that the state program was going to move to a community-based system of delivery and I thought I want to be a part of that. And so as we're looking...when this opportunity came up to help other states, I can't help but get excited because I know that this is the best thing for families. It's not only the best thing for families, it's the best thing for our state, it's the best thing for our system. Because a top down model is not effective. And I don't mean top down in terms of power and authority. I mean around access and availability. And so when we...we have 64 counties in Colorado. We're a very vast and rural community so when this opportunity came up it was an opportunity for us as Colorado to re-look at so where are we now?

And why are...why is it important for Colorado to share some of our learnings with our other friends. And that's what we learned was that in mentoring we learned more and more and more. And that was one of the reasons that we jumped on the opportunity to work with Diane in this learning community model. And again to connect with families and understand so where are we now? And to look at this from an assessment and evaluation perspective and to say five years after we move down the pyramid how are families feeling? How is our staff feeling? How are the people out in the community really getting a hold of this idea? So that was the reason that we joined in, that Colorado joined in. The reasons that we went to the bottom of the pyramid in the first place was again very much what my colleagues have already identified the budget situation, looking at what I, in the business model the 80/20 perspective about having 80% of our funding going to 20% of the population. Not a good business model. Really needing to connect with families in a meaningful way. And so that's what kind of moved us into that place and then moving in with...not moving in literally but joining Diane and this team to put something in place to share with other states has been a really wonderful opportunity.

DIANE BEHL: We love working with Eileen and Cathy. All right but don't sit down because as we said we're going to be working through these steps with you and tell you what this step meant to each of the states and so we're going to go through step one and two and have some small group discussion and we also do have an official break time designated, just so you know it's going to be coming up around 10:30. So on that Eileen, do you want to stay there and kind of...talk about...

EILEEN FORLENZA: Sure.

DIANE BEHL: And again these steps came...oh, let me see, yes, thank you.