

**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

DIANE BEHL: It looks like we're set then and so now...Eileen will you talk about Colorado how you engaged your strategic partners in getting your buy in?

EILEEN FORLENZA: Again in the spirit of understanding that this was kind of a group activity with our state partners we talked pretty quickly with some of the folks we knew we would need support from. And that would include our local children's hospital, which is actually a regional children's hospital so a lot of catchment if you will in terms of services. We also talked with our university center of excellence understanding how critical that would be. We looked at the non-profit sector, faith-based communities; we really tried to think outside the box in terms of how are we...when we move this into the community who are the community partners that are going to really be part of that new safety net if you will. Part of the sense was again as Toni had expressed is that working with the local staff there was this huge sense of but who's going to take care of the kids? Who is going to catch all of these kiddos that we are now feeling like we're dropping off the ledge? And it had to be when you move through this you have to believe that there are other ambassadors who are going to come in. Because it's not the

role of the health department to fix our health care system. It's not. And we had to step out of that role of covering everything for every child because it wasn't working. And so we knew that we had to be strategic about whom those ambassadors are. And being able to ask again, ask the families in those local communities, who are you aware of and you'll be surprised. We engaged in a new relationship, a stronger relationship for example with Shriner's and Shriner's has a clinic in Utah, go figure. But those kinds of things were really important and having the faith that in a new structure that the kids would be okay. And I think that that's part of leadership, sending that clear message. Having a sense of strong leadership is critical during this time because people are looking for someone to assure them that the change is going to be okay. And that is your role in your state is to provide a very clear message about why you're doing this, this is not going to change, we cannot go back the way it was. And even if you fake it till you make it and you have to just keep saying it and then go back to your office and cry and say I really hope this works. But sending a clear message of this has got to be different. We have got to change. And I'm not sending the kids down the water. We really believe that our community will come together because it will. And I think that that's one of the most important pieces in step two.

DIANE BEHL: Thanks, Eileen...Harper.

HARPER RANDALL: So because we develop this vision that said facilitating access and then we looked at what we had, we were this...we were great. We were swooping in and saving the day. We were providing the service at what we thought was

a very easy to understand but not well known schedule three times a week we would swoop down, get the diagnosis and swoop away and send out letters.

UNKNOWN SPEAKER: Swoop down into communities. You're clinic sites?

HARPER RANDALL: Swoop down into communities, thank you. But we were providing it, we were fixing it. We were doing it all. And how...was that really facilitating access and was that really asking and meeting the needs of a community. So we tried to reach out as much as we could in this early part, making calls, trying to identify who wants to be the ambassador, who should come along with them, making sure they knew that they were part of the discussion and part of the solution and not just we're going to deliver the solution to you. Sharing that vision but also sharing the reality. I mean it's all just lofty to say we've got this great new plan but they had to understand that why the system was broken and how it couldn't continue. So we had to share that budget issue with them. Really trying to get that (Inaudible) so that they trust us because there's a lot of distrust. The department of health just cuts services willy nilly and look they're left holding an empty basket so it was really important that they understood community people in the community who were working together and that we would include them in our decisions and our discussions. And then also that it wasn't just a one time thing. That we would be there tomorrow and we would be there a year from now and we'd be coming back and we'd be continuing to better the process. So those were all really key things. One of the things that Diane helped us with was developing a concept paper. And so now we know who we are, we've got this vision statement but we really...people

just thought well they're just people that swoop in and do their clinics and swoop away. So no, we're much more than that. Who are we? So really letting them know who we were and what we could offer their communities and so this concept paper, there is a copy in the back, 2-page...

DIANE BHL: It should be in your folder.

HARPER RANDALL: ...was really important in that. And it also was important in us forming who we were working through developing this concept paper.

UNKNOWN SPEAKER: I just want to talk a little bit about engaging partners outside of our agency, the bureau of health or the Maine CDC. We really started looking at our Medicaid agency called Maine Care because they serve about 125,000 kids birth through age 20 and as I mentioned before we had our Maine Care member services in there and they're the EPSDT arm of Maine Care. And we knew, we have about, let's call it 16% of the population has special needs that there was a large number of kids in that agency who probably were not getting the services or the attention or any information other than their medical services were paid through Maine Care. So it's been a long process to think about how we work with them. But it's been a little easier than I thought because we've been able to provide something back to the Maine Care agency. First of all, we are looking at their numbers and helping them increase their immunization rates by looking at that. We have... I'm sorry epidemiologists in our unit so we're able to help them look at their numbers. We're looking at their bright future

rates and going...they're currently at about 54% and they want to go up to 85% and we're able to look at those kids and actually provide care coordination to those kids with special health needs. We make phone calls to them, we ask them what services they need, what their priorities are and how we can help them. It actually has been a really...a benefit for us. Maine Care just implemented our targeted case management for kids with chronic medical conditions. I have to say that was news to me. The rule came out and I looked at it and said oh my gosh, they're providing targeted case management. Very limited services, they've hired a behavioral health agency to oversee this process. There are no medical people, no RN's, no physician's. They are wonderful at behavioral health and emotional and behavioral issues but no medical. So we've been able to move in and actually we're teaching them care coordination and providing them a medical aspect on care coordination which they are quite please about. And I'm going to let Anna talk about all the things that she does currently with Maine Care.

ANNA CYR: All the things I do currently with Maine Care? I sit on a Medicaid advisory committee which meets once a month and really I go and I listen and I learn about what's happening and what I'm hearing consistently is that people are scared. The budget has been cut, cut, cut...and you know people were sort of rallying around it at first but now people are starting to say whoa, whoa this is really going to start to make a huge difference in how we deliver services. So and families are starting to feel it. I'm hearing from families...I'm seeing...I'm also on a Katy Beckett external work group and an example of some scary statistics is that we had originally 1300 kids in the Katy...around 1300 in the Katy Beckett program and now it's down to 950. The average

number of denials per year was about 55, it's almost 200. So there's something going on. There's something scary happening and you know you can look at it two different ways. You can say this is the perfect time to implement this program because this is when people are ripe to build community services. So that's how I'm choosing to embrace this opportunity and say this is a time when people want to tell you what's going on, what are the issues in their area.

Back to the original question what else am I doing? Oh, I sit on the Katy Beckett external work group. That has been an education as well.

DIANE BEHL: Great.

ANNA CYR: I'm sorry, oh I didn't even see.

DIANE: Yeah, that's great. So what you've heard about here is essentially with step one, working with your staff in talking about why are we all here? What's our role? And getting that by in for vision and mission and then taking it out in step two by engaging that broader stakeholder group to really get them involved as well. And so one of the things we did that we'd like to try here, to give you an opportunity to say well how would this process relate to what we're doing? What are some things we need to be thinking about is developed this action guide that is in your folders. Did everyone grab a folder from the back? If you didn't I encourage you to do that. And what I'd like you to do is pull out that action guide and...because...and what we're going to do is kind of do our own

little learning communities here to give you a sense of that sharing and so what I'd like you to do...what I'd like you to do please is just within your seats, move some chairs around a bit and form groups of about five to six people. And with that action guide, I'd like you to go through and just talk about your answers to those questions. Share what things look like in your state, how you'd work through this process and be considering some of those issues. I'd like you to do it for step one and step two. Form into groups right now. Talk amongst yourselves and then in ten minutes I'm going to kind of gauge where we are. We're not going to be asking...thanks, Diana, she's holding up what it looks like. We're not going to be asking for each group to do a report because I think that gets kind of old. But what I would like...what we will ask for are a couple of kind of those aha's. Some of those brilliant ideas or big challenges that perhaps we haven't been talking about, okay? So ready set go.

UNKNOWN SPEAKER: For those of you who are family leaders in the group look at it from the lens of how could you contribute to the team process? There will be some state folks in your group but think about your role in that partnership.

DIANE BEHL: Very good reminder, thank you.