

HRSA/MCHB 2007 FEDERAL/STATE PARTNERSHIP MEETING

Building Blocks for Promising Practice Models

October 14 - 17, 2007

Promising Practices: Building Data Capacity for

Transition Progress and Practices

TONI WALL: Thank you, Elizabeth. Mallory and I are here today to talk about what Maine has done with youth and how they're involved in the state CSHCN program and other activities that they've been, other agents and activities that they've been involved in over the last it's probably almost nine, almost 10 years that we've involved youth.

Part of the things that we have -- excuse me as I go numb on my voice. Part of the things we've done with youth, originally they helped create what's called Youth Speak and I believe we have sent CDs out to all the MCH and CSHCN directors over the last three, four years ago, I guess, that we finished completing those. We did Youth Speak on what we want our teachers to know, what we want our families and parents to know, what we want health policy makers to know, educators. I'm trying to think of the six. Providers. And the latest version was what we want our peers to know.

They're really very influential presentations that are presented by youth, created by youth and I think Mallory you've done one. Can you tell them what it was like.

MALLORY CYR: What the presentations are, are a PowerPoint, like Toni said, that the youth advisories have come up with about issues and concerns and things that we feel need to be brought up to these specific people.

And I think I actually gave mine to educators at a local college with another committee member. And we just went through and gave the presentation and had kind of a discussion with them. And they were very interested. And a lot of the things they didn't even know.

So it was really interesting to be able to offer them a direct perspective and have them look at things a different way and think about how they do things. So I think they were very effective presentations and hopefully it will continue to be.

TONI WALL: We've also done medical home training with -- they sat on our boards. We've created a service tapestry that was created for youth for statewide service tapestry where actually folks could go on and click on different parts of the state to find out what kind of transition services were available in their state.

We partnered and continue to partner with our Family Advisory Council, and we were one of the first states, I wish we had actually continued it, but I think that now we have Mallory on board to review the Block Grant a few years ago.

Next slide.

MALLORY CYR: Our youth advisory council called YEAME involves youth and young people with disabilities in development and reviewing the public policies for our state. The ones that present barriers to youth that affect our ability to pursue independence, post education and employment and other challenges within the community. Quite a while ago.

TONI WALL: 2002.

MALLORY CYR: In 2002 we formed that group and it was the first youth advisory within our state, obviously. And we came up with the name and we had meetings to review these things and discuss what we wanted to work on. And our big achievements were planning solely the youth planned and facilitated conferences, based on transition. And we had breakout sessions about post-secondary options.

What were the other ones? I can't remember what the specific other sessions were. But we offered --

TONI WALL: We also had -- you did employment and being healthy.

MALLORY CYR: Yeah, the importance of health. Employment options and how to access them. And we had a lot of resources, resource tables set up with programs in

our state and opportunities. And it went over really well. It was really exciting to see that, the committee of youth could plan something that had such a great turnout.

TONI WALL: In the beginning, we should have this big thing behind us with the sun coming up, in the beginning a lot of the questions we always get from folks is where do you find youth how do you get youth involved? I think it's a difficult question. But one of the things -- we run the state Title V agency so we actually have youth that are involved in many of the programs. So that's a wonderful place to start.

At the time we also looked to our Youth Said program which is the center for community inclusion. They were also doing a lot of work in schools with youth. Our main support network, which also does school work, work with schools, had access to kids.

The community on transition, council on transition, in our state actually had access to kids. So it's really to start to think more broadly than past your Title V agency, how you can access kids. Department of Education. Department of Labor. Maine Care has access to children. And we really did a broad, threw a broad net, so to speak to find youth and who could join our youth advisory council.

So we've really started to look at how we're going to, Maine in particular, is really looking at how we're going to start involving youth and look at transition. The Maine's Children's Cabinet has made that one of their primary, as a priority, really, for the

cabinet. The Maine chapter of AAP has also looked at that and it's one of their 10 priorities to look at transition from pediatric to adult healthcare.

We did, but I have to say we did not get our National Governor's Association, they had put out an RFA, actually, at one time on transition and Maine did apply for that. But they were really looking for states that were sort of in the beginning stages. And they felt that Maine was too far ahead. So they recognized all our great work but were really looking for states that were in the beginning process.

We have partnered with New Hampshire on our chronic care model and our youth sit on the medical home advisory team.

And we've also now, with the MACE, Maine Advisory Council on Education, we're making sure that youth are involved with that particular agency.

Next slide. Maine's been very lucky to actually have several of the Healthy Ready to Work phase one and two projects. We have right from the very beginning involved youth in our phase one project. That's where Mallory wasn't involved in that but one of our other youth Elisha Stewart was involved in the very beginning.

We actually asked youth, we went to the users and asked youth what they needed and how they could be successful in the system. They provided us with a lot of information and that helped us design our healthy ready to work phase two project.

These are actually your quotes.

MALLORY CYR: The step that is to involve youth. I'm changed because I want to make changes in systems. And I've learned that to do this you need to speak up.

And I think that's a huge lesson that youth can learn is that in order to make changes you have to be willing to create the changes, because it has to start somewhere.

YEAME is a place where I learn about how people get services and influencing services for others. By being an advocate you really get sort of an insider's look at what goes into the services and how they're created, and you learn how you can effect and make those changes. I think that's an excellent reason why youth should be involved.

I forgot to mention it, but YEAME stands for Young Educators and Advocators of Maine. ME is the acronym for Maine.

Toni wanted me to share a story about the challenges I've faced just in a simple thing like driving that I really didn't see coming when I took driver's ed. I'll just get my license like everybody else. Yeah.

But I enrolled in driver's ed at 15. And I took the course and I did all the academic work. Then the teacher was like when you need to get your hours, just enroll in driver's ed and

we'll get the ball rolling. And so they brought me out to the car that the student driver car when they wanted me to start doing my hours.

She was like what do you need? Do you need a booster seat? And so I sat in the driver's seat and the dashboard was about here. And I was like -- and my legs reached the end of the seat. I was like I don't think that's going to be enough, actually.

So they were like, oh, and then their involvement basically stopped. And we had to navigate the system ourselves and find out how I could drive an adapted vehicle. We had to search out a driver's ed program with an instructor who had an adaptive vehicle already.

And luckily I was able to do my hours with him. And then hi to go about getting an adaptive vehicle by myself. The driver's ed program was of no help after I finished the book work. They were just like, oh, wow, that's going to be rough. Have fun, though, awesome. Have fun with that. So we were like thank you.

But we really had to navigate the system ourselves, and it really taught me to advocate and you have to find out what you need in order to vocalize and try to get it. Now I do have an adaptive vehicle and I'm on my third permit because it keeps giving us problems. But hopefully it's in the future.

So it's one challenge at a time.

TONI WALL: One of the reasons why I had Mallory mention that is because that was not something that I as a Title V director even realized would be a problem for Mallory. Because we look at driver's license and getting that at 15 or 16 is really a passage into adulthood for most individuals. And when Mallory brought that forward to the rest of the YEAME, they were really surprised too because some of them did have their driver's licenses and some hadn't.

What we were able to do, I don't think you were there, I think it was Elijah who brought it forward to the youth legislative committee.

Now, these are youth that are specially selected to the Legislature, very bright, articulate youth, just like our youth on our committee. And I think they were like, oh, you have problems getting a license, driver's license? They were amazed, because of course they just went out, took the driver's ed and got their license. And they thought it would be an easy thing to do for most youth. And I think that they were shocked that it was difficult.

So YEAME does strive to provide awareness to youth centered services. It has provided me an opportunity to see what youth have faced. Mallory and Elijah who some of you may have met are prime examples of what involvement at youth at an early stage can happen. Mallory's now become a youth leader and looking at becoming a national youth leader with the ready to work national center. It's important to involve them so they can

recognize what needs to happen in transition to adulthood and help their peers and mentor us, mentor their peers and mentor others on the journey. And if Mallory has anything to say in closing.

MALLORY CYR: I just wanted to mention Toni said earlier where our status is now. We're working with youth regional coordinators and family regional coordinators for our youth and family advisory councils and we're hoping with that to expand youth involvement to other regions within our state and get family involvement and really sort of pinpoint where the issues are and keep people involved in making changes.

And we're actually doing that through what we're calling a Regional Report Card, which is sort of a written survey for families and youth dealing with special healthcare needs to fill out rating or rating the services they're receiving from various areas with the six indicators.

And we're hoping to combine all of them and look at them and collect the data and be able to really focus where the needs are. And hopefully over time we'll be able to make that change slowly. But that's where we're at right now.

(Applause)

[END OF SEGMENT]