

AMCHP 2007 ANNUAL CONFERENCE

HEALTHY COMMUNITIES

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Title V: Helping to Shape Healthy Communities

LESLIE CARROLL: Good morning. I'm Leslie Carroll and I'm with the Children with Special Health Care Needs program in Washington State. And this morning I'm going to be talking a bit about policy development in Washington State and the role of families. And I'm also going to mix it a bit with my own personal story and my son's needs and compare those needs to one of the performance measures that we're going to be looking at. And really the purpose that I want to achieve today is to expose you to the idea of performance measures and the role of family leaders in achieving those—the outcomes that we really want, that MCHB has established and that we really want and sort of demystify performance measures.

So again, I'm with the Department of Health. I've been with the Department of Health for almost eight years. And when I first—my first AMCHP conference was about seven years ago. And at the time I was completely overwhelmed with all the information I was receiving but it was a wonderful experience and I hope that you'll have a great experience here with your first conference.

So one of the things that the family consultant does in Washington and also in many other states is that we do take a leadership role in involving families as decision makers at all levels. And when we talk about all levels what we're really talking about is that pyramid that you've just seen recently. And families are involved or should be involved both with making it easy to get direct services—that might be the role of a care coordinator or the family support person who helps people get services—also at the infrastructure level, at the bottom, where we're developing integrated systems of care and everything in between. We do a lot of policy and program development, develop community networks and we do a lot of informing and educating.

And just to kind of give you a little bit of a flavor for my own family, this is a photograph that I really treasure of my older son who's graduating from high school. He's now a sophomore in college in Chicago. And then my younger son who is on the autism spectrum and that was—you know everybody has milestones but for me that was a big milestone. And my younger son has this cloth up to his ear, it's actually just a napkin, but he's trying to protect himself from the noise level there, but he got through the whole ceremony with all the clapping and everything without freaking out at all.

And my oldest son, also I'm very proud of him. He's now at the University of Illinois at Chicago as a psychology major and he's the most tender hearted person towards people with disabilities and yet he's trying to also establish his

own life and have some separation. But anyway I'm very proud of my kids and I just want to share that with you.

So I just want you to meet Nate a little bit and kind of get a sense. I'm sure a lot of you have family stories that you can share. Part of being a family consultant really is being able to share your family's story and make real the kinds of policy changes that we're trying to achieve. So my son Nate is 16. He has autism spectrum disorder. He is very bright, social, friendly, inquisitive and he loves to travel. He has always had low tone, a lot of sensory integration issues, very extreme. He's got learning disabilities, significant speech language communication challenges.

Like a lot of parents with a child with disabilities I've had to really struggle to get the services that he needs. And I've had to be his advocate. He has just in the last year, when he was 15, really started to understand how to read. And he's learning to read, you know, more every day. He's very proud, but it's very difficult for him. If we had given up on him when he was 10 and said well he can't read, you know which some—I heard that from some people and I refused. Now he's learning to read.

He's learning how to snowboard and he's very low tone all his life. It's a huge accomplishment for him. He's learning how to cook with lots of descriptions and you know how to do it and take the time. He's learning to play the piano and the

keyboard. He's learning to go to the gym and lift weights. I have to make sure that we go to a quiet gym where that isn't that annoying, you know, squeaky noise and things like that or otherwise he'll just leave right away. And he's got a dog now and he's learning to train his dog.

So the reason I'm talking about this is because it takes a long time to for our kids to achieve their potential. And somebody else might not think that he's doing all these wonderful things that I see, but I know for him it's fabulous. And also he's very happy.

So when I think about creating community resources and systems of care that work for kids like Nate, the kinds of things we need are systems that involve families as decision makers. They're family centered, community based, coordinated and easily accessed. And those actually are the characteristics that are described in the performance measure about community resources.

Why it's important to involve families as decision makers—stakeholder input is really important and we can't under emphasize how valuable that is and how often I think we don't realize the impact that our input will provide on people who may actually be very concerned but they haven't experienced the situations before that we've experienced. It creates a quality and quality improvement, sustainability, system development and we bring in the natural champions and allies that are needed to develop other systems and performance measures like

medical homes. Without parent involvement and parent partnership, we really can't have medical homes for instance. Family professional partnerships are really critical to the success of MCH.

Now ways that we can involve families, these are things that we're doing in Washington, but also around the country and in your state you're probably doing some of these things or you're going to want to be doing these. Family and youth networks and advisory boards, hospital and practice based parent advisory groups, family consultants that work within agencies like Title V.

And then I want to emphasize that budgets are very important and to take a leadership role in encouraging that budgets be created to do the work that we do is really, really important. Don't be shy about that. And agency investment in decisions that families have promoted is also really critical. So we need to create and seek out the natural champions that are in our agencies.

Ways to involve families as decision makers includes—and this is the kind of work that I do. We talk about training and mentoring families which is important. Right now you all are receiving and mentoring to become part of MCH. But there's also the piece about training and mentoring professionals.

And again, often there are some professionals who really get what it means to be a family member and often they've experienced it themselves. And other

professionals may need to have that extra time to really understand what it is that families bring to the table.

So just a couple of quick examples would be recently we in our state have had an oral health action plan, a mini grant that was provided. And the dentist who was doing that work is very interested in family involvement and she approached me and she said she wanted my help in involving families. And then I—but she didn't know what to do. I mean she honestly did not know what to do.

So I said well let's—I put out an email and solicit some people to come and be involved. And then we ended up with three families of different type—where their kids had different disabilities and different diagnosis and they all got into a phone call with us. The first phone call we had we just basically told them about the project and what kind of feedback we were wanting to get. And then we had a call where they actually told their family stories just to two other people on the phone and then eventually it was to a large group.

And when they told their family stories, one story had to do with a child who had autism who really just couldn't be in the room with—was afraid to be in the room. And then another story was about a child who was in a wheelchair who was—there was no place to put the wheelchair in the dentist's office and also no place to change the child's diaper. And so it was very hard, you know, to get into an appointment for that reason. And then another person had to have—her child

needed a lot of reconstructive surgery and the health insurance benefits did not cover that.

So they all told their stories and afterwards the dentist and the other person were really so moved. And their understanding was so heightened that it's carried over into a lot of other ways that they're doing their work. That's just one example. So I'll move on from there.

So now I kind of want to take you into this idea of what is a performance measure. And you've heard mention of performance measures already this morning. When I started working in this position I didn't know what a performance measure was even though I was—I went to urban planning schools, a master's program. I did planning but somehow the idea of what a performance measure was and the indicators that they were talking about and all didn't seem to me to make a lot of sense at first. But what I want to do is sort of demystify what that is especially for parents who haven't been involved in that kind of work before.

So basically it's a way of seeing how you're doing. And I think it's important to create meaningful measures. And what's meaningful will depend on the individual or the group so that's why your input into developing performance measures is really important. Because what's meaningful perhaps to, you know, a physician or an administrator or someone else is going to be different perhaps

from what's meaningful to a parent. Then again, they might be the same thing, so it just depends.

So here are a couple of easy examples to help demystify it. So if you're writing a book you might want to be asking yourself how many pages do I need to write per day in order to meet my goal? Maybe you want to have your book finished in a year. Or with washing the dishes, you know, how many dishes are washed every 10 minutes or how long does it take us to wash our dishes in the evening? Do we want to, you know, speed that up? Or basically do we want—how many people in my family take part in washing the dishes? That's just a little flavor of how we all use performance measures every day in our lives even though we don't call them that.

So what are MCH performance measures? They're measures that help us know if we really are improving systems of care for women, children and their families. You've already heard that there are 18 national performance measures. And in your handouts you've got this blue sheet that actually has a list of the 18 performance measures on the back. And the first six are the children with special health care needs performance measures. And then of course, your own states are going to have some additional ones.

But what I want to do is just quickly run through the children with special health care needs performance measures. We have one on family professional

partnership, one on the medical home, adequate insurance, early and continuous screening, transition to adult life, and integrated community based services. So there's a lot more that I could tell you about those but today I'm going to just focus on performance measure number five, which is integrated community based services. The way it reads is that services for children with special health care needs are organized so families can use them easily and are satisfied with the services they receive.

There's one thing I want to tell you about right now is that I don't have a slide for it but these performance measures, you can learn more about them if you—and we can tell you more about them afterwards, but the children with special health care needs, there's a survey that was done where a lot of questions were asked in 2001 and there was another survey in 2005 and the results are coming out soon.

But basically there were questions asked on a phone survey, a national survey, that got at these questions and these issues. And they were able to get at least I think it was 700 families with children with special health care needs per state to answer questions and then they created sort of an overview of what the issues were. So just a little bit of background information for you to have.

But anyway, the barriers to having these kinds of services are just basically the fragmentation that we experience at times with services, the silos that we

experience. Also geographic barriers and long distances between where a person lives and where they get their services. Multiple service programs—it's very difficult sometimes when you have different funding streams, different eligibility requirements, policies, procedures and locations which we all know happens. And then the lack of cultural and linguistic competence. Something happened, I lost my—I'm missing some slides. Very interesting.

UNKNOWN SPEAKER: Is this a theme today?

LESLIE CARROLL: They're gone. They're totally gone. Well I'm almost finished. So if you look at your handout, okay, so on page six. How to create more integrated community based services. And I'll just go ahead and put my son up here so that you'll kind of have a sense. One of the things we need to do is organize services so that families really know how to get the services that they need. So organizing them that way and then making them available.

One of the things I have learned is that we have great services in Washington, but we often hear families can't find them. They don't know where to go and professionals don't know where to go. It's really a marketing problem a lot of times. How do you make sure that people know what's out there? And so it's sort of a training and marketing issue once you have really good services. And so part of what we're doing is trying to make it really easy for physicians, for NICU

providers, for family support coordinators, for everyone to know how to access what's already there.

And I just want to—on page seven—say that the family perspective is key. The family perspective tells policy makers what works for families and there are many roles that you can take when you're developing your role in your state.

In Washington we've got a couple of things that we've done that I think are very powerful. We already have and I think you probably do too, a 1-800 hotline that's required by MCH, but we have changed that from being called Healthy Mothers Healthy Babies which makes it sound like dads and youth and kids with special kids, and you know that they're not really—that's not a place for them to go to.

And now it's called Within Reach Family Health Hotline and we've also created materials that show dads and show teenagers, et cetera, on the marketing materials. So we had parents working on that with them and I think that's one powerful thing that—just one example of how we can change things. Because that was a bit of an institution, you know, and we made those changes.

So other things that we've done in Washington, we had an autism task force for a year and a half, brought in a lot of parents to provide input there. And now a lot of that work is being addressed through policy changes and legislation. We've got medical home teams with parents and all the teams around the state. We have a

big medical home, a strategic plan that we've developed across agencies involving Medicaid, involving a lot of the players that have to be there and parents have played a very powerful role in that. There are parent advisory groups, hospital based, practice based. And just basically we're looking for ways that parents can be involved in a number of different policy boards.

I could mention to you really quickly that we have a great family network called the Washington Family to Family Network in Washington. We call it WFFN. And basically that spans a lot of the family support organizations that work in our state, from Family Voices to Parent to Parent, Father's Network, Title V, Early Intervention, Medical Home and Children's Hospital which we do a lot of work with and other families are coming into the system. So we use that as sort of a springboard for doing integrated projects and advancing the family voice in our state.

Finally, on page nine there is a resource, a recommended resource, for the Champions for Pragma Center and I would like to add to that one other resource for you to—actually two other things. And we can do this afterwards, but there is a website that's www.childhealthdata.org and I'd like to refer you to that where you can learn more about the national survey of children with special health care needs.

And then on Monday afternoon at 1:45 p.m. until 3:15 there is a session called Comparing Health Status and Health Outcomes of Children with Special Health Care Needs. It's in room F1 of the Grand Ballroom, no it's 1H of the Grand Ballroom and it's called F1. If you have any interest in performance measures or data then that would be a really great session for you to go to on Monday afternoon. So are we holding questions for later? Okay. So that's all I have to say. Thank you very much.