

AMCHP 2007 ANNUAL CONFERENCE

HEALTHY COMMUNITIES

March 3rd to 7th, 2007

Title V: Helping to Shape Healthy Communities

BETSY ANDERSON: Thanks, Bob. Well what a treat to be here always at this session. We love putting it together with the Family Leadership caucus. And as Bob said, in the first part we're going to give some background on Title V. And it's especially—some of you are old hands with Title V, for others of you this is a little newer.

And let me ask, how many people are new to AMCHP or new to Title V? So, a number of people. And how many people here work for an MCH program? And how many people work for a children with special health care needs program? And how many people are parents? And how many people are professionals? So is there anybody who hasn't raised their hand yet? How many people work for another MCH kind of organization or agency that is—no one. Okay, all right. So we know who we are.

This is also a special day because as a friend of mine in Boston likes to say, this is the only day that is a command. It's March 4th. And this is also a day for those of you who know Nora Wells that it is her birthday. So if you have a chance to wish—if you know Nora and see her today, wish her a happy birthday.

We have these booklets are also available—this Power Point is also available. I just want to mention that. And the most—probably the most important thing to know is that Title V is the nation's oldest federal program to improve the health of mother's and—of all mother's and children, including children with special health care needs. And we at Family Voices have put together this Power Point with a kind of family friendly focus and I want to show you people who are part of our committee, some of whom are here today.

And I think many of you know Family Voices was begun in 1992 so we're going to be—and we're going to be celebrating our 15th anniversary this spring in Washington and we have material on the back table. We hope any of you who are interested might come to that conference.

And we also hope that if—that you might have a chance to meet our new executive director, Sophie Arao-Nguyen, whom I see in the back. Sophie, can you raise your hand so people see you? Yeah, so we hope people will have a chance to meet Sophie during our—during the conference over the next few days.

UNKNOWN SPEAKER: Hi, I'm sorry, Bob said the Power Points were over here, but I don't see one for this. Is there supposed to be?

BETSY ANDERSON: This is—no.

UNKNOWN SPEAKER: Okay.

BETSY ANDERSON: This is available in booklet and you can contact us for the Power Point.

UNKNOWN SPEAKER: Okay.

BETSY ANDERSON: Okay. Yes, it's in the back. Nora's holding it up there.

UNKNOWN SPEAKER: Thank you.

BETSY ANDERSON: The Maternal and Child Health Bureau administers the provisions of Title V. So you'll hear the term Maternal and Child Health, Maternal and Child Health Bureau. And it's within the Health Resources and Services Administration which itself is within the Federal Department of Health and Human Services. Money is provided to states through Block Grants and those go to MCH programs and children with special health care needs programs in states and they're usually placed in state health departments.

But what's kind of fun for us to think about is the sort of history of Title V. It's a very rich, long history and I'm just going to share with you today a couple of the

anecdotes and interesting things that I hope you'll kind of keep in your mind because this wasn't set up as kind of bureaucratic program. The Children's Bureau was established in 1912 and it was the forerunner of the Maternal and Child Health Bureau.

And in 1912 that was a time when infectious disease was a tremendous killer of children. It was a time when one-sixth of children were in the workforce and in fact, in a famous—in a well-known article by Arthur Lesser, a great—an early bureau chief, he said that in the south a third of the workers in mills were children and many of them were under the age of 10. So it was a time when in our country there were debates about what was right and good for children. And the Children's Bureau was a real attempt to kind of bring the country together and move things forward to improve children's health.

In 1921, the first grants were given to states for public health and there were many significant, many important groups that opposed that money going to states, including the Catholic Church and the American Medical Association. And they did so because they felt that health was a personal matter. It was a family matter. It wasn't something that the government should meddle with.

And today I think we kind of take it for granted that the government is involved and has a role in supporting healthy children and families. But that wasn't the case in those days. And I mean it's just very sort of tremendous to think about

the fact that a number of physicians who cared for children who were part of the AMA broke away because they felt there was an important role and they formed the American Academy of Pediatrics in 1930. So who are pediatricians here? I know there are a couple right here. So, you know, very kind of exciting to think about those advocacy beginnings and what it took to stand against, you know, well established groups and to really say children's health is important.

And there are a couple of wonderful quotes here that I hope will also kind of give you the flavor or some of those times. Grace Abbott was an early chief of the Children's Bureau and she said—she's kind of imagining herself in Washington with all these big governmental kind of organizations and interests and she's saying, "Sometimes when I get home at night in Washington, I feel as though I had been in a great traffic jam. In that traffic jam there are all kinds of vehicles moving up toward the capital, the conveyances of the army, limousines in which the Department of Commerce rides. It becomes more congested and more difficult and then because the responsibility is mine and I must, I take a very firm hold on the handles of the baby carriage and I wheel it into the traffic." Saying that government has a role for children, for children's health and that's an important step forward.

And in another kind of lighter vein, Will Rogers the social commentator and humorist said, "Well I'm mighty glad so many people in America are taking up children's work. Being a ranchman and a farmer and also a child owner, I've

often wished that when one of my children got sick I could wire or call some government expert and have him look after them like I can do if one of my cows or pigs get some disease.” So he’s making the point, you know, the government provides resources to farmers, how come not to families. So this is all just to give you a little background and a little sense of the flavor of what went in to creating the Children’s Bureau and what is now the Maternal and Child Health Bureau.

So in 1935, Title V was authorized as part of the Social Security Act and there have been a number of changes. I’m going to go quickly through some of these slides, but you have the booklet. There have been omnibus budget reconciliation acts that made tremendous changes in the program, kind of consolidating. And a big change was made in 1989, which some here—some of us here are old enough to remember, when suddenly the government didn’t just give money to states but also said you’ve got to do a needs assessment, you’ve got to set some objectives, you’ve got to turn in some data. You’ve got to provide matching funds. So a lot of changes along the way.

Title V is not just a static piece of legislation, but it changes with the times. And it’s a state federal partnership based on a formula depending on the number of low income children in a state and the states provide a financial match. So it varies from state to state what it is.

There are—the main purpose, as you know, is to improve the health of all mothers and children. But there are also lots of other pieces of the legislation, to reduce infant mortality, which even in 1912 and even today still is an important issue that we need to continue to address, to increase low income children receiving health assessments, provide preventive and primary care and to provide rehabilitation services for blind and disabled individuals and to coordinate things with Medicaid, EPSDT.

In addition to that, the Maternal and Child Health Bureau provides grants to states called SPRANS grants. So those are—Family Voices has a couple of those. Many of you here in the room do also I know. And it also—Title V also requires states to establish a fair method for allocating funds and to make the process open so that low income families can actually afford services if a state feels they must charge for them. States must provide a toll free hotline, coordination with Medicaid. I know I'm going a little quickly here. And provide services to identify pregnant women and infants eligible for Medicaid so to make sure that they're getting the health services that they need and to make the Block Grant application public within the state.

And one of the things that's happened along the way, and I would say this was a change in a way from the way care and services were originally envisioned is that family centered care and family involvement has really become a cornerstone of the Maternal and Child Health Bureau. And I think many of you

here in this room are very familiar with how families are involved with Title V in helping to shape and improve programs.

This was a survey that we did in 1992 and I'm going to skip through this but we interviewed every state Title V program to find out how families were involved. And to our surprise then we saw how many parents were becoming employees or consultants to the Title V program. And you just saw a little bit earlier I think people raise their hands and say that. Now we have—we don't have our little covers, but Nora could you hold up the FIPS reports which somehow didn't make it into the graphic here. We did a new study—yeah, thank you Vanna White.

UNKNOWN SPEAKER: We have many copies (inaudible)

BETSY ANDERSON: So 10 years after the first survey we interviewed all state Title V programs, children with special health care needs programs again to see the progress and the changes that have occurred over the last 10 years—very, very exciting. And I know Bob is going to be doing a session on family employment I think on Tuesday—employment in Title V programs.

Also, in this last survey for the very first time we interviewed Maternal and Child Health programs to see how they were involving families. They have not had quite the encouragement and reinforcement that children with special needs programs have. And in fact at Family Voices we have an initiative to work with

MCH programs and if any of you would like to talk to me about that afterwards, let me know.

This is up on our website and we also encourage people to develop a little public health history. You know the Title V history is so exciting but also in our states there are exciting things. And I'm from Boston so you know can you believe Paul Revere was part of our first public health efforts. So I don't know who you have in your states or what initiatives occurred, but I know that the state of Florida is doing a history right now of their Title V program and they are—Phyllis Lawyer told me how thrilled they are, that it's just very exciting.

In addition, you might want to think about what the history in your state is with families. When did families become involved and why? What were they interested in seeing accomplished? And how are they involved now?

Finally, we're going to move to—just for a little bit here—to some of the goals and challenges for—and I know Jim is going to cover this in more detail—for Title V programs. But they have a big agenda. And they have—there are many challenges. These are some of them, Healthy People 2010 which seemed when that was—you know when we were setting goals for it, it seemed like a million miles away. Now doesn't it seem like it's right around the corner? My gosh.

Title V Block Grants and performance measures are—for those of you who are new, those are things you'll hear about a lot now because there's a real focus on accountability. And the MCH populations that Title V looks at are mothers, pregnant women, infants to age one, children and adolescents and children and you with special health care needs. So often when you're reading material, often it will be described by one of these population groups or a subgroup.

Another thing that was at first mysterious to us as families was the famous MCH pyramid although we have actually taken the initiative to draw this line. Usually it's really the—we call it the MCH triangle, but you know, we made it into their actual pyramid. And they use this to kind of capture the way services are organized and states have to describe their services by levels of the pyramid.

So at the top you see are direct health care and then so the real actual health care services. And in the next level are what's called enabling services like transportation, translation, things that help you to get to or take advantage of those health services. The next level is population based services, so like immunizations, things that stretch across a broad swath of the population. And in the bottom row are what's called infrastructure services, so doing the kind of needs assessments and the planning and evaluation, all of those things that kind of enable them to shape and twist and turn and react and respond to challenges in our states and communities.

Now knowing that this was very important to the Maternal and Child Health Bureau, we made—we decided we would translate it for families. So here is our family pyramid. And we said at the bottom are infrastructure services, the kind of basic family promises are to provide food, housing, clothing, health education, spiritual and moral values. That's kind of the basic kinds of things.

And that our population based we had to—that was a tough one, but we put health promotion and disease prevention actions in that level. And then enabling services and then direct actions, giving your kid a hug, telling your kid to brush his teeth. You know those are kind of direct services that we as parents provide that might be analogous to the MCH pyramid. You might have some additions or recommendations you can give us those.

Title V does a needs assessment every five years. So as some of you know, it was turned in about—a little over a year and a half ago. That is a huge important document in your states. And it contains a wealth of information and that too will be coming up kind of before we know it because the planning occurs, it doesn't just happen in 2010, it really starts happening and being planned for.

If you're a family, you know, think about what would like to know in your state, what questions would you like to have your state asking, you know, over the next couple of years. Those would be good to be talking with your state about. States also identify priority needs.

And an innovation Dr. Peter Van Dyck brought to the Maternal and Child Health Bureau a few years ago was having all states begin to collect similar data so that it can be—so that across the country you can—we can make statements about the health of children and families. And there are 18 national performance measures and other grants collect data on similar measures.

And I'm going to skip a little bit through some of this, but the upshot is really that states have to provide a—they have an annual report due in July. It's an accounting of all their accomplishments over the previous year and then they have a plan for the coming year. Those are things that you might really want to look at because they are—they just contain a wealth of information. Most of us when we start to get involved with Title V have an idea of one or two services or programs. You're going to be blown away if you've never looked at what your state is doing. And these are all available online.

One of the things that states must do is they must show that 30% of the funds that they are given are spent on primary and preventive care and that at least 30% are spent on children with special health care needs and no more than 10% on program administration. So they have 18 national performance measures.

Then states also identify 7 to 10 performance measures, things that might be very important in Ohio or very important in Washington, I used to live in Oregon

or very important in Massachusetts. And sometimes those are similar but there are differences in our states. So states are allowed to generate for state performance measures as well as some outcome measures. And then they discuss their plan for the coming year.

We've been very pleased to work with the Maternal and Child Health Bureau and to involve family members in reviewing Title V Block Grants. So each year about a dozen or so family members attend and are part of the review team for states. And since—that's been since 1997. And all states and most territories have been reviewed by family members.

And what they say is that we bring different things to the table from what others do and that that's something that the bureau values. And in addition, some states actually bring family members as part of their own state teams and I know that happens a lot in region 10, right. So that's a very exciting.

Finally, virtually all of the information about your state and things you want to look at in comparison to other states are available online. Unfortunately cross off that www.mchdata.net because they've had to get rid of that wonderfully easy URL. Instead, see that much more complicated one, that one that you will have a hard time remembering unless you bookmark it. Anyway, that is—that gets you right into the system.

We have easy hand out material on the back table that we could also send to you so you don't have to write all these things out, you can click on it. So I want to just end by saying that we have—at Family Voices we have other material relating to Title V that we'd be glad to talk with you about and share with you.

And I want to just finally end by saying March 4th, make sure that Title V really is true to its original intentions. It really takes us as families and professionals to make it move and change with the times. The framework is there but it takes us to really make it be the living, breathing, responsive piece of federal legislation that it can be. Thank you.