

Federal/State Maternal and Child Health Partnership

Technical Assistance Meeting

MCH Needs Assessment:

Concepts to Catalyst – Capacity to Competency

February 25-26, 2009

BONNIE STRICKLAND: Oh there it goes. Now, some of you are probably saying what in the world is that? If you haven't been here before, I will start by saying that about eight years ago, we launched what is known as the 2010 Express. And we have a large rollout. And during that rollout, we talked about six performance measures. Since then, we have built our entire program around it. We've built our measurement into the National Survey of Children with Special Health Care Needs and the National Survey of Children's Health. And it is what guides every move we make. And that should become apparent in the next 10 minutes, but we used a train as our logo for that initiative. The initiative is -- well, the program is based on our history. We didn't just dream it up, and all of you that have been around for a while know this. It's built on our legislation that specifically charges us with facilitating the development of community-based systems of services for with children special health care needs and their families. We also have a national performance objective in Healthy people 2010, to increase the proportion of states and territories that have services for children with special health care needs and their families. And we also hooked ourselves right on to the president's New Freedom Initiative in the last administration, and we plan to do the very same with this administration. I'd mentioned that we have

built our monitoring and measuring capacity for these six performance measures into the National Survey of Children with Special Health Care Needs.

And for those of you that are relatively new to MCH and Children with Special Health Care Needs, these are an abbreviated statement of our national performance measures. They are family partnership and satisfaction at all levels, access to care for the medical home, adequate financing and insurance, early and continuous screening, easy access for families to community-based services, and services to transition to adult health care work and independence. And these are the results of our 2005-2006 survey. We have had -- actually, we started in 2001, so this was our first opportunity for a little bit of trend data. All said and done, we are pretty much -- we have been prepped a little bit in most of these areas. We had a significant improvement in the area of insurance and transition to adulthood. The transition was mainly because we changed the questions, so that's really not trendable, but the insurance piece is. But what it tells us is a glass-half-empty-half-full, kind of, status, where about half of families in this country feel like that they are full partners and satisfied with services, a little over half. A little less than half of kids have all aspects of a medical home -- and I don't mean just primary care. In this is family centered care and many other variables that we could spend the whole day talking about. I'm going to talk a little bit more about the family partnership and satisfaction, the early continuous screening, and the easy access to community-based services in just a second.

But this is what we've been working on for eight years, and I imagine we'll be working on it for a while.

I could also spend the entire 10 minutes on who are children and youth with special health care needs. What I do want to say, though, is that a substantial proportion of the child population do have special health care needs, and quite honestly the National Survey of Children with Special Health Care Needs doesn't measure the at-risk population. So 13.9 percent of kids in this country have a special health care needs, and not counting those at risk. I should also say that -- oh, I want to go back just for a second. It's very interesting in the last eight years that many of these six have become national issues. There's so much discussion about that family equation in the discussion that's going on now around health care reform and quality improvement. Every one recognizes that there is something to do with family -- well, they call it patient; we know better -- that has to be measured and has to be accounted for in health reform and quality improvement. Access to medical home has almost become a household word for better or worse. The SCHIP expansion has been an incredible piece, but we still got the job to be sure that it's implemented in a quality way and that it's available to all, and that those health care services are available. An insurance card just doesn't necessarily get you access to all the services that we need. Early and continuous screening as a result of autism -- and thank goodness Bright Futures, we've had a huge increase in the emphasis on early continuous screening in this country. And transition is again a huge issue in pediatrics in transition.

I want to make one more point about this slide, and that is that children with special health care needs don't just exist in the children with special health care needs programs. All of you know that. They are in the big -- I call it big MCH, the broader Title V Program. They are in Part C. They are kids who aren't even in Part C or in special education. There, we need to all be concerned with children with special health care needs, because in fact we all serve this population. So for arbitrary purposes, I'm going to divide the rest of top just into our organizational structure. We really do our work across the division. Everybody works on everything. But to make it a little bit easier, I'm going to talk a little about the emphasis for my office, the Office of the Director, and then, our two branches, the Integrated Services Branch and the Genetic Services Branch. For our office, that's primarily me and Rene Newton, our staff assistant. As I said we work on everything, but for me the biggest amount of my time in terms of programmatic time comes around three things: the revision of the National Survey of Children with Special Care Needs. During the past year, we have a -- past two years, we've tried to improve the measurement of all six of those components. And in the last survey, we worked on two. And in this survey -- the current survey that is now ready to be launched, we've prepared new composites for three areas, one being the family partnership piece, which I think you'll be pleased to see. It's now more than one item on do-you-feel-like-a-partner. It's actually built around shared decision making, and I think it is far more reflective of what we're really talking about when we talk about family-centered care.

We've completely revamped the organization of services for easy use composite. Again, it is now more than one question, about our service is easy for you to use. And we've added one question on developmental screening to make it consistent with the National Survey of Children's Health. We still have some work to do there, but we're really not sure how to go about it, so we'll probably do that in the next generation of the survey. We are getting ready to launch a new initiative on universal vision screening for young children. We are going to be funding, if all goes well, a national coordinating center for vision screening. We are hoping here to do for children's vision what you did for Universal Newborn Hearing Screening. They are not quite the same, but if we can do it for hearing we can also do it for children's vision.

And then finally, this medical home is a household word, it really is. And it takes an awful lot of our time to try to work with public and private constituents to protect our focus on pediatrics and family-centered care. If you're familiar with what 's going on in the patient-centered primary care collaborative world and multiple other private constituents and stakeholders, there's a huge focus on adults right now on medical home, and that's fantastic. This is a universal concept. It is something that every one of us needs. But in the current environment, there's a lot of discussion around adults because that's where the big bucks are, and the big potential cost savings. But I think we have a responsibility to protect the MCH population, particularly children, because they

are left out of the discussion right now, a this difference between patient-centered care and family-centered care. And these are two of our legacies. I think it's important that we protect them in the wonderful launch of medical home for all populations. So, then let me move to the integrated services branch. Here are the staff -- well, they are not a big staff. I won't read the names in the interest of time, but I think you're familiar with most of these folks. This branch really supports our core program. And do remember that everybody really works on everything, so these are very arbitrary divisions. But the integrated services branch supports our grant activities, our interagency collaboration, and our work with stakeholders around the core program. And when I say the core program, I mean those six areas that we talked about a little bit earlier. Our flexible dollars which we see diminishing -- thus my comment earlier in the morning about -- a little concern about not being able to maintain the level of flexibility that we have in the past years.

Our said implementation grants are funded through those flexible dollars, and so far we've been able to support state implementation grants for those six performance measures in over half the states. Now those were grants. We've had activities in every single state, but we're really hoping to offer every state that wants a concerted effort in these areas an opportunity to do it through grant funds. To promote those measures we also support national resource centers. You're probably familiar with Family Voices, The National Center on Cultural Competence, our National Center on Medical Home at the Academy of

Pediatrics, the Catalyst Center does our work on financing. Our main thrust there is under insurance, Healthy and Ready to Work, and Champions that does our access to making services easy to use. But those aren't our only national centers. Those are the ones that support the core program. We also have national centers on newborn hearing screening and National Resource Center on Newborn Metabolic Screening.

The other thing that we do -- and Peter mentioned earlier that, you know, we never miss out an opportunity to attract new money. And we've had to do that, in many instances during the last year, because Congress is often fixated on giving money for specific conditions. And at one point, we thought we don't want any of that because we are about all kids with special health care needs. But the bottom line is, this is where it is, so we take it and we try to make sure that anything that we get that's condition-specific gets built in to that system of services that we all care so much about. And by that I mean, if we have a program on autism, we ask that the grantees make sure that there are family professional partnerships, that we're talking about access to care through a medical home, early and continuous screening, adequate financing, easy access to services and transition. And it plays that way in all of these. In the integrated services branch, we currently have programs in hearing screening, autism, epilepsy, and traumatic brain injury. I should also mention -- and I should have done this earlier, though, we are the Division of services for children with special health care needs, but our programs are really life span. We certainly have the newborn screening programs, early

childhood programs, but several of our programs, including traumatic brain injury, epilepsy, hemophilia, sickle cell and thalassemia, are lifespan approaches.

So back to this -- one of our major accomplishments this year will be the funding of a family-to-family health information center in every single state in the District of Columbia. This is a major achievement, and you folks are the ones, especially Family Voices, who has really, really gone to bat to make sure that these centers exist in every single state. And we've reaped incredible results from the centers that we have supported, and we are hopeful that the funding for these centers will continue. Again, we could talk about these all day. And one other thing that I really wanted to mention, and that is our workaround quality improvement, we really see quality improvement as a core value for Title V. Its leadership should be in Title V. And we've done our best to be sure to promote the concept of quality improvement in every state. Now we've done it through learning collaboratives and National Initiative on Children's Healthcare Quality. But what we're really trying to do is make sure that by the time this initiative ends that in every State, Title Vs understands how it wants to lead and support quality improvement activities throughout the state. I'll just say here, you know, we are thrilled with the expansion of SCHIP, and one of our issues here is to make sure that it's more than insurance, that on the other side of that insurance card is the system of services to insure the health and well-being of children and youth. And again, as I think Julie Beckett pointed out yesterday afternoon, underinsurance is one of our big issues.

The last one is the early and continuous screening, and we do this in both of our branches. The integrated services branch works primarily on the developmental screening piece, that broad piece that's promoted by Bright Futures. We also have the newborn hearing screening in that branch it just happens to be there. So on to the genetic services branch, and again, here is the staff for that branch. And you heard yesterday -- so I'm not going into a lot of detail -- but you heard how much was going on in the area of newborn screening both in the Family Voices gala and in the plenary in which Peter participated yesterday morning. It's very important though to -- well let me just back up just a minute. I'll just give you some examples in case you weren't there. One of the things that we are most proud of is supporting the work of the American College of Medical Genetics in the recommendations that they made around screening for core conditions. That report has galvanized newborn screening in this country. And in case you didn't hear it, Peter reported yesterday -- I think Peter, correct me if I'm wrong, as of the first of February, 30 states are now screening for the core panel. And 16 states are screening for more than 60 conditions, and 13 states for more than 40 conditions. That's a vast, a vast improvement over where we were just a few years ago. So, there is so much to celebrate. With that said, I think it's important to remember that it's not just about screening. The screening piece is well on its way, but to remember the follow-up piece, continuity of care across the lifespan, being sure that kids, once they are identified don't fall through the cracks. And that's why I have included these next few slides, because I want to remind you

about that Genetic Services Program and its purpose beyond simply screening. And I'm not going to go into a lot of detail. You have these in your notes. But it really is about infrastructure building to enhance and expand newborn screening, but also to assure continuity of services and to create the infrastructure and community systems of care for children, youth, actually and adults. Genetic services just like the integrated services branch has its condition-specific programs. These happen to be included in our legislation, the National Hemophilia, Thalassemia Comprehensive Care and Sickle Cell Disease. Again, we use our systems approach to form the basis of these programs. In hemophilia, we work on medical home. In sickle cell we work on medical home. We work on easy access to care. And quite honestly, some of these programs provide outstanding examples of integrated systems of services for the population that they serve. We participate and examine emerging issues and technologies. We are very involved in what's going on in HIT right now, and we have a big emphasis on improving genetic literacy of the MCH population. Many of you might have seen the family history tool that has received widespread in the newborn screening community. If you haven't, you can see me and I can tell you how to access it.

Peter talked about the evidence of -- let me move on here. The big work right now for us is around the Newborn Screening Saves Lives Act of 2008. Peter talked about this yesterday in the plenary. I'm not going to go over a lot of it. He talked about the evidence review process. He talked about the regional

collaborative, the go-to entities around genetic resources, and about the national resource center on newborn screening. And he also talked about some of the contingency planning activities that are going on around this act. I've taken these a little bit out of order from the legislation, but in terms of their meaning for you one of the provisions in the Newborn Screening Saves Lives Act is to establish a grant program to provide education outreach and coordinated follow-up care. We don't have the funds for that right now, but you can anticipate that there probably will be a grant program to implement this at the state level. The act expands the responsibility of the Advisory Committee on Inheritable Disorders and Genetic Disease. Dr. Van Dyck is the executive director -- I forgot the real title. He is our leader on that committee and Michelle Puryear serves as the executive secretary. It has a huge responsibility. If you heard Peter's plenary yesterday morning, just how involved that is.

Okay. Some of these -- so these are the two main activities that we're involved in now. But the act also provides for facilitating the creation of federal guidelines, helping states meet those guidelines once they're established. We're going to be developing a clearing house for newborn screening educational materials once we get funding for that. And we will be responsible for establishing an interagency coordinating committee on newborn and child screening. I didn't include the contingency plan on hearing. I think I just forgot it. Anyway, that is just a very quick overview of what we're doing. I'll be here for today and tomorrow, and if you need any further information on what we're doing in the Division of

Services for Children with Special Health Care Needs, let me know. The main message is, we want to work with you on all of these initiatives. The state and community is where it all happens, and we want to support you in that work. Here's my contact information. It's in your slides and you also have this, but don't have the sound effects on this slide. So thank you very, very much and welcome. I'm looking forward to a great meeting.