

HRSA/MCHB 2007 FEDERAL/STATE PARTNERSHIP MEETING

Building Blocks for Promising Practice Models

October 14 - 17, 2007

MCHB Divisions and Offices

BONNIE STRICKLAND: Ciao. Buona Sera. Is that at this time of the day? Hi, everybody. Good to be here. I know you're glad to be here too.

How many of you are really new? I saw five or six people that are not new. I've been seeing you here for years. Well, you're going to get the same treat you've gotten for the past few years from me. It's not--it actually always is a pleasure to come here and meet the new people and see old friends. We don't get together often enough, and there really is a lot of new stuff going on, as well as continuation of many ongoing efforts. So let's see. Where's the go forward? Oh, green. Okay. Let's see if this works. Oh, the sound didn't come on it.

How many of you have been with this program since 2001, Children with Special HealthCare Needs Program or of Title V? Couple of you. Then you remember this train. This is when we launched the national campaign for systems of services for Children with Special Health Care Needs. And in 2001, it was the topic, the theme for Child Health Day, and it was all aboard the 2010 Express. It's hard to believe that it is already 2007, and we're well on our way.

Our mandate comes from Federal legislation, first of all, through the Title V of the Social Security Act, and many of you are very familiar with this language, to facilitate the development of community-based systems of services for children with special healthcare needs and their families. But we also have a national health objective. And, it's Healthy People--we have several. But the main one for our systems initiative is Healthy People 2010 objective 1623, and that language, I'm sure looks very familiar to you too, and that's to increase the proportion of states and territories that have systems of services for Children with Special Health Care Needs and their families.

In more recent years though, we have also been given responsibility under the president's New Freedom Initiative to, again, facilitate the development of community-based systems of services for children and youth, and adults with special healthcare needs and disabilities by the president's New Freedom Initiative. So we have several national mandates to work on pulling together the system of services for this population in children and families.

I heard Michael talked to you about the National Survey of Children with Special Health Care Needs and the National Survey of Children's Health. And we're just about, as I'm sure he told you, about ready to get the second set of data for the National Survey of Children with Special Health Care Needs, and we'll see how we're doing nationally on what we considered to be indicators of a system of care for this population of children and families. These--for those of you that have

been around for a while and maybe even for some of you that are newer, these are the six indicators that we tend to consider representative of systems. It's not that they're the only ones. There are hundreds of systems indicators. But we feel like if we can get a handle on these six that we--that probably if a child has all of these, they probably are in a system, a good system of care. Those are family partnerships and satisfaction over on the right. You've got the national data from the original survey of Children with Special Health Care Needs. Access to care through a medical home, access to affordable insurance, early and continuous screening and intervention, easy access to community-based services, and services to transition--for successful transition to adulthood. That status on transition hopefully is going to be significantly different in the current survey because we've changed the measure somewhat to focus primarily on health care rather than vocational education, and those kinds of things. So we're all looking forward to the data from the new survey in the next month or so.

For those of you who are new, Children with Special Health Care Needs are not what they were 25 years ago when we used to think of this population as crippled children. It's a very, very broad population of children and families as you can see by the definition here. It's not only children who have a condition, a physical development or behavioral emotional condition, but also children who are at risk for such conditions. We probably have the broadest definition of special health care needs of any federal definition in any federal agency. Just about all children with disabilities fit into this definition. It helps us in our discussions with other

federal agencies. And according to the first survey of Children with Special Health Care Needs, about 12.8 percent of children under the age of 18 have a special health care need.

Who are we? Well, I'm Bonnie Strickland. I'm in the Office of the Director. We have two branches, the Integrated Services Branch that has broad responsibility for the system, those elements that I just talked to you about, and the Genetic Services Branch that has taken a national lead in implementing newborn screening programs and very specific genetic condition programs across the country.

Now, I'll tell you a little bit more about those. The Office of the Director, that's me and Renee Newton who is our secretary, and takes responsibility all the way across the division for keeping us all on task. We have lot or responsibilities in the Office of the Director, but primarily what we do is interact with other federal agencies to try to make sure that our initiatives are congruent with and coordinated with work of other agencies around individuals with the disabilities, that's children, youth, and adults. All of our staff work across all federal agencies, but we just take the lead for trying to coordinate that. We lead the development of emerging issues, impacting children with special healthcare needs. For example, autism, we are--there is rumor, and we expect that we're going to be getting funding for autism, but we haven't really had specific funding for autism in the past. In our division, though we have tried to keep some work going on in that

area, we've been represented on the Interagency Autism Coordinating Committee. We support a national resource center to work on medical home and autism. So we may not have a specific program in place but we have emerging issues that we believe are coming our way that we have to get started on. And we try to coordinate those through the Office of the Director. And then we lead the data initiatives that across the entire division, specifically the Children with Special Health Care Needs survey.

In the Integrated Services Branch, that branch that has responsibility for the broad systems of services is Diana Denboba, she is the acting branch chief. Lynda Honberg who has responsibility for the financing piece and epilepsy. Janie Martin Heppel who directs the TBI Program. Irene Forsman who directs the Newborn Hearing Screening Program. Elizabeth McGuire who directs the Healthy & Ready to Work transition program. And Bev Jones who provides administrative support for the branch. For those of you that have been around a while you know all of these people. For those of you who are new, you will be seeing all of them during the week. They are not here today but they're going to be here tomorrow through Wednesday.

In the Integrated Services Branch, as I said, this branch has responsibility for the broad system. So we promote family-centered care, cultural competence, family professional partnerships, and Diana Denboba leads this effort along with support from other staff. And this is the program where the new Family to Family

Health Information Centers are housed. And, oh, and within two years we'll have a Family to Family Health Information Center in every one of your states. So if you don't already have one you should be looking to apply for these in the coming year. The medical home--Marie Mann, who's actually in the Genetic Services Branch, but she takes responsibility for the medical home initiatives. We have a national center with the American Academy of Pediatrics, and if everything that's going on around medical home has escaped your attention over the last year, see me after this meeting. Medical home has really, really taken off on a national level. And as you may well know, there's a lot of activity around legislation, around medical home as a mechanism for comprehensive quality care, and it's also taken off in the adult world with Medicare demonstration projects being plan through Medicaid.

The adequate health insurance and financing piece is coordinated by Lynda Honberg. She directs the Catalyst Center, which is our national center for financing issues. Now, one of--we don't--we're not the agency responsible for necessarily paying for health care, although certainly the Title V--you do, you pay for some services. But we try to work closely with the centers for Medicaid--Medicare and Medicaid services to increase the adequacy of insurance. As many of you know, children with special health care needs may be very under-insured, although they may have insurance, it may not be adequate to cover their multiple health care needs.

Early continuous screening and surveillance, we have multiple programs. This is an area that in our strategic plan we're trying to improve over the next year so that we can begin to approach developmental screening rather than just newborn screening and hearing screening. So you'll see some new work from us in this area over the next year.

How many of you are familiar with Champions for Progress? The--there you go. This--out of Utah State University, this has been our primary national effort around the--integrating the community systems. That's with Rich Roberts. Diana Denboba is the project officer for this effort, and that center has worked with us over a number of years to help to work with Title V agencies and work at the community level.

Transition to adulthood, Healthy & Ready to Work. How many of you are familiar with Healthy & Ready to Work? Most of you are. They do a lot of work in transition with multiple agencies and families.

And then the last thing, and I just I want to mention this briefly, is we get a lot of direction from Congress around categorical programs. That means we get our money categorically, sometimes this much money to work on this disease, this much money to work on this condition. And we try very hard to take all of those conditions and integrate them into that broader systems context. So, for example, epilepsy, we have a funded program, an earmark program in epilepsy, and we

then try to make sure that children and families covered under this program have access to medical home, access to adequate financing, integrated services in the community and so on.

The Genetic Services Branch is led by Dr. Michele Puryear, her deputy is Marie Mann. I'm going to go quickly through this. Penny Kyler is on the--works on the ethical issues around genetics. Jill Shuger does the regional collaboratives. Lorraine Brown and Judy Hagopian administer the sickle cell program. Jack Arner administers the hemophilia program. And Carrie Diener provides administrative support across the division.

The Genetic Services Branch has very broad national responsibilities in genetics, primarily related to services. They are responsible for the health care and public health infrastructure for developing that, for improving that. As you well know, genetics is a huge issue these days and building the infrastructure at the community and state level is of paramount importance. Second, there are a lot of ethical, legal, financial issues around expanding newborn screening and genetic services. And the Genetic Services Branch is responsible for those as well. Genetic literacy, one of the big issues for us right now is making sure that the MCH population understands the issues related to genetic testing and the role of genetic information in improving health practices. And we're--developed numerous materials in this area designed for the consumer. And fourth, provide--the branch provides leadership in defining the educational needs in genetics for

health professions, and like the integrated services branch, the Genetic Services Branch also supports categorical programs. It just so happens at the National Hemophilia Program, the Thalassemia Program, and the Sickle Cell Program are specified in our legislation. So we have a long standing grant program related to these three programs. And then the branch is also responsible for the building on the expertise gained in MCH to provide national leadership on expanding and enhancing genetic services for the entire population.

Last, and not the least though, and about what takes up a lot of our time these days is the secretary's Advisory Committee on Heritable Disorders in Genetic Diseases in Newborns and Children. This committee advises the secretary on the science and technology for expanding or enhancing screening for heritable disorders, and you have seen this. In your state, as most states over the past few years have dramatically expanded the panel of conditions for which we screen from just a handful to now in the teens, and some as many as 17, some more.

As I said before, we'll all be here over the next few days, and we're happy to be here. We're looking forward to working with you. I didn't put everybody's email address on here but you'll meet us and you can certainly see me if you want contact information from any of our staff. Again, thank you for being here, and we are looking forward to working with you.