

## **HRSA/MCHB 2007 FEDERAL/STATE PARTNERSHIP MEETING**

### **Building Blocks for Promising Practice Models**

October 14 - 17, 2007

#### **Plenary Panel**

CHARLES N. ONUFER: Good morning, everyone. I'm humbled to follow the previous two speakers. I like to spend the next few minutes talking to you about a few of the projects and the activities that we are engaged in in Illinois that have a sort of direct or indirect impact on families that have children with autism.

First, I want to clarify, though, and that is that Illinois, like many of your states, our CSHCN program does not qualify children with autism for medical eligibility, and as a result, we do not provide any kind of financial assistance to those families. Obviously, the primary reason for not expanding the program is fiscal constraints. But I think, on a personal level, many of us have found ways to engage ourselves in activities that help to promote the support that families need for autism in our own states.

I think that, as we mentioned, that the critical rise in the autism, the incidents, that there are very few individuals across the country that are not, in some way, touched by autism. A good example of that is that I was at a training session in Rockford, Illinois recently, and as we went around the room and I had people introduce themselves, I asked them to tell us if they had any relatives with autism

or if they had any friends with autism. And as it turned out, out of 27 people in the training session, only six people indicated that they did not have a relative with autism or a close friend with autism. And on my own personal level, I have my friend, my grandson, Ben, who has been my teacher and my inspiration for learning more about autism and wanting to get involved in autism activities. Ben turned 8 years old yesterday. And as Lee was describing his son, I think Ben has covered all of the symptoms of autism at some time at the--since he has become to manifest the symptoms of autism. He has a younger sister, who turned 6 just two days before him, and she is developing relatively normally. If you can say that a 6-year-old who is acting like a teenager is normal, then that's okay. I think, you know, as I look back over Ben and his mom and dad as they were first experiencing the information about Ben being diagnosed as having autism, that it became very obvious to me that it's so important for these families to have a medical home, and I know that I'm talking to the choir when I say that they need a medical home. But I think, if you look at the seven components of care that are related to the medical home model, you can see that every one of those components are very critical to the families that have children with autism. And probably, the most important component of that medical home model is that relationship that they have with their primary care physician. They need to be able to go to that physician who they trust, who they feel comfortable with, and relate and share their concerns, because after you go through magazines, books, you talk to your friends, you search the internet, you want to go to a professional that can really personalize the symptoms and the signs that Ben has and how do

all those things meet and mesh with his situation. And so, you need a professional that knows the community resources and is able to refer you to the appropriate specialist, the appropriate providers, and provide the appropriate support that's available in the communities.

So, I know I would be remiss if I--talking about programs that I don't talk about or at least mention medical home, because I think that is something that is very critical to these families.

I like to talk to you a little bit about Care Notebooks. Now, Care Notebooks don't necessarily apply specifically to children with autism, but they apply to all children with special healthcare needs. And about two years ago, I invited Lorry Lupin, who I think is in the audience, who used to work for AAP, and now, she works for AMCHP. And I invited her to a workgroup that was critiquing final stages of a Care Notebook. And during the course of the discussion, the question came up, "Do we describe this child as being eight weeks premature or 32 weeks gestation?" And we begin to realize that there's no perfect way to make statements that are going to apply to all families, and in a broader sense, there's no perfect Care Notebook that's going to be appropriate for everyone. And Lorry suggested that she had access to about 20 different state Care Notebooks, and that it would be neat if we could divide up the Care Notebooks into subsections and make them available on the Internet.

She left for AMCHP, and so we continued the project in Illinois. And as of about three weeks ago, our project has come to fruition, and if you go to the Web site that's listed at the bottom of the page, first, you'll start with medical home info and then scroll through the various screens, and then you'll come to this page that says, "Build you own Care Notebook." If you scroll down, you'll see four examples of complete Care Notebooks, and at the top of the screen, if you click on that link, it'll take you to Building Your Own Care Notebook. Clicking on that shows you sort of the structure that we designed for a Care Notebook. There are six major sections, and if you scroll down, you'll see the other four sections.

But going back at the top, if you look at Care Providers, there's one example. And you click on that, it'll take you to this page where, in this example, there are 19 versions of just that one subsection of care providers. And at the end of each of the titles of the sections is the name of the state that the notebook had--the Care Notebook came from. So, if families are--find one particular state's notebook or Care Notebook to be appealing to them, they can follow those through the other subsections. The versions are available in both Word and PDF format. So, if they have Word on their computers, they can copy several versions, copy and paste, and really customize that Care Notebook to meet their needs.

Now, this is the first phase of this project. The next phase that we're going to be working on is developing a tutorial so that families can walk through the tutorial--

will help them to walk through the Care Notebook to really be able to customize the notebook for themselves. In addition, we're gonna use the tutorials as a teaching guide for Family Voice representatives around the country, so that they can use it to facilitate workshops for families if they're interested in building their own Care Notebooks.

Another project that we're involved in, and again, it doesn't apply specifically to children that have autism, but to all children with special healthcare needs; we recognize the fact that many pediatricians and many families don't have easy access to community resources. And again, about two years ago, Lorry put together a workgroup of representatives across the states. And we worked on developing a database of categories that could be used for a community database that included all children with special healthcare needs. And Illinois, at the time, we had the Illinois Life Span database, which was an online database that was funded for people with developmental disabilities. Mike Kaminsky runs that, and he got more funding and agreed that if we could expand the database for all children with special healthcare needs. We have just completed that phase of the project. And now, we have people from the autism program, people from the brain and spinal cord injury program, human services in our own 13 regional office care coordinators beginning to populate that database. The reason I present it to you is that if you want a copy of the taxonomy database, just contact me and I'll be glad to share that with you, and also, Mike's contact information.

Now, a few years ago, the Illinois General Assembly recognized the growing crisis across the country, and particularly in Illinois, of the number of children that are being diagnosed with autism. And so, as a result, they passed legislation to establish the autism program, which really has three focuses. One is training, consultation, and the development of model programs in Illinois to help in the process of managing, identifying and caring for children with autism.

The program has five major clinics across the state associated with universities. And they've developed an infrastructure to train physicians on the early identification of risk signs associated with autism. And they partnered--the autism program partnered with the Illinois chapter AAP to develop an office-based educational program for early identification of autism. It's a one-and-a-half hour presentation. It's scripted, and we've trained about 15 to 20 pediatricians who go out to communities and they train physicians in their private practices on recognizing the early signs of autism. The program provides one and a half hours of CME credit. Now, EDOPC is Enhancing Developmentally Oriented Primary Care, and its real focus is to encourage pediatricians to implement early developmental screening throughout the course of the early development of children. And so, there's a presentation on developmental screening, social emotional screening, postpartum depression screening, as well as autism screening, and we recently just added domestic violence screening.

The reason that they're promoting this idea of using developmental screening instruments is that studies show that if you only use surveillance and not standardized, validated, commercially available developmental screening tools, that you're going to miss a great number of children. Eighty to ninety percent can be identified in mental health problems with standardized screening instruments, and seventy to eighty percent using standardized developmental screening tools. And Cutler, who's a developmental pediatrician at the University of Illinois in Chicago, did a study in 2001, where she found that 92 percent of pediatricians are monitoring development, but only 36 percent are using standardized validated screening tools, and most of those were using the Denver, to a lesser extent, the ages and stages, and very few were using--and doing social emotional screening. The barriers that physicians indicated on the survey was that they didn't have the time, they lacked the staff, and of course, reimbursement was a major issue. In Illinois, none of the private health plans pay for developmental screening. Our public aid does pay for up to 20 different types of screening instruments. Lack of training of their staff. And also, the perception that it was difficult to communicate negative results to families. But we've tried to make a very strong point about developmental screening and that it really makes a statement for the practice to say how important developmental screening is throughout the early stages of childhood. And so, we try to really strongly promote this type of screening. Now, let me go through, very briefly, the presentation on autism is divided into four parts. And I'm going to take some

samples of each of the four parts of the presentation to give you some idea of what it looks like.

The first part provides basic information about autism. And it really focuses on the three areas of dysfunction: social interaction, communication impairments, and restrictive repetitive behavior and interest. The second part of the presentation presents an overview of what normal social development is, because social development is certainly a key issue with children with autism. And looking at the earliest signs of autism, we look at joint attention, social interaction and play behavior.

One of the nice features of the PowerPoint presentation is that we've used a number of video clips from first signs to demonstrate normal development as well as some of the risk factors that are associated with autism. And I'm just gonna show you a quick video clip of one of the examples.

Dr. Greenspan: Well, you should be able to be very warm and very happy and very joyful. So, mommy's smile (inaudible) light up and just be so overjoyed, that mommy's smiling that daddy's smiling. We can see a formidable (inaudible) self-absorbed that looks very despondent, for example, as this kind of thing (inaudible) and staring off into space rather than at you. Well, you know that that expectable social, emotional and cognitive milestone has not happened.

CHARLES N. ONUFER, M.D.: I always enjoy watching Dr. Greenspan. The third part is the early identification, and probably the most important part of the presentation. And here, we, again, we try to emphasize the importance of using developmental screening, either the P or the ASQ. And again, we emphasize the point that we don't use developmental screening just at the 18 to 24 month period, but we use it throughout the spectrum, and that it should be just a part of the ways in which the physician can identify children that are at risk.

We also talked about the AMCHP and the QCHP, and the AAP promotes the use of the AMCHP with a very strong caveat, that it's only a screening instrument. The validity of the sensitivity and specificity of the AMCHP is not that good. And there are some kids that fail the AMCHP and still--and through evaluation, do not have autism. This is the slide, I think, that shows all the behavioral red flags, and this is where I can take advantage of my experiences with Ben, because he exemplifies most every one of those.

Part four is very important. And the ICAAP group; the Illinois chapter group, really tries to support the practice by making them--making available for them the resources for referrals to specialists, referrals to therapists, support groups, so that they can support families in a better way. We also invite the early intervention people, so that they're very familiar with referring children to early intervention. And then I would conclude again with the medical home model, and that is how important it is for that physician to invite that family back so that they

can talk about their anxieties, their frustrations, associated with the child that, perhaps, was just recently diagnosed with autism.

If you're interested in this PowerPoint presentation, you can contact Sarah Baur at the ICAAP office. She'll give you the copy of the slides, the script, and also the support materials that go along with it. Thank you very much.