HRSA/MCHB 2007 FEDERAL/STATE PARTNERSHIP MEETING

Building Blocks for Promising Practice Models

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Plenary Panel

GEORGE S. JESIEN: Thank you, Ann, and good morning to everyone. I want to thank you for having me here and for bringing this panel together around this topic of autism. But I'm sure it's not new or strange to any of you and it's something that you've been hearing a great deal about. I want to take my 12 to 15 minutes to set a context, talk a little bit about the current legislative activities and where we may be going next, a little bit about how the LEND programs fit into this particular context.

First, let me start with a quote from a terrible sounding report, Morbidity and Mortality Weekly Reports affectionately known by MMWR that CDC produces. You probably saw this had made a tremendous impact in the news media when it came out in February of this year. You've probably all seen it, the quote that keeps being made over and over again is that 1 out of every 152 children, or 1 out of 150 has autism, at least across these 14 sites that looked at children of eight years of age.

The next, I just took--and I think Lee may talk a little bit more about the prevalence--I just took this graph that looks at data from '92 to 2003 just to

substantiate what I'm sure many of you have been experiencing in your states, have experienced in your Part C programs as you are assessing children in your programs for children with special healthcare needs, school districts and preschool programs in their special education programs, and certainly our health professionals as they respond to parents' needs. The bottom line here is this a condition and disorder that has been increasing at a tremendous rate over the last 10 years.

A report that was put out in 2005--and there are some people in this room who participated in the Autism Spectrum Disorders Roadmap, identified, I think, in very succinct and clear language what the major challenges facing this country are. Effective services and funding options tend to be scattered, fragmented and poorly coordinated. That are--those are probably the touchstone words of what families and parents are facing across this country. No widely accepted or implemented service guidelines for autism spectrum disorders, significant gaps in knowledge among professionals about the disorder, its causes, the ways to treat it, what parents and families and professionals should be doing.

And then lastly, financing is inadequate to meet the needs of most individuals and their families. I think a pretty clear statement of the context in which we are all working. The report also identified the directions toward which we needed to head, what our collective work needed to go toward. Very clearly, they stated that the success and well being of individuals with autism spectrum disorders will

depend on communities and the resources that those communities provide. We need systems that are integrated across service sectors. I'll tell you, I've been in this field for--oh, I don't know, 30, 35 years. I cut my teeth in the early intervention system, Part H and Part C, and we haven't yet figured out how to have education, health and mental health work together in a consistent coordinated way. It's really amazing. I was at a health meeting the other day where I heard the education system sort of being bashed. I was among a bunch of educators three weeks before that and heard similar kinds of statements on why they didn't think the health sector was really responding to needs. This is an area--if there is a disorder that will force us and make us look at cross-sectoral collaboration, it is autism. And part of my presentation is that this disorder does provide an opportunity, as Donna said in her talk, an opportunity for us to truly move that collaboration agenda further down the road. So we need communities that are integrated across service sectors and are collectively responsible for achieving appropriate individual, family and community outcomes. And I hope in some ways that we can incorporate these reports' goals into our daily practices, our daily discussions and meetings, and then lastly a tremendous amount of information, training and technical assistance that's needed for parents and professionals alike.

Let me move a little bit to where we stand right now in terms of legislation around autism. Let me first talk about the characteristics. A disorder that truly has had bipartisan support, those of us who have worked on the Hill have always tried to

manage disabilities as not a political issue, but a human issue that crosses borders across conservative and liberal, Democrat and Republican. And I think one can say that the autism work that's being on the Hill truly is bipartisan and in fact if you talk to anybody on one side of the aisle, invariably in the conversation will be, "Who can we work with on the other side of the aisle to move this legislation through?" There is a plethora of advocacy, disability and autism specific groups that are working on legislation behind the scenes. I was glad to see Lee here ASA or the Autism Society of America has been instrumental and a tremendous partner with other groups to recognize the needs, not only of children with autism, but also children with related and other developmental disabilities. So they've been a stellar partner, as well as a number of other disability groups like Easter Seals, Autism Speaks there's a wide range of groups that have been working in this area.

I think one of the strengths that the legislation that is currently working its way is the incredible strength of the grassroots. It almost reminds me of back in the '70s as parents got together, pushing for special education and the predecessors to IDEA, it's an incredibly vocal, committed and energetic grassroots that can't be underestimated. Somebody once said to me about a year and a half ago, "If you want 150 parents on the front door of a congressman's home, just give me their address and where they stand on autism and this related disability." Very effective, very strong and certainly to be worked with. Champions on high places from the CEO of NBC to celebrities to congressional members, there is this sort

of stratification of champions all along from local chapters and communities throughout this country all the way to the highest seats of power in the United States.

Personal knowledge, many members of Congress either have staff, family members who have experienced or lived with a child or a sibling or an adult with autism spectrum. So it's not a disorder that is unknown of when you go up to the Hill. And I think that's very, very important because many of the congressional members, both on the Senate and the House side, respond from personal experience or from personal experiences of those whom they know.

Lastly, this is a disorder that there are many controversial issues that churn and each new study that comes out feeds one or the other side of a whole range of controversies. And yet it's a very, very clear that if policy is to move forward, we have to find a common ground and emphasize the common needs that children with autism and related developmental disabilities have rather than the differences in particular points of a particular study. So the consensus building is really critical for moving legislation forward.

Let me give you two overriding needs that I think were discussed and felt on the Hill as well as among the advocacy groups. Two overriding needs are: first, research, knowledge and understanding of the disorder, and secondly, an expansion of services and supports. The initial idea was to create an omnibus

autism bill that might really look at that whole continuum of research all the way to direct services. That was found to be unfeasible for a whole range of causes and issues that would be raised and really Congress decided to split these two topics into two. The first that looked at understanding and the research and the knowledge we needed, and the second around supports and services.

So the first bill, Combating Autism Act, was signed by the president last year. It authorizes $168 million in FYOA. Now, not to get too excited that 168 is not all new money. It's actually about $25 million more than the previous year. And most of that money goes to NIH with the substantial sum both to CDC and to HRSA. Let me go over each one of the sections.

To NIH, the basic bill asks that it conduct, in its various institutes, basic and clinical research across multiple fields and it names over 10 individual fields that research has to be conducted in into the causes, diagnosis, early detection, prevention, control, intervention and cure for autism spectrum disorders. What was really interesting in looking at the NIH section and I think it's one of the hallmarks of HRSA's and MCH's work is this aspect of interdisciplinary. I've said this often. If there's a disorder that demands an interdisciplinary approach to its understanding and treatment and the supports and services that are needed to be provided, it is autism spectrum disorders.

CDC is charged with epi-surveillance programs and regional centers of excellence and HRSA is charged with disseminating information, establishing lead agencies within the states, development and utilization of screening tools and expanding interdisciplinary training in autism and other related developmental disabilities, as well as the promotion of evidence-based interventions. So that's the work that's coming up as this bill moves through its various stages.

Combating Autism Bill also talks about the LEND program, Leadership Education and Neurodevelopmental and other Related Disabilities. It is the intent of Congress to provide existing LENDs to immediately train addition developmental pediatricians and all of the other disciplines in its 11 core disciplines in the area of diagnosis assessment and provision of intervention for children with autism, as well as expand the number of LENDs in this country. Currently, there are 34 LENDs in the United States. These moneys, if appropriated, would actually expand that network to states that do not now have a LEND. Emphasis on that training is to include an interdisciplinary approach, cultural competence, family-centered care and leadership development, some of the basic tenets of all MCH work and that was able to be gotten into the legislation. And I think Congress truly realizes the central role that MCH plays in developing future leaders in this area.

Let me mention the second bill, which now was introduced by Senators Clinton and Wayne Allard in the House. It's called Expanding the Promise to Individuals with Autism Act. If you just take the letters, it's become affectionately known as the EPIAA Bill by many sectors and as you walk across the halls of Congress, you walk in and you say, "I'm working in EPIAA" and congressional staffers really already now know what you're talking about. Representatives Mike Doyle and Chris Smith introduced the Identical Companion Bill in the House. So these bills have been introduced but have not yet been passed.

Expanding the Promise Act includes the following sections. Authorizes demonstration and planning projects that go to the states, and this is important, for supports for children, as well as adults. The adult area is one that has not achieved significant focus and emphasis, I think, in previous autism work. Grants to states to expand post diagnostic care, trying to shorten the amount of time between receiving a diagnosis and receiving appropriate services. They wanted to deal with the whole finance structure but didn't know what the answer was. So Congress, in its great wisdom, when it doesn't quite know how to decide, says, "Well, let's develop a report and how we should proceed in the future." And so, there is call for a GAO report that would study and provide recommendations of how--about appropriate financing structures. Statewide interdisciplinary technical training--training and technical assistance, continuing education, and the promotion of community-based services--this is addressed to the university centers for excellence and developmental disabilities. Another provision is the

expansion of protection and advocacy to make sure that children and adults with autism have access to health, education, employment, et cetera, and a technical assistance center to inform state agencies, organizations, and families about best practices.

And then lastly, I just want to mention, there is another bill working its way called Empowering Children with Autism that Representative Yarmuth introduced that establishes a task force to identify and disseminate evidence-based interventions. And there is some thinking that this might be included in the No Child Left Behind legislation that is currently working its way through Congress.

A quick statement about current status. Combating Autism Bill has passed both Houses. It's been signed by the president so it is now current law. Unfortunately, many people think that you can relax when something's been signed into law. That's very far from the truth. What authorizing language does is set dollars aside or authorizes the use of funds. It's the appropriations process that actually puts dollars into federal agency budgets to carry out the work. This bill will have very, very little force if the appropriations process does not work its way. Both the Senate and House versions of the Labor-HHS budget have increases directly specified for the Combating Autism Bill. Once that those bills are passed out of the House and Senate, they need to be conferenced and then will be sent up to the president for his signature. There's about a $13 billion difference between the administration's budget and what these bills proposed, and the president has

threatened to veto the Labor-HHS budget. So, there is some clearly some work to be done. If the Labor-HHS Bill is not passed, we will have serious difficulties to implement any of the provisions of this bill as well as other provisions such as the Block Grant increase, for example, that's both in the House and the Senate so a critical time for many of us.

Expanding the Promised Bill has been introduced in the House and the Senate, as I said, still has to go through committee floor action and presidential signing. All right.

Let me stop there and leave that as the context for the rest of the discussion. I think this is as critical a time as we've had in terms of some of the provisions for the work that we have to do in respect to children, families, and mothers, and especially children with special healthcare needs. My hope is that we do our part to be able to have the kinds of provisions and dollars that have actually been ascribed to things such as the Block Grant, the Combating Autism Bill; and that we show the leadership that is needed in order to allow us to do the kind of work that we will need to do in the coming year. So with that, I will turn the podium over to Lee. And thank you very, very much for your time, and I look forward to your questions at the end of the session.