

HRSA/MCHB 2007 FEDERAL/STATE PARTNERSHIP MEETING

Building Blocks for Promising Practice Models

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Plenary Panel

PAUL CARBONE: So I'm--I know we're running a little bit late. Okay. All right. I know it's close to lunch so I'll try to get you all out on time, and we'll get started. So, I appreciate the organizers of the conference today for allowing me to speak. It's my great pleasure to be here and talk to you a bit about autism spectrum disorders. Good.

I guess I was asked to speak to you a bit in that. Somebody thought that I was a good poster boy for all of these programs that you've been hearing about today. And I was asked to share a bit of my perspective and my experiences with this disorder from a bunch of different vantage points. So the first one I'll share with you is, I, too, am a parent of a child with autism that's been there, and he's now four years old. He was diagnosed at two. And like most kids with autism that we see and work with, he's continued to make very steady strides and is doing quite well, thankfully. I'm also a pediatrician that participates and staffs a number of Title V supported clinics in my home state of Utah, so I'd like to tell you a little bit about those. And I've also just completed my LEND training, and I wanted to tell you a little bit about that great program and how it's benefited me personally. I'm also a general pediatrician in academics at the University of Utah, and I'm truly in

the trenches; I've come from five days in Vancouver straight to here to Washington, D.C. Normally, this is not my gig. I'm in the trenches usually full-time with an active clinical practice, taking care of mainly children with special healthcare needs with a definite emphasis on autism spectrum disorders.

So, rather than give you my experience, my, sort of, end-of-one experience as a parent of a child with autism, I thought it would be more helpful to share with you the collective experience of what the medical literature tells us about parents of children with autism. And what we know, first of all, is that they're less satisfied with their medical home than children--than parents of children with other special healthcare needs. In fact, data from the National Survey of Children's Health shows us that only 25 of--25 percent of parents of children with autism report primary care that's consistent with that of a medical home. Now, if you tease some of those components that Chuck talked about of the medical home out, you find that what seems to be lacking or what's less prevalent is family-centered care, and care that's comprehensive and coordinated.

There also seems to be a lot of frustration on the parents' parts around the diagnostic process. And we recently talked again about autism screening and primary care that the American Academy of Pediatrics has recommended an autism specific screen be done at the 18-month visit on every child in the United States. And the reality is, is that we're nowhere near doing that these days. And rather, there are still this traditional wait-and-see approach to developmental

problems that parents often tell me about when they finally get to me. And it breeds a lot of parental discontent once the diagnosis is made, and sometimes it even poisons the relationship between families and their medical home provider. And we also know that there's a high level of parental stress. The same data set that I spoke of earlier shows that parents of children with autism are far more likely to report high levels of stress than parents of children with other special healthcare needs. So what parents are telling us is they really would like to see some improvements in the medical home.

So that's a quick foray through parenting. I wanted to briefly discuss my personal experience with the LEND program. Overall, it was incredibly positive. I think that we had weekly didactic sessions that were spectacular and all around the issues that we all talked about with regards to disability. And I think what I gained most from it was the--this ability to collaborate with people across disciplines. And George talked a lot about that, and I couldn't agree more. I think that autism has shown us that we really need to get comfortable talking to our colleagues in education--talking to our colleagues in other disciplines like occupational, physical and speech therapy. And I think through those sessions throughout the year, I become very comfortable working collaboratively in--with folks across disciplines. I also got to participate and hone my skills in advocacy, which I'm very passionate about. And probably the highlight of my experience was being able to be here in D.C. in March for the National Disability Seminar.

Also, I got to participate in a number of clinical activities, again, using that interdisciplinary model that George spoke of. I was also with some great mentorship, they--able to design a leadership project looking at the medical home of children with autism spectrum disorders. And with this project that continues to be on-going now, we're looking--not only about into the aspects or the challenges that families face in attaining or accessing the type of medical care that they need through their medical home, but we're also looking specifically at providers and looking at those aspects or what are the challenges that you face in providing that valuable medical home. There seems to be a great disconnect between providers and parents, and we're hoping to bridge that gap and hoping to use that information to ultimately improve the medical home of children with autism. I was happy to be able to submit--this is a grant and it's being funded by the American Academy of Pediatrics.

Even though--technically, my time with LEND has ended, I continue to be active in the program. I have LEND trainees that come and see me at the various clinics that I still staff. I continue to be active in advocacy and I feel like the contacts that I have made through the program as well as just this, sort of, toolset in advocacy and research and education continues to serve me as I go forward. I certainly wouldn't be here in front of all you today if it weren't for the LEND program.

Even though my research career is, sort of, just starting, I was able to collaborate with one of my LEND instructors on advocating recreational activity for those with

disabilities, which I know we spoke of earlier today. I was also able to collaborate in a cross-disciplinary way with an occupational therapist, and I'm trying to study a specific form of recreation for children with autism spectrum disorder. So I'm excited about those opportunities. I also get a chance to pay it forward. I'm at a Academic Institution has a great collaboration with our Department of Health. And I'm lucky enough to give quite a few lectures to medical students and residents in our program around developmental disabilities including autism, and I'm beginning to be invited to more of these regional and national meetings. So I think LEND is, gosh, the perfect program for developing leaders in these areas and I'm hoping that it continuous for a long time.

So that was LEND. I'm going to briefly summarize my experiences within the Title V Program, which I'm very proud to be a part of. It's called the Utah Children with Special Healthcare Needs Program. It's administered by the Utah Department of Health. It provides a lot of the population-based services that many of you are familiar with. But uniquely, I think for some of the states, we actually offer quite a few direct clinical services, and I want to focus in those for you.

Children are eligible if they have or/are at increase risk for chronic physical developmental behavior or emotional conditions and have ongoing health-related services, and certainly, children with autism spectrum disorders qualify for our program and our--one of our most common patients that we see. Funding is not only through Title V and MCH but through the various agencies I've listed there.

And I wanted to just spend a very brief amount of time because I know we're running a little bit late on two of the clinics that I helped staff through a collaborative effort through the University of Utah in the Health Department.

The first is called the Child Development Clinic. It's based out of Salt Lake City. And what the clinic provides is comprehensive assessment in case management services for children birth through five with special healthcare needs or developmental delays. Many medical home providers aren't that familiar with autism or don't feel comfortable and would rather have a consultative service in their town. And so that's the niche that we can fill. The clinic, as George described, is truly interdisciplinary. We have a nurse, various physicians. We have representatives from the major therapies: speech, occupational and physical therapy. We have social workers. We have probably the world's best audiologist and that's not influenced by the fact that he's here in the audience with me today at all. And we really try hard not to take, or not to be the medical home for that family. Rather we coordinate the delivery of the services with the medical home and try to steer patients when possible to other agencies that are able to provide services. So specifically, for the child with autism, we really offer a comprehensive evaluation around diagnosis, and we stick with the families and we help them treat all those associated medical conditions that we mentioned because oftentimes, there's nowhere else to go.

I'm going to breeze to the Satellite Clinic Program because, essentially, the

reason the Satellite Clinic Program came into existence in our state is because of the fact that our population is so concentrated around the Salt Lake City metropolitan area. So 70 percent of our population lives in what's called the Wasatch Front, which is very close to Salt Lake City. And then the rest of the population gets very rural pretty quick. And so, the basic child development clinic model is then just put on the road. And so, the interdisciplinary team goes to where the patients are, rather than having children with developmental disabilities have to travel up to where we are.

Again, through our staffings, there's ongoing collaboration with the medical home provider and the educational team so that the people who take care of the child locally are present at our staffing meetings that take place in these locations and collaborate with us to help come to--come up with the treatment plan. It's a sort of a homegrown process. So the clinic is managed by the local health department.

So to give you an idea, specifically, the service that a child with autism could have, I, sort of, randomly plucked the chart out of our clinic and--I'm being told that I have one minute. So, I'll briefly show you what a child with autism might get from our clinic. So a two-year-old boy is referred to the early intervention program by his pediatrician for some language problems. He's then referred on to our child development clinic by his case worker for some further developmental concerns. He's seen then by the pediatrician, who suspects an autism spectrum

disorder and identifies a number of other those medical problems that Lee was talking about, sensory processing difficulties, sleep problem. He's seen by our audiologist because of language difficulties right there in the clinic. He's documented to have normal hearing. He's seen in our clinic by the occupational therapist, who looks at sensory issues. And he's seen by our psychologists who staffs the clinic, who does some psychometric testing. Uses one of those gold standard tests that I think Lee mentioned, the ADOS or Autism Diagnostic Observation Schedule, consistent with autistic disorder. And then various folks in the clinic continue to work with that child throughout to manage other problems that come up as we go along. And I'll try to just zip through. I don't think I have any--the last slide. Can I do the last slide?

Ann Drum: Sure.

PAUL CARBONE: Okay. Thanks. And these are--I guess, points for discussion. So these will be good to see. I think that we--I wanted to just outline some future challenges. We obviously need to--continue to work on efforts like we're outlining today in Illinois, to improve screening of children with autism spectrum disorders. We need to not only after we have a positive screening, we need to have quick access for a comprehensive evaluation. Just on my way back from a conference in Vancouver, where in British Columbia, the wait for an evaluation for a child with a positive screen was nine to 12 months. That's simply too long. We need to have improved access to appropriate and evidence-based services. This is a

huge challenge that we all face. The LEND Program has taught me that we need to work collaboratively, unless in a fragmented way to provide the best possible services. Again, I think the LEND Program is a great training ground for highly trained professionals. And as Lee said, the whole family is involved so we need to identify those informal and formal support networks for families. And I'm done. So thank you.