

HRSA/MCHB 2007 FEDERAL/STATE PARTNERSHIP MEETING

Building Blocks for Promising Practice Models

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Plenary Panel

LEE GROSSMAN: I'm glad that the slides are wonderful. It's an honor to be here today as a parent of a child with autism and an advocate for the autism community. It really is a pleasure to be in front of you and to present where we are with autism today and where we hope to be. It's very important for this message, this national crisis to be discussed. And for you that are, in fact, providing services and looking over and attending to the autism community to have a very good understanding of where we are and where we think the autism community will be heading.

It's always a pleasure to follow George when he presents and I don't think I've been able to do that a few times because he basically did my speech. And so, that will allow me to really skip through my slides quickly, so I won't be redundant.

My talk is who we are, where we're going, and where we should be in talking about the autism community. And we define the autism community at the Autism Society of America as all those that are affected by autism. And what does that that mean?

Well, first of all, this is my son, *Vance, who's 20 years old. He's the one on the right in the picture. And he is basically your Joe Blow autism person through the E2E3 checklist that the ADOS, ADIR, the CARD, everything that we've ever diagnosed him with. He's considered mid-spectrum. Just recently though in the last two years, in spite of the efforts of his parents, he's improved quite a bit. And as a result, he's been moved up to a high-functioning autism. And I bring that up because these are--these terms like low-functioning and high-function are ones that I really don't like. Now that he's high-functioning or consider him high-functioning, everybody was like high fiving us and congratulating us. Isn't that wonderful? Well, what happened was that the services he was receiving then became much more limited because they were saying he's not as severe. Well, the reason he was able to become high-functioning, relatively high-functioning, was because of the high-level and appropriate services that he was receiving. And now to restrict those, and to take them away doesn't bode well for him continuing that projectory that he was on.

The other side of the coin is low-functioning. And I bring this up to talk about people that are on the spectrum because I don't think these categories really do individuals with autism justice. I have not--I have yet to meet a person with autism on any part of the spectrum that doesn't have phenomenal abilities. It's really up to us, service providers, parents, et cetera, and advocates to identify what those are.

A couple of years ago, a group TASH brought two individuals into our office that were, by anybody's standard, highly involved. They needed aids. They were a little bit self-abusive. It could--were non-verbal. And they brought them to our office for us to have a discussion with them, and we did. We had a discussion with them. They were using alternative or an augmentive communication devices. And through that, we could see the brilliance that they had.

One of the gentlemen was 44 years old that spent 35 years in an institution, had no formal education, and was perhaps one of the most well-read and brilliant individuals I had seen. They had finally found a way for him to communicate and to expose the true talents that he had as an artist. And now, he's actively selling his artwork throughout the world. The other individual was about 22 years old and had spent about 15 years of his life in an institution as well, and he is a brilliant poet.

And it was just wonderful sitting there and talking to these individuals knowing what their true abilities are, as well as their great sense of humor. But on top of that, finding out what their life experiences has been and they've been--they were pretty dreadful, and the experience that they were sharing were frightening. And beyond all of that, they still had a great sense of humor, tremendous compassion, they were flirting with my staff, which was very interesting, and we had a very good time with them.

So let's just throw these labels out because as far as the autism community is concerned and the individuals with autism, they're meaningless. And we can't pigeon hole any of--anybody that's on the spectrum. And as you could tell, people on the spectrum are ones that are certainly affected by autism. And what did I just do? I went back. Here we go.

These are Vance's brothers. And I call the siblings of those with autism the silent victims of autism. The reason is, is that their lives are changed forever and greatly because when autism comes into a family's home, it dominates, it creates a chaotic situation that families are more often than not in crisis mode the entire time. And to say that they're not affected by autism and to say that they're not part of the autism community, would be doing them a tremendous disservice. And when you include them and the parents and the grandparents and aunts and uncles and the immediate family, you could tell that this is a very expanding community that we're dealing with.

The gentleman in the middle of this love sandwich, the main meat here in this sandwich is Dr. Jim Ball. And Dr. Jim Ball is my go to person when I have issues dealing with Vance, and he has been my main consultant. And he, to me, epitomizes, and as a tremendous representative of the professionals in the community. And I call them, they're our silent heroes because these are folks that, and I include teachers and OT, and agency people, and speech pathologist,

the full gamut of service provision, medical doctors, psychologist, psychiatrist that really put themselves out tremendously for our community. They're the people that, as a parent, that I rely on to help us, to lead us through these lifespan issues that we're dealing with. Many of them who really put themselves out for autism and in some cases particularly those that are promoting some fairly credible, but alternative medical treatment are subject to incredible harsh treatment by the medical review boards. Many people that are on--that are professionals haven't really put themselves out for the community aren't supported. And I think that we need to change that.

To say that professionals are not affected by autism is doing them a tremendous disservice and we need to provide them what the supports that they need so that they can better serve the community as well. So when you add all of this up, we're looking at--in the U.S., a community that's in the tens of millions large, and it's growing. And it is indeed affecting all of society.

George went over very well the CDC findings of 1 in 150. And I was at the congressional briefing when the CDC announced their results this past February. I was asked to speak. And I--to the CDC's credit, they bent over backwards to explain that the state that had the highest prevalence rate, which is New Jersey, which was about 1 in 97, 1 in, I believe, of 63 boys. They really, really spend a lot of time to show how the New Jersey figures we're not an anomaly. The way that the CDC drew their figures together was by evaluating educational medical

records and New Jersey just had the best access to those records. So if you look at that, if you think about that, and looking at what the other surveillance studies had shown, really where there's not necessarily any clusters that exist in the country, and there's certainly no higher ethnic or social economic class that has a higher prevalence than any others, we probably are looking at this country of a number of about 1 in 100 as what is going to come up to, which is it should be if it doesn't frighten you, it should.

These--the costs of autism as--I'll quickly go through these. The costs of autism are just tremendous. And when you're looking at about one percent of our population and we'll have this about higher, you can see that these costs are going to go up tremendously. One of the--what we're finding in ASA recently has done a tremendous amount of work internationally is that our figures here in the U.S. are again, are not an anomaly. The U.K. is now reporting 1 in 83. I just took a trip through Asia. The government reported numbers there are in the millions in China and India, half a million people in the Philippines. These numbers are very real, and they are all over the globe.

And by looking at this slide here, you can see that the majority of these kids now are under the age of 18. And we have this huge, huge issue of these children entering the adult service sector, which now is inappropriate and unable to handle its current to population of individuals with autism. And if doesn't scare the hell out of you now, just think of what it is going to be in the next five to 10

years as this tremendous load of new diagnosis hits the adult sector. Are we time up?

ANN DRUM: (Inaudible).

LEE GROSSMAN: Okay. I'm going to rush through this. One of the other things that we need to talk about are the economic costs of autism. They're sky rocketing. We're saying that it's about \$60 to \$90 billion a year. Now, if we were to service the entire autism community, unfortunately, what we're finding out is that it's probably in the low billions of dollars that we're spending now to service the community. So where is the rest of the money not coming from? It's usually coming out of parents' back pockets or it is money that's just not being spent, so that the community is not receiving the services that it's getting. So on this part where the community is right now, as you could see it's a social, economic and health crisis, and it's a national emergency, and these are not Lee Grossman and the ASA is saying this, this is the CDC and the NIH declaring NSO. And autism is considered an epidemic and that is our congressional--our congress' determined to be--to be that as well.

Now, if you look at the basic definition of autism, it's a genetically based neurological condition. And I bring this up because we feel that the medical aspects of autism have not been adequately addressed. And there's growing evidence particularly on among the younger children that are being diagnosed,

that they suffer from chronic medical conditions that contribute greatly to the behavioral symptoms of autism. With that said, we are taking the position that autism needs to now be looked at as a chronic medical condition. We--from a public policy standpoint, that is a tremendous shift. Right now, autism is looked at falling in the developmental disabilities or mental health category, and that has its limitations in terms of what lifespan services, what is appropriate for, and what is available to service our children with autism. If it is considered a chronic medical condition as we believe it should become, then it opens it up to the type of reimbursement, the type of help that other chronic medical conditions such as diabetes or cancer, et cetera are then receiving. It is a tremendous public policy shift, but it's the only way that we're going to get into the point where people with autism are receiving the types of services that they need. We all know about the complexity of the disorder and the interest of timeout. I'm going to skip through these.

But among the realities of autism that we know being--that it takes a multifaceted or multi-agency approach to lifespan needs. We do not emphasize enough. And I cannot say it enough is that autism is treatable. And when you are looking at an individual with autism, regardless of what anybody has said prior to that, if you're a physician for example, or a service provider, you now have to look at it as a treatable condition as it is because what we're finding is that even adults that have gone through their life without receiving appropriate interventions. Once they receive that in their adult life, they improve tremendously.

Let me get through here since my time is--George went over the autism roadmap in tremendous detail, and I thought that would--that is a great working document for all of us to move forward. There are about 103 bullet points on there in terms of what needs to be done to comprehensively address the autism issue throughout the lifespan. Each one of those 103 bullet points needs to be developed into a white paper, and that's--that is an aspect of what we're going to do in the EPIAA legislation. Where we need to be? He talked about the congressional caucus. We need to expand that. We need to look at treating the medical aspects of autism, and I'll be happy to answer those during the Q and A section.

The environmental concerns in neurotoxicology are real. They are very real in autism. And we believe strongly that that's contributing tremendously to the rise in autism particularly when you look at the figures that's happening internationally. When you look at the blood studies that are coming out in these kids, they're poisoned. And what is coming, the effect of those poisons of the environmental issues is that these children are demonstrating the effects and symptomatology of autism. We need to address adult issues. Ninety percent of the costs today in autism are spent in the adult service sector because these folks live a normal lifespan. And those costs can rise tremendously once they hit the adult sector. So 90 percent of the cost of that \$60 to \$90 billion is in the adult sector. I will skip over that.

We're also treating autism. We feel that autism needs to be looked at as a whole body condition. What I mean by that is that looking, again, at the medical side of this that we feel that we look at this as a whole system approach that we can then get better at predicting the cause of autism, and in some cases even preventing the symptoms of autism, and in many cases reversing the most terrible aspects of autism. And all of this is really based on a service delivery model that will improve the quality of life and maximize potential of individuals with autism.

From what we believe, if we just do what we know today, if we provide the medical treatment to the community, if we provide the behavioral psycho-social and educational supports that we know today and we apply this universally to the community, we believe that in this next generation, if we would just do those things that we know today, that autism in the next generation can be an accepted part of the human condition. And by doing that, we will definitely improve the lives of all of those affected by autism. Thank you very much.