THE BROOKINGS INSTITUTION

AUTISM AND HOPE

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PROCEEDINGS

MR. O'HANLON: [In progress] -- and Michael Fux. Everyone has been very helpful in this work, in making it possible.

I'm just going to speak for a couple of minutes to give you a sense of what we're trying to do with the afternoon's events. We have three main panels and sort of three main messages, although, of course, every panelist is going to speak for him or herself, and I don't presume to be able to do so. We have, again, some of the very greatest experts in the country here speaking today, and I am in this field as the parent of a child. Actually, several of the panelists have children on the autism spectrum as well. So we have a combination of parents and non-parents, of researchers and clinicians, of MDs and PhDs, of others who have been involved in the legislative effort in regard to autism. You'll hear a little bit about that today as well, truly a broad and diverse group.

The three panels and the three themes--and I'll very quickly mention each--Panel 1 is going to try to give you some sense of the nature of the autism spectrum disorder problem, and they can say better than I, but when I say "autism spectrum disorder" I mean classic autism; pervasive development disorder not otherwise specified, quite a mouthful, PDDNOS; and Asperger's syndrome. It's a broad umbrella, and you'll hear more about the nature of the issue today.

But the nature of this epidemic really in our children today, an ailment or a series of ailments that is at least 10 times more prevalent on a per capita basis than it was even at the time that I was a child, or even since the 1980s, and we'll hear more discussion about that. It can be, and usually is, a very, very serious set of disabilities even for those children who are considered higher functioning or more mildly affected, often impedes their formation of friendships, their ability to hold jobs. Some of them wind up going to school, but often not doing as well on the workforce, not doing as well in their social lives, and that's even for those who are at the "higher end," quote, unquote, or less severely afflicted.

So it's a devastating set of problems, and yet, message 2 and Panel 2 will talk about how much better treatments have become in the last 15 years or so, and this is something that as a parent of a child who's been involved in these sorts of treatments now for a year and a half, I can personally attest to and witness, and am extraordinarily grateful for. And we have some of the people here today, again, who are working with my daughter, but also who are working around the country with many others and also trying to advance the research. So Panel 2 is going to try to talk about how we do therapy today. There still is quite a bit of flux, quite a bit of debate, but there's also a great deal of consensus about what works and an increasing amount that's known, that intensive intervention is the key. Intensive one-on-one intervention with people who understand this set of problems and have geared programs to this set of problems.

There's very vigorous debate, including among some of the people who are here today, about which methods are optimal in a given situation for a given child, but there is virtually no debate anymore about the need for intensive intervention, which means expensive intervention, and this gets us to Panel 3's theme, which is most of us can't afford it. Of all the parents in the country who have children on the autism spectrum, there are various estimates, but perhaps 10 percent are getting the kind of intensive intervention they need, especially in those preschool years, but then even also in the school years, to really give them a good chance of making the kind of progress that would allow them to live as fulfilling lives as possible.

I'll just give you one very short anecdote about my daughter, and then I'll stop and pass this along to Barbara Firestone, who is a very distinguished woman who works on these problems in Los Angeles. We have Barbara, and she'll be talking, and also Laurie Stephens from the Help School will be talking later about what they do, and Barbara's going to give a little bit of a talk after mine.

But what I want to tell you about, now having laid out the agenda for today, I'm going to finish up here in a second. Barbara will talk about her school. We have a brief DVD we'll show from Senator Clinton, who was kind enough to welcome us electronically, even though when I asked her a month ago to do this, she didn't think she'd be in town today to do it in person. Turns out she is in town, along with the rest of the House and Senate, but they have other things on their minds at the moment. And then after that we'll proceed through three panels, taking a brief coffee break after the first.

So, again, Panel 1, the nature of the problem, the prevalence of the problem; Panel 2, the promise of therapy, and hence the name of this event, Autism and Hope; Panel 3, the kinds of options we need to start thinking about from a public policy point of view to make these therapies accessible and affordable.

I promised you the short anecdote. I'll make it very brief. When my daughter was diagnosed at age 2, she was considered to be relatively mild, relatively high functioning, but her disabilities were extraordinary, and they still are quite worrisome in many ways, but she's made remarkable progress. However, almost all that progress has come from privately supported and private groups. Montgomery County provided two hours per week, when the National Academy of Sciences and the American Academy of Pediatrics say that 25 hours a week are the minimum recommended. Our private health insurance company provided one hour a week for speech therapy. The other 30-some hours a week, and therefore 90 percent of the cost, were provided by us out of pocket at the rough annual cost of $75,000 a year.

You do the math in a country where typical family incomes are in the range of 50,000, and even if you're not living in the relatively expensive Washington, D.C. metropolitan area, these treatments are simply unaffordable at the intensity that's necessary to make them work.

I'm not complaining. We're lucky. We've managed to figure out a way to make this happen. But what's obviously a real troubling reality in this country is that most parents don't have this option, and that's got to change as far as I'm concerned.

I want to make a very personal thanks, as I wrap up, to Dr. Christine Caselles, who you'll be hearing from later, my child's primary psychologist. Her team of Candice Felske (ph), Kaori Inoue (ph), Alison Norwood and a number of others--Stanley Greenspan has helped us; he'll be here later talking. Steve Gutstein, who development the technique called Relationship Development Intervention, has also been helpful. I'm extraordinarily grateful to all these people. I'm extraordinarily grateful to all of you for being here, and to fellow speakers.

Now we'll hear from Barbara Firestone, and then the Clinton DVD, and proceed to Panel 1. Dr. Tom Insel, we're honored to have. He will be the moderator of Panel 1, from the National Institutes of Mental Health, and then he will proceed to introduce other panelists, as will Barbara and I later in the day when we get to Panel 3.

So thank you again for being here.

Barbara, please.

DR. FIRESTONE: Hello, everyone. This is a watershed day. Our Autism and Hope meeting has convened a most distinguished panel of experts who share a collective commitment to making intensive early intervention available to all children with autism spectrum disorders.

Today we begin the first of a series of ongoing Autism and Hope dialogues, discussions to stimulate positive and potent change that is long overdue for the children affected by autism spectrum disorders, and the growing numbers of children who will be identified with each ensuing year.

This meeting of the minds is called Autism and Hope for very good reasons. We are in a new age of autism, a new era of breakthrough research, earlier identification and diagnosis, and increasingly more effective early intervention and treatment. The evidence is clear and it is compelling, autism and hope are no longer mutually exclusive. With as many as 1 in every 166 children affected by autism, the race is accelerating to find the causes and cures and interventions that hold promise. It is a race, however, that can never, never, never be fast enough for the parents who are engaged in their own marathon to find the program, services and funding that can make the critical difference.

For three decades the Help Group has been committed to serving children with autism. Helping reach parents and children as early as possible is a critical part of our mission. The Help Group is delighted to co-present Autism and Hope with the Brookings Institution. It is my privilege and pleasure to co-chair these proceedings with Michael O'Hanlon. We salute his personal commitment to this mission and his efforts to bring this important meeting to fruition. Thank you, Michael.

I join Michael in thanking all of the co-sponsors in our extraordinary group of presenters. Over the last 20 years, early intervention regimens for autism spectrum disorders have become more effective. Giving intensive early intervention, ideally beginning before the age of 3, many children with autism spectrum disorders now have prospects for more productive and fulfilling lives. That's the good news.

But there's also bad news, and that's the reason we're all gathered here today, and that news is that access to intensive early intervention is still very limited in our country. We must continue our efforts to accelerate awareness, early identification and diagnosis, but as importantly, we must also ensure that these services are available throughout the United States, and that they are available to all children, regardless of family income and ability to pay.

Access to help is the right of all children with autism, not just a fraction of them. Identification without intervention is an incomplete and seriously flawed policy, very deficient. It denies children of the benefit of the treatment during that sensitive window of opportunity that can be of such great benefit during the early years of their development.

A commitment to helping all children realize their fullest potential should be at the heart of our national effort. And we also can forge change with the important message that early intervention will surely result in significant economic benefits for our society. The agenda of finding causes and cures is a compelling one, worthy of all of our support. Equally compelling and deserving of our efforts is the agenda for the ongoing development of evidence-based treatment approaches, the empirical validation of current approaches, the development of national practice standards, the timely delivery of quality intensive early intervention, and for comprehensive and innovative public policy at the national, state and local levels.

We can no longer delay. There is a generation of children who need our help now. Let us work to fill the gap so that we may provide a seamless system of early intervention for all of the children. Autism calls for our collective attention, efforts and resolve, so let's make today a spirited and meaningful exchange of ideas, a catalyst for change.

Through the years I have come to know many hundreds of children with autism spectrum disorders and their families. I am always inspired by the parents' dedication, tenacity and courage, and in each child I see the unique and special potential they possess, no matter how great their challenges.

So let us dedicate these proceedings to the children and their families.

Thank you very much.

Now it's my pleasure to introduce electronically, Senator Hillary Rodham Clinton.

[Video played of Senator Hillary Rodham Clinton, off microphone.]

DR. INSEL: Good afternoon. I'm Tom Insel, and I'm just delighted to be here. I would come to any meeting that had autism and hope in the title, and Mike and Barbara have done a really wonderful job here in organizing a set of presentations which I think will help to really lay out for us some of the major issues. As Mike formulated this, the task of this first panel, which you'll be hearing from, is to describe the landscape, to give you a sense of what is the scope of the problem, not only in terms of prevalence, but in terms of what this means for people at an individual level, not just at population level.

I would like to introduce that topic just very briefly by making a couple of remarks, and then I'll turn this over to the panel. I guess my main point that I want to convey before we start into the details is that, to borrow a statement from Senator Clinton, this is an area that really takes a village. This is not going to be done by one sector, not going to be done one laboratory or one part of the service community. There are so many issues tied up in being able to both get to the new treatments and hopefully a cure for autism, as well as the dissemination of what we already know, and it's going to take a very broad community to make this happen.

In the Federal Government we have a mandate which came from the Child Health Act of 2000, which stipulated that there would be an Interagency Autism Coordinating Committee, and such a committee does exist. I chair it from my role at the National Institute of Health, which we sometimes affectionately call the National Institute of Hope. In this committee what we do twice a year is bring together all of the federal partners involved in either research or services for people with autism, and that includes not only various--I think there are five institutes from the National Institutes of Health, it also includes the CDC, the Department of Education, SAMSHA, ARC, FDA, and a number of other groups that come to the table, and go through this exercise every 6 months to say, what are we doing, what do we need to know about from each other, what can we do better together, what are we missing?

We have a number of parents on that committee who help us. There are some representatives from the advocacy community, and these meetings are entirely open, and there's actually a part of every meeting that's turned over to the public to make sure that we can hear from them those issues that will be important for us to be focused on.

Now, what has come out of that, one of the things that I think has been most useful, is about a year and a half ago we sat down and said, to really move this forward in the right way we need a plan, a strategic plan. So we laid out for ourselves what we've called a matrix, which is a list of targets that need to be addressed, essentially prioritized from what is short term, what's long term, what's sort of modest risk, what's high risk, and through that came up with a whole series of issues that we are trying to address in a very coordinated and a very aggressive way.

Many of those things you'll hear about in the next few minutes. Some of them are really kind of long shots, trying to improve the way in which we develop new treatments, trying to make sure we have repositories, which are so important not in science, so that we have the tissue that we need, we have the DNA that we need, we have the information that we need so that we can get those kinds of materials to the people who have been able to make discoveries in other illnesses that have been breakthroughs. We want to make sure that happens for autism as well. And we are perfectly aware that research is in many ways the best hope we have, but that it is going to take time, and that we can't wait for all of the research answers before we begin to do something better for the children with autism today.

I often use the analogy that if you think about the situation in 1954, 1955 for polio, where we had to do something to address the tens of thousands of cases of polio acutely to make sure that we had a way to get iron lungs and other kinds of treatments that were then available to the people who most needed them. But it's important that we didn't stop there, that somebody thought about how we also needed to develop a vaccine. And so for autism, as it was for polio, it's finding this balance between making sure that we're investing in research that will really make a difference, as well as taking those things that we know now make a difference, and making sure that those are provided to the kids and to the families who most need them.

So this does take a village. It's a village that involves federal partners. It's a village that involves parents, and I've often said, and I continue to believe this, that parents in this case are some of the best experts, and we've learned a tremendous amount from them about what needs to be done and what can be done better, and it certainly involves the advocacy community, which has become in this case a very important partner in the future research effort and the current way of setting research priorities.

So we'll hear about this landscape in more detail from each of the panelists. I think for the sake of time what we'll do is, instead of introductions now--and if we can, let's hold our questions till after the third speaker, and then hopefully we'll have time for some discussion before we go to the coffee break.

So it's my pleasure to introduce the first panelist, Dr. Jose Cordero. Dr. Cordero is, as I think you'll see in your program, the head of the Unit on Developmental Disabilities at the Center for Disease Control and Prevention, the CDC, in Atlanta, Georgia. He's been very heavily involved in both the epidemiology and studies of also early detection in autism, and I think he'll be able to tell us very quickly about some of those issues.

After that we'll be hearing from Peter Bell, who is the CEO of Cure Autism Now, one of the most vital of the autism advocacy groups. Peter's been there for just a little over a year, I think, and he'll be giving us a sense of the perspective on autism from the advocacy community.

And then we'll hear from Dr. Rafael Castro, who is a psychologist with CEC in Boston, and we'll hear more of the clinician's perspective about what does this problem look like from someone who's on the ground trying to make a difference for those children and families with this illness.

So once we hear those presentations, hopefully we'll have some time for questions, and then we look forward to hearing from all of you as well.

Dr. Cordero.

DR. CORDERO: Good afternoon. It's a pleasure to be here in this very important meeting.

And in 12 minutes I would like to summarize basically three things: one, what is CDC doing in terms of tracking and monitoring; very briefly about some of the studies we're doing; and then spend a few minutes about the early recognition for autism in terms of learn the signs, act early.

Basically the question is what is it CDC does related to autism? One thing that we have been doing for some years is developing the methodology so we can answer the questions of what the occurrence of autism, is it going up or down? We're also funding studies and looking at risk factors and causes of autism. But we are also interested and concerned about early identification because we recognize that that's one of the keys in terms of helping children with autism.

So on the tracking and monitoring we're asking the questions: what's the prevalence of autism in the U.S.? Are there certain groups that are more likely to develop autism? Is the rate increasing? What factors may contribute to the changes in rates? Is the type of autism changing?

You've heard already that there's a spectrum there, it's really more than one condition, and probably there are more subtypes still have to be identified or defined.

In terms of the specific activities, we have the Metropolitan Atlanta Developmental Disabilities Surveillance program that provides the group or the area where we learn how to do tracking of autism, and that has translated into about 10 to 12 different areas in the country that now are conducting the monitoring of autism. There also have five centers that are doing research on autism, but also we have a collaboration with a college in Denmark that's allowing us to do some work in terms of causes of autism that we cannot do in the U.S. That's all I'm going to say about research in these 12 minutes, and obviously we are concerned about identifying children early, and that's the learn the signs, act early, and I'll spend a few minutes on that.

First, how common is autism? I think it's important to have data in the basis of the more common developmental disabilities, and based on the Atlanta data, mental retardation is about 1:103, and you can see there the different rates for some of the most common and serious developmental disabilities.

How does autism fit into this prevalence? Dr. Insel made the point that autism's changing, and others have made that point. In fact, when we look at studies that have been done in 1980s and 1990s, the rate of autism was reported at .3 to .4 per thousand children. In the more recent studies that CDC conducted in Brick, New Jersey, autism disorder was about 4 per 1,000, and considering the spectrum was 6.7 per 1,000, while in Atlanta for about 3.4. And the most recent estimates from outside the U.S., you can see what the rates are. So the number of 1:166 is coming from a combination of all, both the U.S. and international data. That's where we get that number.

We also have seen these slides, many of you have seen these slides that show the number of children that are being served until special education, the IDEA, and as you see, for autism there is a pretty significant increase in the number of children served.

Just a little bit about how frequent the condition is, it is as common in whites as it is in African-American, and actually, we don't have data here, but I can tell you that's the case too in Hispanics and other groups. But also important is that it is not only common, but that it is only about 38 percent have autism and nothing else. Most of the cases in Atlanta, 62 percent, have autism and other developmental disability, and that's something to keep in mind because it has implications for both for intervention and for treatment in general.

One of the things we know from the study of the National Academy of Science that was published some years ago is that early identification and early intervention is the best hope we have for children with autism. We have developed this campaign, and the main message is how do we change people's view about child's growth? Our mission in this campaign is to ensure that every child reaches his or her full potential. What we are trying to do in this campaign is to increase awareness of developmental milestones. One is that children have the key steps in development, but also increase the knowledge about the benefits of early action, especially early intervention, but also we want to develop a dialogue between parents and provider about developmental--there are milestones to also developmental disabilities, and ensure that that translates into early action.

Our target audience is first we are going to the health care providers, then to parents, and also to child care and early education providers. For health care providers we have a message that's pretty direct about autism, and the message is: the 4-year-old with autism was once a 3-year-old with autism, which was once a 2-year-old with autism. And it's about how to ensure that pediatricians and all the health care providers actually get the message that it is very important to identify autism.

In terms of parents, I'm going to pass that one. We also have developed, together with the autism group, or the developmental disabilities groups and the Academy of Pediatrics, this one-pager--basically you're seeing both sides of one page--that actually helps pediatricians have some key messages about importance of diagnosing autism, but also provides some process that they could use in the office for developmental screening.

In terms of parents we're trying to reach the public in general, and it's been terrific that in February when we launched this campaign, there was a big series in NBC that many of you probably saw, but also the Newsweek publication on autism, and that actually has brought a great deal of attention to the issue of autism.

How is this translating into action and an impact? First off, since we started the campaign--this is only about a year ago--in a survey with pediatricians and parents, nearly 43 percent, we're getting close to half of the pediatricians saying that they have heard about the campaign, so those e-mails and those thousands of e-mails at least are reaching. But also parents are becoming more aware of the campaign. Also, I think that knowledge has increased in terms of parents knowing what behaviors do suggest early developmental delay. And we had that before we started the campaign, and after, as you see, gone from 37 to 50 percent.

Also, it looks like we are having some impact in improving or enhancing the dialogue between parents and health care providers, where 55 percent of parents are saying, one, doctors are asking about development and developmental delay, but also that more pediatricians now are saying that they are better educated about early developmental milestones.

One of the major problems in terms of parents raising the issue of developmental delay and whether this is autism or is this another developmental disability? The pretty standard answer, "let's just wait 6 months." And one of the things that we are beginning to see is that fewer pediatricians are saying that. Basically it's a nearly 50 percent decrease. In the early survey, about 30 percent said "Let's just wait," whereas now in a more recent one, only about 14. But still, 14 percent too high.

But certainly I think that in the short year of this campaign, I think that we have had some impact, but more needs to be done, and we'll continue to move forward, increasing a bit, knowledge both from providers but also from parents about early development and how can that be signs of autism.

Thank you.

[Applause.]

MR. BELL: Good afternoon. It's a pleasure to be here, and I'd like to thank the Brookings Institution, along with the Help Group for cosponsoring this event. I'd also like to pay particular attention to Mike, because meetings like this don't happen because, really of an organization, but rather, because of a person. Mike and I met a couple months ago on the phone, and I could tell that he was really motivated to make this happen, and having been a person in a very large organization who organized a similar type of meeting, I know what it takes to make this happen. So, Mike, thank you very much for putting such a great panel together, and it's indeed a privilege to be here today.

I speak because I also have a child with autism. My son actually is this young guy here. This is Tyler when he was probably about 6 or 7. He's now 12, and I say that with a big heavy sigh because, as any other parent who has a child with autism, as they grow older, it gets a little bit harder. My wife and I have been at this for almost 10 years, and we are still very motivated to do what we can to bring improvements and a drastic increase and improvement to Tyler's life, and feel very much like we're going to be able to make that happen.

Prior to coming to Cure Autism Now a year and half ago, I was in the pharmaceutical industry. I used to work for Johnson & Johnson, and it's been a remarkable experience to be able to kind of go from industry into the nonprofit sector, and to be 100 engaged in this advocacy community. We're making great strides, and we're, I think, very proud of what we've been able to accomplish, but we also recognize there's a long way to go, and there's a lot that we can do to make life better for these children and these individuals that have autism.

I wanted to take a moment to just very quickly review the history of autism, because I think it's important. It was first characterized by a psychiatrist up at Johns Hopkins, Leo Conner, in 1943, and for the first 20 or so years I call it the Age of Denial. It was blamed on parents. There was a term used call "refrigerator mother," which was horrific, and it wasn't until the mid '60s that we were able to more or less convince everyone that there was a biological basis to autism.

And unfortunately, we then entered the Age of Defeat. There was no hope. When you got a diagnosis of autism, you were told that there's really not much you can do. Go home and hug each other. Eventually the child may require institutionalization. There really was a very dark period in the history of autism.

The good news is that we're now living in the Age of Hope, and we may be overusing the word "hope," but I am really happy that Barbara and Michael chose to use Autism and Hope as the title of this, because there's every reason for us to hope for our kids. They have a lot going for them and they're going to have a very bright future, but we need to figure out ways in which we can take these services, early interventions and so forth, and bring it to them at a much more rapid pace, and that's what I think today is all about.

Dr. Cordero talked a little bit about the prevalence, but I want to just bring to everyone's attention is what has happened, what brought us to this level of the Age of Hope? I think part of it has to do with the increase in prevalence that we've experienced particularly over the last 10 to 15 years. This is a very crude--and I'm not submitting this for scientific abstracts or anything, but it's to give people just a general sense of what we have seen in terms of the prevalence of autism over the last 30 or so years, and what was once considered to be an extremely rare disorder that occurred in 1 in 10,000 individuals is now 1 in every 166. If you plot this along this very crude graph--and believe me, I just created it about three hours ago--you will see a very marked increase in the prevalence of autism.

When my son was diagnosed in 1994, actually, '95, we were told that it was 1 in 500. About five years later it was 1 in 250, and today it's now 1 in 166. We've seen a significant increase, and that's contributed to why it's getting the attention that it is.

What else has changed is that we've had some very powerful organizations that have come onto the scene in the last 10 years, and specifically the organization that I represent, Cure Autism Now, and also the National Alliance for Autism Research, both of which were basically founded within six months of each other about 10 years ago. What these two organizations have done has been rather remarkable and radical. We've created a field for autism research when essentially very little existed 10 years ago. There were maybe about a dozen people who were dedicated and spending significant amounts of time doing autism research, and what that number is today is well over 600.

We have an international meeting for autism research that occurs on an annual basis. Last year we had over 700 people attend that, and I expect that it will continue to grow as more and more people come into the field.

We've also been able to develop resources for the research community, probably the crown jewel of the whole community is what is known as the Autism Genetic Resource Exchange. This is basically a biomaterials databank that was created by Cure Autism Now in 1997. We've spent about $8 million developing this resource over the last 7 or 8 years, and today it's probably one of the most published and usable resources within the autism community that we have. In addition, Cure Autism Now has created an Internet Web service that allows us to bring in data around the children that are diagnosed in different studies that's called ISAAC, and also there's the Autism Tissue Program which is a brain bank that was developed by NAAR over the last several years and is a great resource, and will continue to be expanded.

These organizations have also lobbied for more government spending. In the year 2000 we were successful in getting the Children's Health Act of 2000 passed, which helped create some of the things that Dr. Insel and Dr. Cordero have been referencing in terms of the studies. We now have centers of excellence around the country. There are 8 of them. We have CPEAs, which are also a consortium of universities that are collaborating together to work on specific types of autism research.

We have surveillance studies that are occurring at the CDC, and most recently we've introduced a new piece of legislation called the Combating Autism Act of 2005, which we anticipate will take this research to the next level. In addition to funding that research, we're identifying ways in which we can have early identification programs in every state, and also having treatments centers located around the country so that parents can actually take their children to a physician and feel good about what kind of services and what kind of clinical care that their children are receiving.

We've also managed to get awareness on the map. They're on the covers of Time and Newsweek. NBC, ABC, New York Times, Wall Street Journals, they're covering this disorder. Ten years ago they essentially were not doing much of anything, and I think most importantly what these organizations have given to the families is hope. Ten years ago there was no hope. No one ever talked about the word "cure" in terms of autism, and today everyone's talking about when the cure comes, this is what's going to happen, and that's tremendously exciting.

I want to just talk about a couple of myths out there because I think you'll probably hear some of these. Some of these are just my personal ones, and I apologize for that, but I think there are things that many parents probably can relate to. I think first and foremost we have to assume intelligence in these children. The statistic that two-thirds of them are mentally retarded, personally I don't think is accurate. In fact, I know many people have said that there's not a very good substantiation to that number. There are a number of studies that actually have been done that have shown that barely a third of the population has mental retardation. But the problem is, is that many of these children can't speak. They can't participate in the kinds of standards or tests that are used to measure intelligence, but they do have incredible cognitive skills, and we have to figure out and find that voice for them.

Early identification is absolutely the best treatment. We need to be able to identify these kids as young as 15 months, 12 months, 8 months, because the best outcomes are when you get a child very early on. Intensive intervention will lead to the best outcomes. I think you're going to hear that many times over the afternoon. Autism is absolutely treatable. Unfortunately, a lot of people think that you can't do anything. These kids have medical conditions that can be treated. There are behavioral treatments that can be very, very effective with many of them as well. We need to assume that we can treat autism and make it better. It's an extremely heterogeneous disorder. We need to figure out the subtypes and identify the, as some people would call them, the different types of autisms. Once we can do that, then we can start developing certain types of programs and treatments that are addressable by certain types of autism. The increase in prevalence is real, and hopefully the CDC will come out with some data soon that will help us understand whether or not that is in fact correct, and also there's a strong evidence that points to an interaction that's going on between the genes and the environment, and that's something that needs to be explored further.

I just want to very briefly give you a real quick idea of what we are doing at Cure Autism Now in terms of the science. The NIH has their matrix, and certainly there are a lot of wonderful ideas there, but as we approach this disorder and try to figure out how we can bring improvements, this is how we're approaching it. First of foremost we need to find the problem. We need to understand the biological basis of autism. We need to understand what it is we're dealing with. We know what it is from a behavioral perspective, but we really don't have a very good sense of what is happening at a molecular and cellular level, and that's why it's critical that we really understand what's going on inside of these kids. In order to do that, we need to identify the pathways that are affected, and also be able to subtype these kids so that we can say, "This group of kids has this type of autism, and this type of kids has this type of autism."

Second, we need to find the children. We need to get the early identification models working. We need to identify biomarkers that can spot these kids as early as possible so that we can put them into interventions earlier on and get the best outcomes. We need to find treatments. We need to set up clinical care centers.

As I said before, we need to be able to take these kids and have them get medical supervision to address some of the underlying issues that many of them experience, and we also have to set up clinical trial networks so that we can actually start testing various medications that are out there that are being used, but unfortunately, they're being used on an anecdotal basis and we don't have a very good sense of which ones work with which children, and these are critical for us to be able to establish.

Lastly, we need to find the resources. We need to have better databases and be able to bring it all together and understand the population of kids. We need to also be able to take these biomaterials and put them into a set that's easier for the researchers to use, and that's exactly what we have done with AGRE and a number of other resources that are available to the research community.

As I said before, juts a real quick sense of the autism community. We're young. We're basically 10-years-old. Yes, there are some organizations that have been around for longer, but the vibrancy of the autism community really has been in the last 10 years. We're strong. Our numbers are increasing. There are over a million families that are now affected in this country, and we're rallying together to create a unified voice. We're passionate. We're smart. Thank you, Dr. Insel, for saying that we're actually pretty intuitive, and that, generally speaking, we're usually right. You can look at the history of autism and know that a lot of the changes have been brought around by parents basically not willing to conceded to the medical establishment.

We suffer from a little autism ourselves as a community, and by that I mean we don't always necessarily communicate very well with each other. We're not socially appropriate at all times. We also have some abnormal behaviors. But that being said, I think these are the things that we have to identify and figure out how do we come together as a community to solve this thing, and I agree with Dr. Insel, we have to all come together. It's going to take a village. And we need to work together and put our egos aside and figure out how we can bring real relief to our children. And last but not least, we're going to conquer this disease in our children's lifetime. I know it, and I know a number of other people believe that as well.

I'm going to finish off on just kind of here are our core beliefs at Cure Autism Now, and I would like to think that it matters to the entire community. First of all, urgency matters. No doubt about it, autism is a national emergency. We're experiencing an epidemic. We've seen the increasing numbers over the last 10 years. It must be addressed. It's everyone's problem. It's no longer the problem of those people that are directly affected. A cure for autism is going to come in our children's lifetime. Improved quality of life is possible. In fact, it's essential. These kids deserve it. Historically, they have not had the quality of life that they deserve. Every American deserves to be able to realize their potential and we need to figure out way that we can make it happen for these children that have autism.

As I've said before, autism is treatable. It can be treated, and we need to figure out how do we bring treatments available to all children, and early identification leads to better outcomes.

The last point is that science is key to the solution. We know that science can be hurried. A lot of people will say it cannot, but we know that it can, and we also know that collaboration and sharing is going to be key to solving this solution.

Thank you very much for being here. It's a pleasure to be a part of this esteemed panel, and look forward to your questions afterwards.

[Applause.]

DR. CASTRO: There's nothing in a conference like following the act of a passionate parent, tough to top, and it's probably one of the reasons why I enjoy my work the way I do, because there's nothing like working with families who are undergoing the difficulties that they face with their children.

I come from a particular area of expertise that has somewhat a sense of obscurity. My discipline is neuropsychology which is a blend between developmental specialist and psychology, and then sort of a touch of sort of the interest of the discipline in general, which basically tries to look at the relationships between brain structures and cognitive and behavioral outcomes. Historically, neuropsychology hasn't necessarily attended to the needs of kids with developmental disabilities; that was left to either child psychologists or the developmental psychologists. And so I've attempted to bridge that gap in terms of measuring psychometrically some of the challenges that our kids face.

So my remarks today, I would like to focus on two particular areas. The first one has to do much more with the nature of autism, but I would like to step a little bit outside of the traditional more stereotypical ways of viewing our kids, the ubiquitous image of the rocking child or the nonverbal individual, and to step outside of what we're considering much more a spectrum of disorders despite the fact that it extremely encompasses our more involved children, and we take pride of having them as part of that spectrum, that there is a set of conditions nowadays that is much less pronounced, but nonetheless can have marking consequences for our children, and it's very important that we don't circumscribe the interventions and the policies exclusively to those who are more involved, who I must admit, they're dear to my heart, but the reality is that there is a full continuum of these disorders.

And the second, as has been the case with the other panelists, I also chose to talk a little bit about hope. It is a very apropos choice of a title for our children. We are coming to an age where our kids are fortunately benefiting from a set of interventions that are much more intensive, much more specialized, and it is a little bit of a time without letting our guard down, to take stock of the benefits that they have received from those specialized interventions. There were a number of individuals in the early '80s that fought boldly and innovatively about reversing and mitigating the tendencies that we see in our children, and the results are coming to fruition at this point, and it's extremely exciting to be in this field at this particular point.

With regards to the first comments about the nature of autism, one of the things that I would like to talk about is the natural tension that we see nowadays between our efforts to try to identify our children as soon as possible, and the research that lets us know that the lower we go, the more difficult it is. But obviously, what is showing up, and you will hear it time after time, is that the earlier that we identify our children, the better off we're going to be in terms of outcome. It used to be that our children wouldn't be identified prior to the age of 4, and by that point the diagnostic exercise was not necessarily very difficult, it was quite evident.

More recent research shows that we've been able to lower the age of identification down to 3, and that's for the most part thanks to the work of a number of agencies, mostly driven by parents who have educated primary providers, early childhood providers, to submit these children for closer evaluations once those symptoms are recognized.

In our center, we're fortunate nowadays that the majority of the kids whom we see are basically identified by the age of 2. As a clinician, you get extremely excited about the malleability that you see at that particular age, and we know that the sooner that we get the intervention in place, the better the outcome is going to be. We get even more excited when we are able to identify kids below the age of 2 years, and as we've mentioned before, we're trying to figure out how we can identify these difficulties early in infancy, but it does require personnel who is particularly trained, so we shouldn't season our efforts, and even though we should praise some of the campaigns that have been held to educate our primary providers to refer our children, I think that the specificity and the susceptibility that we need to use in determining criteria for referral needs to be lower so that these children are able to arrive at--you know, to be seen by people who have expertise in this particular area for diagnostic purposes.

The second thing that I would like to talk about which is colored certainly by my discipline is the issue of measurement. In the past there have been some mixed messages sent to the families with regards to the efforts to measure the children psychometrically, meaning that to figure out where they're at from a developmental perspective, and I suppose that part of that comes from experiences in some cases, negative ones, where people who may not have the full expertise would talk about nonverbal children as not having the capacity or the intelligence or the cognitive capabilities that would get them through the intervention, and that's absolutely erroneous. Our children, as has been mentioned before, if they're evaluated by the right personnel, they can demonstrate many,

many strengths, and it is very much necessary that we somehow figure out a way of measuring their progression.

The second point with regards to measurement, it's not an issue of ranking the children. In the past people have been concerned that the efforts were to come up with a coefficient of intelligence, et cetera, et cetera, in our center, what we try to do is use the psychometrics to inform the intervention. Oftentimes our children are very much uneven in the way that they present cognitively, and one of the things that we try to do is to create that synergy that can stem from the assessment to be translated into the intervention, and in that regard you can have a very exciting process.

The third point is what I was referring to at the beginning, and that's the changing face of the disorder. It's been truly trying for the best diagnosticians to be able to classify our children over time. There have been instances in which they have been grouped with kids who had childhood schizophrenia. Atypical autism was used in some ways to reflect the fact that there were a lot of variations to the presentation in our children. Most recently they've added other diagnoses such as the Asperger's disorder and PDDNOS, and it does reflect the variation that we can find in the presentation of the symptomatology.

The point that I would like to make is that even those children for whom the occurrence of the symptomatology is much milder from having the luxury of seeing these kids progress over time, they can still have very marking consequences in their lives, and we have to be a little bit more permissive and get more latitude to those who should fall under the categories that receive intervention.

With regards to the issue of hope, the one thing that our center likes to talk about is what we call the changing numbers. Peter was talking a little bit about this, and in fact, at one point our children were considered--three-quarters of our children were considered to fall in the additional category of mental retardation. Nowadays those numbers have been formally revised downwardly to 50 to 55 percent. So this is just based on the recent studies, and I wouldn't be surprised if those numbers do in fact go further down. Parenthetically I would say that the ones that pushed and talked about the fact that this was in fact a case where the parents--and so they should always remind us, the clinicians and the researchers, to listen to those who truly understand and live with our kids.

But think for a moment the consequences of that statement, that from three-quarters of the kids falling in the mental retardation range, all of a sudden we're moving a quarter of our population out of that arbitrary line of mental retardation, which obviously, adds many consequences to their presentation. It's really a striking accomplishment.

And most of the glamour of that statement goes to those children who actually move from being in the mentally retarded range to the area where no longer fall under that arbitrary categorization, but they move into the normal cognition. But the one thing that I always was attracted to from the beginning was the fact that you also, by offering intervention, you still have an impact on those kids that don't fully discard the diagnosis of mental retardation, those children for whom something like affirming or negating a want or a need is something that they have to be taught. If you think about those achievements, it's truly remarkable.

An extension of this, unfortunately, is that in some ways we're becoming so effective for certain children, when we're able to implement interventions early on, that by the time they join their school system at age 3, they no longer appear as involved as they once were, and oftentimes we find administrators at the school level basically pointing out that this child doesn't present with the typical characteristics of a kid on the spectrum.

I will leave you with one last comment, which also again comes from my particular vantage point, and that is that oftentimes, even when we are successful at diminishing the symptomatology in our children, there are what we call the hidden challenges. There is a number of factors that once we have been able to accomplish linguistics and social relatedness, and diminish their behavioral atypicalities, there's a number of layers that remain that are not necessarily tangible to the lay person, and that require ongoing management. I'm certainly a proponent of very aggressive intervention, even beyond the point where our children don't fulfill criteria. The occurrence of issues such as attentional difficulties, anxiety disorders, specific aspects of learning disabilities and somewhat obscure neuropsychological profiles, remains with them, and that still can pose obstacles to their progression.

So the management of those issues also becomes a very significant factor in ensuring that they maximum their outcome.

Thank you.

[Applause.]

DR. INSEL: Thank you to all three panelists. We do have some time for questions, and the panelists will need to use their microphones to respond, and I will repeat your question because it may be--we do have mics, so we can have them transmitted that way. The floor is open. If you'll just identify yourself, and let's try to keep the questions relatively short.

QUESTIONER: Thank you. I was going to ask Peter in particular if he could say a couple of words about--first of all, thank you to everyone. This was outstanding. I want to hear, if I could, a little more about the Combating Autism Act of 2005, where that stands, what your aspirations are over the next few months. If you could just--even though this panel--that is more about other kinds of possible legislation, which we'll turn to in Panel 3, I wonder if you could take a couple minutes to tell us more about the state of that legislation that you've had so much to do with.

MR. BELL: Sure. The Combating Autism Act was first introduced in late April by two Senators, one being Senator Dodd, and Santorum, and then it was followed up about a month later when it was introduced in the House of Representatives by Representative Bono and Representative Diane DeGette. We have amassed, I think, at this point, a little bit more than 20 Senators who have signed on as being sponsors of the Combating Autism Act, and roughly, almost 100 Representatives.

We are in the process of there may be some revisions made to that act, and that will be introduced probably at the beginning of next year, but I would imagine that--the community has really rallied together behind this, and that's, I think--

[Change tape.]

MR. BELL: [In progress] -- and that it will continue to move in that direction, with the hope that it will be signed into legislation before the election next year.

QUESTIONER: I have a question for Dr. Castro. I wasn't clear on the work that your partners--that the CEC does. Do you measure IQ in autistic children? And if so, are they verbal or nonverbal?

DR. CASTRO: Sure. We're a multi-disciplinary center that addresses the needs for children with a number of disorders. The group that I work with addresses the needs of kids with autism in particular, but other developmental disabilities.

With respect to the specifics of the question, we do, as part of the intervention and as part of the assessment, we attempt from very early on to get a sense of where the child is developmentally--it's very difficult to have to accountability that you want from the programming if you don't have what we call touch points that you can plot the progression of the child. And oftentimes the best way that we have to do that is with developmental measures, and at some point that translates into IQ. But the thing to remember, again, the thing that we try to accomplish is not to rank the child against either other kids with autism or typically developing kids.

But the point remains, how can we inform the intervention? We work with our behaviorists at all points to try to emphasize areas where the child's not up to advancing the way they were expected to. So it's creating that synergy between assessment and intervention that we try to do through the assessment.

QUESTIONER: Lou Vismara. What an excellent panel. Thank you very, very much. This is very exciting and very informative.

I have a question I guess that I'd like to direct to Peter and to Dr. Insel. Peter mentioned that two important studies that CAN is focused on is understanding the various types or phenotypes of autism and also the potential interaction between the environment and autism. These are certainly critical and crucial issues. I'm wondering if you could identify or share with us kind of the strategic plan in which your organization interacts with other research entities, public institutions, et cetera, in developing this strategic plan, being sure that it's maximally effective and also how funding might be integrated to achieve common goals?

MR. BELL: I think those are two really critical areas and ones that need to be addressed. The reason that I presented what I did is that it really is where we feel like we need to go. It doesn't necessarily represent what has actually been accomplished. Certainly I think the MIND Institute and David Amaral have taken a lead in terms of identifying a study that will actually, hopefully develop and get to the root of identifying phenotypes, and I know that the NIH is going to be looking at doing a similar or comparable study on that, and we certainly would favor and hope to participate in those in various aspects.

I think the critical thing is that we as a community need to identify and hopefully establish some common ground in terms of what kinds of things need to be done. I think the matrix is a great start, and there are a lot of great projects that have been identified, but unfortunately, there's very little funding that necessarily has been put aside to make sure that that happens. So we need to work together, both on the private and public side, to identify resources that can be available to address those things, and hopefully we can marry up the roadmap with what we're doing. I don't think they're terribly dissimilar, but maybe different takes on what is really critical going forward.

DR. INSEL: I'll just add to that briefly. I think Peter summarized it very well.

There's an increasing recognition, if you ask where we are now in terms of the landscape of autism. I think there's an increasing recognition that we should probably be talking about autisms, that this is multiple illnesses with one umbrella term.

We don't really understand that whole landscape very well. We don't know where the dividing point was, or is. Should it be around language? Should it be around neuropsychological function? Should it be around time of onset? There's just a whole series of questions that we need to begin to define answers to much more precisely, and Cathy Lord has been very involved with that, so she may even say a bit about that. How we do it really will take, I think, a multi-pronged approach, and it is an important piece of the autism matrix.

From the NIH's perspective, one thing we've decided to do is that this may be one of the areas where we need to do some local research. We have our own hospital, our own intramural program for research, and we've just launched that research program only in the last two weeks, in fact, bringing in the very first people, many of whom will be local families Montgomery County or in this area. Ironically, this is such a high priority for the National Institute of Health--and we have a large hospital and a huge clinic--with 18,000 people here in Bethesda, there has not been an autism program here until now.

So this kind of question will be addressed, and we'll be working very closely with the advocacy community, with the MIND Institute, with many other places that are also trying to wrestle with this as well, and I think, you know, if we were going to put up that--I really like that slide that Peter used with the Age of Denial, the Age of Despair, the Age of Hope, and I think what we'll see over the next decade is an Age of Delivery, but also an Age of Better Definition and clear understanding of boundaries here.

QUESTIONER: Hi. My name's David Cordell and I have a 9-year-old autistic son.

This is really a question for Peter Bell. You talked about joining together and having the autism community speak together, but it seems to me that we have, you know, Cure Autism Now, we have the Autism Society of America, and we have Autism Speaks out of New York. Would it not be more helpful to have like one organization that speaks for people with autism? That's just a question.

MR. BELL: Certainly a good question and something that I think may play out over the coming months, if not years, and what-have-you. I do think it's important though that we have to be careful that we don't fall into necessarily one group and have just common think. This is a disorder that has profound impacts on the families and the people involved. I think we have to rationalize the community and be able to identify what groups can focus on what, and we have to be sure that people are not being redundant with each other and play nice, and are willing to go at this together, and it's not a competitive sport. Our kids don't deserve competition.

I think it really requires all of us to rise above it all and to work together. And whether that means under one organization, we shall see, but I think that we recognize that this is a disorder that has many components, and there's always going to be a need to have different organizations that focus on different aspects, whether it's research or advocacy or education or what-have-you. Autism is too encompassing for, I think--I mean as a parent, you know, it's incredibly difficult to manage all of these things. We wear so many different hats. And I think it would be difficult probably for one organization, at least at this stage, to be able to do it all. So maybe we're better off by having different organizations focusing on different aspects. Just one theory at this point.

QUESTIONER: Stuart Spielman. This is a question for Dr. Insel or Dr. Cordero. We're speaking about autism, and we're really doing it in the context of autism in America. When we talk about a prevalence rate of 1 out of 166, we're talking about a prevalence rate based on American data.

I'm wondering whether the American data, to the extent we know, how that data compares to the worldwide data?

DR. INSEL: Well, Jose, you might want to respond to that. There are a number of studies done in Europe. Do you want to--

DR. CORDERO: Yes. Actually, the data presented in terms of autism going up, some of the studies are from Norway and from Denmark, and the rates are pretty similar.

Unfortunately, there isn't enough studies done, say, in Central America, South America, but from the organization of the groups--and I visited Guatemala, Argentina and others--I think that when studies are done, probably the answer is that the prevalence is not very different from what we are experiencing in the U.S. But there are just not enough well done studies to be able to say precisely.

DR. INSEL: So if I can follow up, I think this is a really important question, because from the standpoint of cause, I mean, it's going to be difficult to explain a tenfold or even fivefold increase or any increase based on genes. They don't change in a decade. So we are always wanting to look at what would be the environmental change over this period that could lead to this increase?

The way to disentangle that is to find places where it hasn't happened. Again, you may be able to answer this better than I can. I haven't yet heard of a place where the study has been done, where someone can say, well, you know, the rate was 1 in 1,000 in 1990 and in 2005 it's still 1 in 1,000. That would be actually quite useful to know that there were some communities or some countries or some parts of the world where this change had not taken place.

There is Japanese data which is perfectly in line with what we have from Denmark, the U.K. and from Scandinavia.

DR. CORDERO: I think that one of the challenges is that even if we want to have good scientific and precise data, it should be done using the same methodology every time, and so the longest running we have is the Atlanta data, that we have 1996 and on, and actually, last December 11th, we had our last data collection. I'm not sure if we would be able to continue to collect data.

DR. INSEL: So we can take one more question.

QUESTIONER: Just following up on what you were just saying. I thought--and maybe I misread it--one of the slides did show a longitudinal study in France, was it, where the population was stable, and I was curious how long a period of time that followed and what the speculation is about why.

DR. CORDERO: It was only a few years, and it was a small study, and actually I think that in all this you want to have enough time and using similar methodologies to see, and I think Denmark and actually Norway probably would be our best indicators, at least in the European region.

DR. INSEL: So at least the way this has been disentangled in other illnesses, there's often these long-term longitudinal epidemiological studies, and as Dr. Cordero mentioned, there's one going on currently in

Denmark, and there's also another very large-scale study in Norway, and both of those, the children are in the 2 to 4 range.

So within the next couple of years there will be a data set that really will allow us to, with great precision, go back and ask for those several hundred children in these cohorts of 100,000 who developed autism, was there something about the second trimester? Was there something about the third trimester? How did the birth go? You know, looking at all of those issues and the data that were collected over time to be able to get a better handle on this, extremely important point, which has yet to really yield much in the way of, I think, important clues.

We've got lots of ideas, but actually very little evidence to pin on any single environmental factor.

And on that slightly dismal note, why don't we take a 10-minute break? That means we'll be back here at 25 till.

[Recess.]

DR. FIRESTONE: Well, that really was a terrific first panel, and I hope you all feel as energized as I know Mike and I do.

Mike and I were lamenting the fact that given the time constraints that we couldn't adequately introduce all of our very distinguished presenters, we only can say a few lines. But let me tell you, their bios will be at the Brookings website, so in case you don't know a lot about our panelists, you can surely take the opportunity to learn more by going to the website, and there really is a lot to know about these panelists.

Second panel, extraordinary people doing extraordinary work in the area of early intervention. These are some of the people that give us the opportunity today to use the word hope. These are the people who have created and deliver services to kids that are really demonstrating to us that many children with autism spectrum disorders can make significant progress when given the opportunity. So we are going to hear from four really great individuals in the field.

First, Dr. Catherine Lord. It's hard to say a few sentences about Dr. Lord, but formally she is the Professor at the Department of Psychology and Director of the Autism and Communications Disorder Center at the University of Michigan, and Catherine Lord has been ground breaking and pioneering, and has contributed so extraordinarily to the whole area of early identification, diagnosis and early intervention for children with autism spectrum disorders.

Next you will be hearing from Dr. Laurie Stephens, who I am very proud to say is the Director of the Autism Spectrum Disorders program at the Help Group. For those of you who may not know this fact, at the Help Group we serve more than 500 children with autism spectrum disorders in our specialized day schools on a daily basis. Laurie makes tremendous contributions to those programs, and several years ago developed a remarkable therapeutic preschool for children with autism spectrum disorders which we can write books and books and books about hope when you can see what these children are able to accomplish in this program.

Next you'll be hearing from Dr. Christine Caselles, who, like Laurie, Director, Community Services for Autistic Individuals and Children in Rockville, Maryland. You heard earlier from Mike about the extraordinary difference she and her organization have made in the life of his daughter, not unlike the difference they've made in the lives of many children, and she approaches her work with tremendous passion and dedication, and I know you're going to enjoy hearing her perspective.

The next speaker, let's see--oh, gee, what could I possibly say about Dr. Stanley Greenspan. Let me see. Let me stretch a little bit. George Washington University Medical Center, creator of Floortime, prolific writer, expert authority on child development, contributes so greatly and vastly to our knowledge about child development and children with special needs. And it is such an honor to have these four distinguished individuals with us.

So, without further ado and saying 10,000 more things that could be said about all of you, I'm going to stop myself and turn it over to Cathy Lord.

DR. LORD: A technical time out.

[Pause.]

DR. LORD: It's very nice to be here and to be in this environment, and I think doing something a little bit different than a lot of the autism meetings where we're either focusing on research and just what are we doing in research and how is this going to impact preventing or curing autism, versus more practical things, and we're really here trying to bridge the gap I think, from how do we go from the research that tells us what we can do and what the options are, to actually making things happen, and this seems like a very important step that often sort of falls by the wayside.

I'm going to talk from two sources today, one is a longitudinal study that we've been doing, where we've been following children who were referred for possible autism at 2 and who are now 14- to 16-years-old, so I'm going to talk about the things that we've learned from that. And then the other thing I'm going to do is talk a little bit about the report of the National Research Council, National Academy of Sciences group that I led, which will then actually lead you into Dr. Stephens' talk, who will talk more about that report and also how they have been making this come alive.

I'm also going to stress which other speakers already have talked about. One is heterogeneity, just the differences among kids with autism even though they do have a lot in common, and the second is the notion of a developmental disorder, and that's where I wanted to start here.

I think it's really important to remember that calling something a developmental disorder means two different things, both of which have implications for treatment and hope. One of them is the disorder changes. It's different for people at different ages. A 2-year-old with autism does not necessarily look like a 14-year-old, the same child at 14 as an adult. I think that one of the issues in providing services is that services are not necessarily the same for very young kids, school-age kids as adults, and we tend to focus on often one to the detriment of the other, and I think we need to remember that this is a disorder that affects many individuals throughout their lives, and to think about what we're going to do about that.

The second thing I think is that what we see when we meet an individual with autism is not just the autism that they were born with or that they developed fairly early, but the consequences of that autism on the experiences that they have, and we know that kids with autism, for example, spend less time looking at people, particularly looking at people in social interactions, than other kids. So that if you think about what you would know if you spent one-hundredth of the time doing a particular behavior, how different you would be from other people. On the other hand, we can see that, I think, as a place to intervene. If we can prevent some of the things that don't have to happen for individuals with autism by giving them experiences that more closely mean to them the kinds of experiences typical children have, we really may be able to change those trajectories.

I think a second really important point that others have alluded to is that autism is defined not just by the presence of abnormal behaviors like licking your fingers or making funny sounds, or repeating things people say, but also absence--well, often not really absence, but difficulty in normal behaviors. And that again I think has implications for how do we intervene. And what I think many people have said and will say again is that much of treatment for autism is teaching, it's helping kids learn how to do things that other kids know how to do automatically, and often it's helping kids who are perfectly capable of learning those things, but who might not have done it on their own. Then I think the next step is helping them learn when to do them and when not to do them, and that again means that this is often a lifelong learning process.

Now, our longitudinal study that I'm going to talk about is a study that was conducted at North Carolina and also University of Chicago, and what we did was over two different close to year-long periods, we assessed any child that was referred to a variety of different clinics, under the age of 3. And what we did was try to use multiple users, so parent report, direct observation, standardized testing. We wanted to get a pretty large sample. I tried to do this before with just 30 kids, and this time we were able to get about 213 kids to start, and have a fairly diverse population. So the kids in North Carolina were referred to free state-funded clinics, which meant that they were a much more diverse group ethnically and in terms of education and income than most of the kids who end up getting studied for autism who are generally white, upper middle class kids with really on-top-of-it parents.

This just shows you--and I'm going to sort of fly by this pretty fast--but this shows you the relationship between the best-estimate diagnosis, the best diagnosis that we could come up with at age 2, and we knew we didn't really know what we were doing, and at 9. And you can see in fact the largest numbers are in fact the kids who had autism diagnoses at 2 and then seen by a completely different group of people, continued to have autism diagnoses at 9, and then also kids that weren't in the spectrum. All the kids had some kind of difficulty, but they might have had language impairment or mental retardation. You can see here we had one miracle child who had a very clear diagnosis at 2 and at 9, and in fact, at 5, and really almost at 3 did not have any hint that we could see of being in the spectrum.

Another important thing is these are kids who had diagnosis of PDDNOS at 2, which basically met they had some autistic features, but the clinicians were a little reluctant to say this is full-blown autism. What happened was, by 9, most of them did have diagnoses of autism. But you can see here that about a third stayed in the PDDNOS category, which actually in our group is very mild, having very mild problems, and six kids really did move out of the disorder.

And then we also had two kids very early on in the study that we said to the parents, "It's wonderful. We don't think this is autism," and they came back the next year and we said we were wrong. So I think there was a case where we really learned something from seeing all these very young kids.

Now, I'm going to talk a little bit about individual trajectories over this time from 2 to 9 or 10. This shows language development, so this is language age, so this goes from a language age of basically not talking--actually, this is their chronological age, so this goes from 2. There are some of the kids seen under 2 up to 10. And this is their language age. What I want you to see here is this is--these are kids who had autism diagnoses at 2. These are kids who had diagnoses outside of the spectrum at 2, and these are the kids who had PDDNOS diagnoses at 2.

So I think what's important here are a couple of things. One is there is a group of kids within the spectrum who actually make more progress than we would expect, even though they start out behind, they're catching up, and in fact, for the non-spectrum kids this is sort of staying--it's leveling off, whereas the PDDNOS kids are really continuing to catch up.

The other thing is that many of the kids with autism who are behind stay behind, but it's not that they're not making progress. They're making slow progress, but continuing to make progress long after 5, where often people would say, you know, if you don't make progress by 5, then forget it, and that's obviously not true.

Now, this is the same data, and each line is a different child. What I want you to see here, these are kids who had autism diagnoses at 2. They started very similar down here, and then this is a line of their language progress. And what I want you to see--this is normality--is that there is a huge range, just as everybody's been saying. And there is a cluster of kids down here at the bottom who are making very slow progress, there's no doubt it. But there is also a range all the way up to kids who are shooting off the scale. Those are kids that never stop talking, probably, whose parents are saying, "Why did I say to you at 2?"

This is the same sample. These are kids who had PDDNOS diagnoses at 2, and you can see that they have a similar very broad range, but fewer kids making very slow progress.

I think that what I want you to do is both get a sense both of the hope of these kids and these kids, of the fact that these kids are making progress, even though it's slow, but also the range we have in this population.

One piece of good news is that when we looked at the kids at age 9--and these are just kids who fell within the autism spectrum, so there's 151 one of them--we looked at the samples in Chicago and North Carolina, who are very different. These are mostly rural, half African-American, half-white. These are urban upper middle-class kids, but you see that the proportion of kids at 9, who could talk well enough to do an ADOS Module 3, which means they have to have complex sentences and talk about something that's not present, was actually about 40 percent. The number of kids who didn't talk at all or who had fewer than five words was 14 percent. This is a huge difference from the 50 percent that people used to say of kids with autism who are nonverbal. And we were really surprised, because these kids do not know these kids, had very different treatments, different experiences. What they had in common were parents who at age 2 said, "I need help, and where am I going to go?" And these parents ranged from rural North Carolinians who lived up in the mountains, to very highly-educated, mobile urban Chicagoites.

I think where the difference is--and we don't know what this means because this is not a random controlled trial--is in here, but again we had--you know, there is nowhere this is--no way this is close to 50 percent nonverbal.

I wanted to talk just briefly about the Committee on Educational Interventions for Children with Autism from the National Research Council. This is just a list of all the people on the committee. Probably most of you know that in this kind of a report, you have to get consensus. So the things in that report were not written by me. They were written by a group and agreed upon by a group, and our mandate was to conduct a systematic and rigorous assessment of research studies to look for what could we say about the effectiveness of early intervention.

I'm not going to talk about details, but I think one of the most important things that we saw from collecting data from all of the major early intervention programs across the U.S., is that there really aren't pure treatments any more. People take information from all sorts of different treatments and put them together, and to contrast ABA versus Floortime is really not a very useful thing to do, because most people doing Floortime know something about ABA, even if they don't call it that, and most people who do ABA or verbal behavior or RDI, are using techniques from other strategies.

In addition, if you think about all that variability, each one of those lines being a child, we need a variety of different strategies to try to help kids, both different strategies for different children, and then different strategies for different times. And the last thing is that none of this is going to come cheaply, that we can't do this without funds and trained individuals.

I just wanted to end by showing you some data from a new study we're doing, where we're trying to identify toddlers where someone has a reason to think that they may have autism, and most of these kids are younger sibs of children with autism, but a fair number of them are parents who just found us because their child had a seizure or seizures. They were concerned and they started looking things up on the Internet or talking to their friends. We're seeing those kids once a month, and we're trying to see them as early as we can.

And these are social scores. High is not good. So this is social abnormality. Seeing this child once a month from about 10 months up to 25 months. These are repetitive behaviors. What I want you to see is just that, first of all, even within this child, their socialed behavior is actually remaining relatively constant. But their repetitive behaviors have actually steadily increased since they began to walk. I think the point here is just that no one number is going to represent a child, and that we have heterogeneity not just between kids but even within symptoms within a child.

This is another little boy, who I would say if we had just seen him here and here, we would have said he had a regression. So social difficulties are going up. But my point here is that again his pattern looks quite different than the previous child, and here he's actually having somewhat more social difficulties here, yet repetitive behaviors are remaining more constant.

Again, I just want to illustrate the point that no two children are the same. There is something to do with autism, there is something they have in common, but they're not peas in a pod that are going to pop out identically, and that affects what we need to do for them.

Here I just wanted to show you these are the same social scores, so high means more abnormality. These are the kids in our longitudinal study, and this is just grouping kids who had essentially had the same trajectory. So you can see a group who have consistent--

although they got better--social difficulties, another group where they've actually gotten worse, a group that's gotten better but are not down to normal, and then this group who are sort of hovering in the just very slight difficulty range.

To conclude, what I wanted to say is that autism spectrum disorders involve complicated problems, and because they're complicated there's not going to be one answer. We're not going to be able to say, "Okay, everyone gets 14.6 hours of ABA, and they're going to be fine." The solutions to these problems will mirror the difficulties. On the other hand, in children identified by age 2--this is a Christmas card a family sent me one year--a higher proportion of children with complex language and spontaneous raises at 9 occurred in our samples, even samples that weren't getting a lot of intervention. The one treatment variable that actually predicted changes in language was the parent involvement in the child's intervention.

I wanted to end just by telling you a story briefly that I--or something about a child that I saw yesterday. Frequently when I'm working with kids, they are trying to get rid of me, especially if I'm talking to their parents and they want to go. So one of my favorite stories, there is a little girl who really wanted to leave, and mom was telling me something very important, and the little girl finally came up to me and said, "Sorry, hon, gotta run."

[Laughter.]

DR. LORD: But yesterday I had the opposite happen, and I think this is just an example of the range of roots to social behavior, that there are lots of ways of getting places. I'd worked with a little boy, who again, initially was not at all happy that I was going to be determining what he was going to be doing for the next three hours, but eventually got into the rhythm of it all. And then yesterday, as he was going on the elevator, he looked up at me and clearly thought I was coming with him. I think he thought he was doomed for life. But he said, "Come on, little buddy," to me, which is what his mother says to him. And I think the point is I knew and thought that was a wonderful thing to say. And I think that there are ways to communicate and ways to tap all those thoughts that are going on in the heads of the kids and adults with autism with whom we work.

Thank you.

[Applause.]

DR. STEPHENS: Good afternoon. First of all, I want to thank Michael and Barbara for inviting me to participate in such a monumental event, and hopefully, my words will help inspire people to continue in the fight to get appropriate treatment, intervention, identification and the funding for such in place.

It's interesting that Peter talked about the Age of Denial and the Age of Defeat, because I actually became interested in autism right at about the cusp of those two times. I first read a book called "Sunrise" by

Ron Kauffman, when I was very young, and I was amazed by this group of children that was being described. And I thought, this is interesting. I want to see what these children are really like. I went and volunteered at a local agency that served children with autism, and I was amazed at how often I was told there is no hope, there's nothing we can do for these children. This is just who they are, and they sort of trained me to be a baby-sitter.

And I thought that can't possibly be right. There's no way there's something that cannot be done for these children. There have to be ways to get in there, work with these children, and help them to be all that they can be.

When I was an undergraduate I saw a videotape that Ivar Lovaas had made in the late '60s, and this was a videotape about doing behavioral intervention, applied behavior analysis with very young children with autism. And I thought, aha, there it is. You can make a difference. You can help these children. They can learn. They can grow. And this is not a disease that does not have promise that goes along with it. There are so many things we can do.

And that's what lit my fire and has kept my fire going all these years, is to be part of the body of people that are here today that are trying to change, and who no longer believe that this is the Age of Defeat, but that it is the Age of Hope, and it's the Age of Growth for this population.

We know that it's never too late to intervene with children with autism, but we also know that there's this critical window of opportunity that you keep hearing about. The age has kind of been set between zero and 5 years of age, when children's brains still have much neuroplasticity. You're sort of able to get in there with your interventions and really make a critical difference in terms of brain development, not just in terms of teaching the child a script of what to do, but really making a difference in their neurophysiology and their neuropsychology.

And so this is the main area that I'm focusing on, is to the time when we want to intervene is those ages between zero and 5. We say zero and 5, even though of course there are very few children who are identified at 8 months of age, but we know particularly, as you heard Cathy talk about, with baby sibs projects now, that many parents who already have one identified child with autism are extremely vigilant with their next children and oftentimes identify those children as having some difficulties very early on, so we do see children at younger and younger ages in our clinic at the Help Group, and I know in clinics throughout the United States, and probably the world, we're seeing children at younger ages.

We also know that if we can provide intensive intervention prior to the age of 5, we give children a significantly improved chance of moving into a general ed. population by the time they're kindergarten age. And for those who might not at kindergarten age be able to move into a general ed. population, we know that we can significantly reduce the amount of special education and intervention that the child requires throughout their life span, which of course, in the end is going to save us dollars and save us money.

So the place to put so many of the dollars is in early intervention and finding the right treatments, and doing the appropriate identification of the disorders.

We know that autism can be reliably diagnosed at 18 months of age, and we know what many of these early warning signs are, so we know that children who don't respond to their name by the first birthday, children who aren't using their eye gaze, eye contact to share attention, children who aren't pointing to share interest, all have the early warning signs of autism. And there are also checklists, like the modified checklist for autism in toddlers, that can screen, a 10-minute screening tool that can screen for some of these in a pediatrician's office, in a local clinic.

But we also know that there's absolutely no legislation. It is not mandatory that children be screened for any type of developmental disability. And what happens is that oftentimes from the time a parent has their first concern that maybe something is wrong with their child's development, to the time they actually get the diagnosis, can actually be as long as four years, and that's four years that the child got no intervention. It's four years that we've lost of that child's life, and it's four years that could effectively have been changed by a 10-minute screening tool, and that just cannot continue to happen. 10 minutes is worth our time. It's worth the legislation to change the health care rules and regulations so that all children get screened.

And even if it means that we're over capturing younger children, children who have speech and language delays still need services. Children who have other developmental disabilities still need services. In the long run, if they don't meet the criteria for autism, we didn't lose anything by providing them with these services when we initially picked up on the fact that something was going wrong with their development.

We also know that there are great diagnostic tools that are available, and we can thank Catherine Lord for that, who helped, developed the ADI, the Autism Diagnostic Inventory, and the ADOS, the Autism Diagnostic Observation Schedule. And these are tools that have been shown to be relied and valid when it comes to identifying autism spectrum disorders in children. And this is what we should be using, everybody should be using, to make this diagnosis, but it just doesn't happen. One of the reasons why it doesn't happen is because these tools take time.

It takes a lot of time to do a good and valid and clinically sound diagnostic evaluation for children, but yet, we're told by managed care and by our insurance companies that we should be able to do a diagnostic evaluation in 60 minutes. That's taking your developmental history, seeing the child, hopefully contacting other service providers that are working with the child. Doing all of that in 60 minutes is not possible. And so we need to be able to look at how we're going to be able to fund for appropriate identification. We need more people to be able to have the time and to be able to be funded to do the ADI and the ADOS, so we know that we are capturing the right children, and that we're being able to provide them with the appropriate intervention.

So what is it that we know about intervention? What are the intervention methods that work? What I did in preparing for this talk, is I took sort of all of the national standards, and different clinicians who have written about this, and sort of looked to see what are the commonalities, and you'd actually be surprised that there's more commonalities than there are differences amongst treatment protocols. They have different names, and they might be focusing on different issues in a child. They might be focusing on the social development of the child. They might be focusing on the compliance or the behavior of the child, but they almost all have the same goals, and they're almost all working with the children in very similar ways.

So one of the things that we know is mandatory in a successful program is that the program be individualized to the child. There is not a one-size-fits-all treatment protocol for children with autism. You've heard already that it's probably autisms, so there are potentially various causes and there's various treatments. There isn't one thing. You can't just prescribe 40 hours a week of ABA. You just can't provide 40 hours a week of Floortime. You have to be flexible. You have to look at the child's needs and tailor the program accordingly.

We also know that intervention needs to start immediately once that child is diagnosed, not four months later, not a year later, but immediately once that child is diagnosed. And there are many advocates that will tell you that the minute people are even considering a diagnosis of autism, that child should be afforded the intensive intervention, whether they have the full diagnosis or not, whether they've officially been diagnosed or not, they should still be given the intervention.

We also know that intensity is the prime factor in early intervention. Your definition of "intensity" might vary. National practices basically say a minimum of 25 hours a week, but I know that our personnel feeling and many of the people on this panel's feeling is that between 30 and 40 hours a week at a minimum--

[Tape change.]

--in terms of the type of attention that the child gets. So one-on-one intervention for very young children is going to be more effective than group types of interventions. And, again, it doesn't necessarily matter what methodology you're using. One-on-one intervention is going to be stronger.

If a child is in a classroom setting, you need a very high adult-to-child ratio, so it's recommended that you have one adult for every two children as your ratio, if not a one-on-one. Unfortunately, very few programs can afford to provide one-on-one school education intervention programs. But if you have one teacher, an aide, a behavior interventionist, a Floortime specialist per every two children, then that should be a highly effective program.

We also know that interventions should be behaviorally based and developmentally sequenced. And so you need to be taking empirical evidence, that is, you need to be taking data; you need to be measuring where the child is at when they start your program, and on a regular basis, you need to be taking data to see that what you're doing is being effective with the child. And if the child isn't making progress, you want to hope that the treatment team working with your child is going to be willing to try some new intervention techniques or change what they're doing if the child is not showing any progress.

You want to make sure that the interventions aren't limited to the classroom, so we need to be able to work on generalization and maintenance, and teaching instructions have to happen in the classroom, at home, on the playground, in the community. They need to happen everywhere, and somebody needs to be facilitating that program. So you don't just want your child to go to school and that school program never to be involved in your home environment also, because the two environments have to go along.

And speaking of that, we know that parents have to be an integral part of the treatment team. Somebody said earlier parents know their child best, and that's absolutely true. But parents also are the ones who are going to be spending the most time with the child. So in our program, we get six hours a day with a child, but that's six out of 24 hours. Parents are with their children more. Parents need to be a part of the treatment team, and what you're designing needs to fit also with how the parents are going to work with the child, because if the parents are willing to buy into the program and really work with the child when they get home, again, the child has the best shot for making the most progress and for maximizing their potential.

So I come from a program, as Barbara Firestone mentioned, that's called Young Learners Therapeutic Preschool. We have two preschools--one in Sherman Oaks, which is in the San Fernando Valley in California, and the other one in Culver City, which is right outside of Los Angeles, in California also. And our preschool program is what we would consider an extremely intensive, integrative program. As I said before, it's six hours a day, five days a week, so it's extremely intensive. And we're very lucky. Our program is considered a non-public school, which means that the local school districts do fund the children to attend our program. So everything that I' about to describe to you is provided to the parents at no charge, regardless of the parents' socioeconomic status, regardless of anything like that. This is a service that's available to the children who qualify for it at no cost to the parents.

The primary goal of our program is to try and get the children to be ready to move into a general ed. kindergarten program and to be able to maximize the individual potential that each child comes in with. They have different potentials, they have different strengths and weaknesses when they start, and we like to capitalize on those particular strengths and weaknesses.

We try and draw from the proven and effective strategies that we know exist out there, but we are not a program that believes the child has to fit the program. We believe very much that the program needs to be malleable to meet the needs of the child. So it's a philosophy that should be seen in more and more educational programs. Again, it is not one-size-fits-all. It's what is going to work for the child that we do.

Our teaching ratios range from one to one, so one adult per every child in the program, up to one to three, so that it's for children who are more ready to learn in a group paradigm. There will be one adult for every three children.

Teaching paradigms do begin in a discrete trial or applied behavior analysis format, and then as the child develops better attentional controls and develops more intrinsic motivation, we move into much more naturalistic paradigms.

And we begin by teaching the children both compliance, but also we begin by trying to make the staff in the classroom the primary motivators for the child. That is, we want the children to come into our preschool every day and look at the staff and think, wow, these are the people who help me; these are the people that make me happy to come to school. So it's not necessarily just about the reinforcement that they're getting, but that they see the staff as their primary motivators and want to do well for those children.

Even though most of our children are in one-on-one types of programs, we also do include traditional circle times, and we also have speech and language therapy, occupational therapy, sensory integration therapy, floor time, and other emotional relationship types of programs that are built into the program at the needs at which their--or in order to meet the particular needs of the child. And then we have music therapy and art therapy programs also that are incorporated throughout the day.

Initially, we start working on compliance, communication. Social relatedness is very important and can never be underestimated, as Cathy was just talking about, and as I know that some of the speakers following me are going to speak about. So social skills programming is a strong part of Young Learners Preschool. And we also work on reducing any type of maladaptive behaviors. And we work--our program works so that, again, children might start in an applied behavior analysis type situation, but as soon as possible we're going to move them into more naturalistic paradigms, and then we have a pre-kindergarten program for those children that we know are about to integrate into a mainstream environment. They're in what would be much more of a typical kindergarten program so that it's easier to make that transition from our program to a mainstream program, and they kind of get a leg up on what the academic expectations--California has extremely strong academic expectations for kindergartners, and so we attempt to teach those skills to the children as early as possible so when they get into a kindergarten program they have a leg up.

Our program has been highly successful. We've had--about 80 percent of our children each year are able to meet all of their IEP goals, and this past year we were able to return 50 percent of our graduates to a regular education program without requiring any further special education other than speech and language therapy, which I think is pretty remarkable.

In many ways, though, we are very lucky because our program is in California and our local school districts are very good at funding intensive preschool programs. But this isn't true for every other state, as we all know. Oftentimes major autism centers are located near major universities, and people don't all live near major universities. And I had a mother who recently wrote to me and she said, "If you say one thing, please remind the audience that autism does not only happen in the big communities. Autism happens everywhere." And what are the parents supposed to do who don't have access to a school like the Help Group or the other schools that exist out here, who don't have access to the major autism centers that exist, the Centers of Excellence? There's eight of them. But there's many, many, many states. And so where are those children supposed to go?

We also know that a lot of the highly specialized programs, early intervention programs for children with autism have very small enrollment numbers. So sometimes these programs are capped at 20 students. So what is the parent of the 21st child to do? They go on a waiting list. And, unfortunately, what we know is those waiting lists can be as long as three years, which means that the child has lost that critical intervention time if they have to be on a waiting list for three years.

So these are all the policies that we're going to be talking about later and that I hope everybody's going to be working toward trying to change so that we know that the minute a child gets identified with autism, the parent knows what to do, where do they go, and what do they do, what are the services that their child needs; and also that we get to the point where we do realize that autism is autism regardless of where the child lives and that a child from Los Angeles or a child from, you know, Washington, D.C., has the same opportunities as a child from--you know, as this mother referred to where she lived--"Corn Country, Illinois," has exactly the same access to services, the same intensity, the same degree of services as anybody else does.

So I want to just conclude a little bit by talking also about services for children that are under the age of three. In California, again, we're very lucky. We have what's called the regional system, and that is state-funded programs that are designed to provide intervention for children throughout their life span, but they provide all of the early intervention for children zero to three. And, again, this is provided to parents regardless of their socioeconomic status or anything like that.

The problem with the Regional Center is that when are most children with autism identified? Between two and a half and three years of age. So parents get a diagnosis. They go to the Regional Center. The Regional Center does their evaluation. They hold an IFSP to determine what are the services that the child needs, and, uh-oh, the child is 34 months old by this point and is now too old to get the services from Regional Center. Now they get referred to their local school district, and now the school district starts the process all over again: evaluates the child, you know, holds their IEP. And this is a lot of critical time that is lost to the child. So we need to be able to have a seamless system of care where it doesn't matter, you know, where the child lives or what the age of the child is, that all of the services are going to be the same.

So, in conclusion, I just want to say that in my role at the Help Group, I'm oftentimes the first person that either tells the parents that their child has autism or the first person that's there to help them get the intervention that they need. And too often the parents come in, and they're thinking, my child has autism; this is a life of dependence and isolation. And we work toward letting the parents know that that's actually not the case, that getting the diagnosis is the first step to opening the doors, not shutting any doors, and that today should be all about finding the keys that will keep these doors open for the children forever.

Thank you.

[Applause.]

DR. CASELLES: Good afternoon. I've been working with CSAAC, which is an agency in Rockville, Maryland, in Montgomery County, Community Services for Autistic Adults and Children, for about ten years with their intensive early intervention program. When I started working with the program ten years ago, CSAAC was an agency that served adults and adolescents with autism. And what happened was it was a parent-run organization, there was a parent board, and many of the parents who were on the board began to have grandchildren, younger grandchildren who were diagnosed with autism and wanted to start an early intervention program because there was just nothing out there for young children with autism. This is in the mid-1990s.

So they started the intensive early intervention program, and I began that program, and initially, interestingly--kind of following up on what Laurie was talking about--all of the children who were referred to us were referred by and fully funded by their local education agencies. So that was either for children over three, their local school system, and for children under three, the infant and toddler program.

Within the past three years, that has changed, and the school system, the local education agencies have stopped referring children. So, unfortunately, at this point most of the children that we see are funding the interventions privately and through other sources.

I want to talk about three things today, make three main points in my talk. I want to describe the program and, in general, the intervention that we deliver. I'd like to talk a little bit more specifically about the methods and procedures that we use to address the deficits and some of the maladaptive behaviors associated with autism. And then I'd also like to talk just briefly about some of the research that the intervention is predicated on, just kind of give an overview of some of that research.

In terms of a description, this is an intensive intervention. We serve children--generally early intervention programs, behavioral intervention programs provide 20 hours or more per week of intervention.

But the research shows us pretty consistently that the best results result from 35 to 40 hours a week of intervention.

It's a comprehensive program. We address a broad range of behaviors and skills, including expressive and receptive language, play skills, peer interaction, eye contact, task completion, learning readiness, compliance, nonverbal communication, the variety of social skills that these children need to be taught, things that come intuitively and naturally to children who are not on the autism spectrum; problem solve, coping skills in older children, perspective taking, self-care--a broad range of skills. It's a very individualized program, so when children present to us, we do an assessment of what some of the skill deficits are and begin with that child addressing some of those areas.

Parental involvement--we've been talking a lot about that today. Parental involvement is the crux of our program. All of the parents are very involved in the program. We have weekly meetings for all of the kids, basically like a staffing, and parents are present at that meeting to contribute, to share with us what's happening, what skills they're generalizing, what skills they're not generalizing, what some of the behavior problems are at home, how the child is functioning in the community; if they're in school what's happening in school; how sibling relationships are.

So this is extremely important in our intervention. The intervention happens primarily in the child's home, at least in the initial stages, so the parents are usually present during a majority of the intervention, are able to actually observe the intervention if they're wanting to.

Now, I should mention we do have for the first time one child who has two working parents and is actually in a daycare placement, and we're fortunate that we're able to send our staff into that daycare placement to work with the child. It's just a community daycare, and they've been very nice in terms of setting up a room and allowing the child to work in that setting. So it's nice that it's sort of evolving in a way that at least can serve children where one of the parents cannot be at home.

Parents are trained in the intervention, particularly in the initial stages. For the children who were referred to us through the local education agencies, there was a requirement that they provide ten hours a week of the 40 hours to the child. So they were actually trained as technicians or therapists to work with their child so that they could understand everything that was happening, so that they could generalize the skills. The intervention is occurring constantly. It's occurring during dinner. It's occurring during bath time. It's occurring as you're putting the child to bed. So the parent is really sort of the primary therapist to the child.

School inclusion is also a part of our program. In later stages, for children who are higher functioning or have the ability, we get them into preschools in the community at a very early point in the intervention, and we send them to preschool with a shadow, who is someone who's trained as a member of the treatment team and is able to prompt the child and facilitate interactions and reinforce appropriate behavior and all of those things--basically carry over the intervention to the school setting.

We do peer play with kids, so we try to find friends from the neighborhood, cousins within the family, friends from school that we can invite over for a facilitated peer date where we can generalize and apply the skills that we're teaching the child in the one-to-one intervention.

And we talked about individualizing programs. This is a behavioral intervention, meaning that the procedures that we use are based on behavioral principles, but it is very individualized in terms of the skill set we're working on. So there's not a curriculum that we follow, a specific curriculum that teaches children things in a particular order. We individualize the treatment based on what the child needs, so if there's a deficit in a particular area or if there's a maladaptive behavior that's occurring that we want to address, we develop a program for that.

In terms of methods and procedures that we use, there are really four behavioral kind of strategies that we use in this intervention, and I'll talk about how these are used at different points during the therapy when I talk about the phases of treatment. The first is discrete trial teaching, and this is the one that's most commonly associated with behavioral interventions. The thought seems to be that all of the teaching is through discrete trial teaching, and this really isn't true.

We do use a lot of discrete trials, and this is a very highly structured, very systematic way of teaching that makes things very clear and very concise for the child. It sort of breaks them down. We teach in a distraction-free environment, and we make sure that there are no other things that are going to confuse the child. We use this a lot in the beginning phases of the treatment and primarily to establish--initially to establish learning readiness and to help the child to bring the behaviors to the teaching situation that they need in order to learn. And we also use it to establish some of those basic skills in terms of language and some other areas.

A second procedure is called direct instruction strategies, and this can also be referred to as skills training. This is more flexible than discrete trial teaching, but it's also very systematic, and it has two phases. The initial is skill acquisition, and this is where we teach the child the skills that they need to do something in a particular situation. So in a social situation, if we're trying to teach a child to join a group that's playing together, we might in the first phase give the child instruction and say, "Well, when you want to join a group that's playing or when your friends are playing and you want to join them, what you need to do is to go over and ask if you can play." And then we model it. So I would say--you know, I'm going to be the child first, I'm going to be the kid, and I would model the behavior for the child. And then the child rehearses the behavior. They try it out, and then we give them feedback.

So this is sort of a procedure that we can use in a more flexible way to teach children behaviors that don't lend themselves to discrete trial teaching. And then there's the application phase, and this is where--we use this during the peer sessions where we have another child present or in a school setting or in a community setting. So this is generalizing the skill to the natural environment.

We do also use some incidental teaching in the intervention, and that's really kind of setting up a situation in which the child's going to perform a particular behavior and then rewarding them for it when it does occur, and really using subtle prompts and sort of some engineering of the environment in order to encourage a particular behavior to occur so that it can be reinforced.

The last procedure, the fourth procedure, is called free operant instruction, and this is essentially just watching the child--and this is what most parents do most of the time--watching the child for particular desirable, positive, appropriate behaviors to occur, and then rewarding them when they do occur. And this is a part of the intervention that hopefully is happening all of the time. The parents are trained and educated and they're involved in the intervention so they know what's going on, they know what we're targeting, and they're able to see those behaviors occur more naturally and reward them when they do occur.

So these are all procedures that we use for increasing skills. There are also some procedures that we need to use for addressing the maladaptive behaviors. So we know that with autism there are these huge deficits in particular areas, like language, social skills, interaction, toy play. But there are also a lot of maladaptive behaviors that occur, disruptive behaviors that can be a major problem, and I've seen many kids who are very smart and they have a lot of great skills, but their behavior interferes with them being able to participate fully in the community and in school and in social situations because their behavior is so disruptive.

I'm going to talk a little bit about the research, but in the early, early phases of behavioral intervention, the early research was based on some aversive procedures, actually, to address the maladaptive behaviors. So there was this belief in the field that we couldn't accomplish the same kinds of things without using aversives. But the more recent research has shown that aversives are absolutely not at all necessary, nor provide any advantage in terms of addressing these behaviors. They can be effectively addressed through positive means. Primarily what we use are differential reinforcement procedures, which is when the desirable behaviors occur, when alternative behaviors occur, we reinforce those behaviors, at the same time not providing any rewards for the undesirable behaviors. So these are sort of the primary procedures that we use to manage the behavior problems.

All of the children in our program have behavior plans that we follow, and this is kind of a written document that helps anybody who's working with the child to know exactly how to respond to particular behaviors. And what we do is we measure the behavior initially. How often is it occurring? In what situation is it occurring? We perform what we call a functional assessment, and then we write a behavior plan based on that assessment, and then we follow up and we measure the behavior after we've been following this treatment plan for a period of time to make sure that the behaviors are actually decreasing, because if it's working, if it's effective, if it's an appropriate plan, it should be actually decreasing the behaviors.

In terms of phases of treatment, I sort of touched on this. We start off and the initial phase for most children in our program is really establishing compliance. When the children come to us, most of the children that I see are two, three, four years old when we start them, and usually they're not too happy to be in a teaching situation. They haven't had a tremendous amount of success learning. They have a lot of difficulty sitting still, and they have some difficulty responding to stimuli in the environment that are going to be important for them in order to learn.

So the first step is usually just establishing compliance, getting the child to sit at a table, getting them to attend to a task, getting them to finish a task, not just when they want to do it but when they're asked to do it. So that's really important that they're able to demonstrate these skills at appropriate times.

So we spend a good deal of the initial phase of treatment just establishing that compliance, using a lot of positive reinforcement for any level of compliance and sort of shaping it over time.

We also teach the early skills that promote learning, so attention to task, task completion, actually just looking at the stimuli, the teaching stimuli, and then reducing those behaviors that are interfering with teaching in those early phases. And we're teaching basic skills, so, you know, basic imitation, watching a model and then doing what they do, following very basic instructions; early, early language development, so imitating language, labeling items, very kind of concrete things. And the majority of this teaching is discrete trial teaching in the beginning, so it's done at a table in an environment that is free of distractions. It's very,

very structured. We do keep data on everything that we do throughout the program, actually, but very, very specific data in the beginning phases.

Many kids who come to us and children that we see who are on the autism spectrum require this type of teaching really probably throughout their educational career, require to some degree to learn new skills, so they need a very, very structured situation, and they're always going to need that as a component of their education. But there are many kids who are able to move on to kind of more natural king of teaching strategies and more complex teaching strategies. So in the middle phase of our program, we start expanding their language, so this is where we try to establish sentences, speaking in sentences, and using more complex language, using more descriptors, being able to comment on things, teaching some play skills and some basic social interaction--you know, having a very basic conversation, teaching daily living and pre-academics, communications, making your desires known.

And here we're using still a lot of discrete trial teaching, but a little bit more incidental teaching. So in teaching kids to ask for things that they want, we work with them by just setting up situations in which they're going to want an item. We take some favorite items, and we, you know, restrict their access to those items, and we sort of let them know that they're in the environment, that they're available, and we use lots of as subtle as possible prompts as we can to get them to request those things. So even just kind of looking expectantly at a child can be enough of a cue to get them to ask for something and to use their language to communicate.

In the final phase of treatment--and, again, this is for some of the children, for the children who do very well--we're teaching the development of more complex skills, so things like observational learning, understanding and following social rules, coping skills, problem solving, participating in the classroom, social and community activities. And here obviously this is more of an application phase, so a lot of the basic skills are there, and we're really getting the child out into the natural environment and getting them to apply and generalize these skills. And this is difficult for a lot of the children that we work with.

There still is a huge instructional component to this, so these skills that we want the child to use, we find that we can't just bring them into the classroom and teach them in a social situation. Usually we have to be able to pull them aside and use some of the direct instruction strategies, allow them to rehearse some of the skills with us, with an adult first, and then maybe with a child that we've sort of almost trained to respond in reinforcing ways to the child, and then get them to apply them in more natural situations. This is really the most difficult phase for many of our kids in the program.

I want to talk now about some of the research and give you an overview. I think many people are familiar with a lot of research that this is based on. Ivar Lovaas started. He was sort of the pioneer in these intensive behavioral interventions and had a couple of important publications, one in 1973, so this is, you know, 35 years--now 40 years' worth of research. He was really one of the first people to find and to publish that children with autism can respond actually very well to intensive interventions. And that was an important study, but in that first study what was found is that the children didn't maintain the gains that they had made. They made very significant gains in terms of IQ and general functioning, but didn't maintain those gains.

It was followed up with what has become sort of the seminal and controversial paper, which was published in 1987, where he found that half of the children who were treated with this intensive intervention were able to do very, very well and were mainstreamed into general education classrooms, achieved cognitive functioning within the normal range, and did quite well on a number of different measures. And those kids, who were referred to as "the best outcome group," were followed up a couple of times, and it was found that they were maintaining their gains.

There has been--you know, in addition to this, and prior to Dr. Lovaas, there are many, many hundreds of studies that have been published that just document that specific behavioral strategies are effective in addressing skill deficits and maladaptive behaviors for children with autism. So there's a huge body of literature that supports behavioral strategies in general.

After this 1987 study, Dr. Lovaas got a grant through NIMH to replicate the findings of that study and set up several sites around the country, and CSAAC actually became one of those sites, and that's how--one of the ways in which this program was started.

That data from the multi-site grant is currently under analysis, and what we're finding is that the results, although somewhat variable from site to site, have been consistent in terms of finding that children are responding to the intervention, that many, many children can do extremely well and can be mainstreamed and function very well in general education classrooms, can achieve language, complex language even, and can function much more effectively in their environments.

There have been a couple of publications that have looked at global measures since Dr. Lovaas' study and have had sort of varying results. Some of the studies have not applied the 35 to 40 hours a week, so they've been fewer hours, and the findings--although, you know, the children did well and many of the children made a lot of gains, the gains were somewhat more modest.

I think an important study that just recently was published is a paper by Salas and Graupner, and this was one of the sites in the multi-site grant. And they had 24 kids, and I think this is a neat study for a couple of reasons. One, it demonstrates the importance of parental involvement and the power of parental involvement. They had 24 children, and one of the problems that we had with setting up these studies at our sites was finding a comparison or control group. So it was very difficult. You can't assign kids with autism to a no-treatment control group, obviously, and there's so much overlap in terms of the treatments that are being provided and that parents are seeking. So it's very difficult to sort of keep it clean.

But one of the things, one of the advantages that we had is that there are many--in addition to centers, behavioral centers, like we have at CSAAC, and there are many wonderful centers around the country that are providing this intervention, there are many parents who are implementing the interventions on their own, with supervision from a clinician.

So this site in Wisconsin had a group of parents that had psychologists as consultants who would come and teach them the program and train their staff and develop programs for the child and then would come back for follow-up. And they used that group as a comparison group.

So there were 24 kids total in these two groups, the center-directed and the parent-directed group. And what they found is that there were no significant differences in terms of the progress that the kids made. Although the parent-directed group was receiving less frequent supervision and they were responsible for hiring their own staff, those kids still did as well overall as the kids in the clinic-supervised, more closely supervised group.

But this study actually did replicate Dr. Lovaas' 1987 findings, which I think is really exciting, and found that 11 of the 24 kids achieved average-level IQs and by the age of seven were succeeding in general education classrooms. And I do want to mention one of the things that was found--and this just shows us that this is a disorder where kids really do need to be followed for the long term rather than the short term. Of those 11 kids, 30 percent, although they were doing very, very well academically and in many other ways, 30 percent still had mild to moderate social delays. So this is something that we also see at our center that a lot of the kids, even the children who do very well, continue to need some support. We have social skills groups and we continue to work with those kids. But there still are some of those kind of residual issues that need to be addressed.

Thank you.

[Applause.]

DR. GREENSPAN: It's a pleasure and honor to be part of this I think almost historic occasion. I want to thank Michael and the others here at Brookings who helped organize this, and it's a special honor to be here with distinguished colleagues, and the whole day I think is putting not just autism and research but what you're hearing about now, services and how we can help kids right away, not just in the future when we discover the causes, and that's where the real hope is.

Now, the hope, I think, is more tangible even than we realized with what we currently know and what we currently can translate into interventions that start early, that are comprehensive, that are individually tailored. But there are some fundamental differences in philosophy that are guiding these early interventions. While we share the commonality--and I think Cathy and her group at the Academy of Sciences really captured it beautifully, individualizing, intensity, but there are two groups that they identified: one group focusing on what we call developmentally based approaches, and what we call the DIR/Floortime model, which I've been, obviously, working in, was one of those development approaches they cited; and then there was a wide range of behavioral approaches, including the discrete trial that you just heard about. And all these approaches, the academy pointed out, have some evidence behind them, but there have been no horse races between the approaches, no clinical trials comparing approaches, and really no definitive data showing a clear correlation between an approach and an outcome.

But here's where the promise comes in, I think, and why the hope is so tangible. The academy pointed out--and I agree--that the general field is moving a little more in the developmental direction, more towards naturalistic, which is a little more developmental, and even behavioral approaches are moving in that direction. And with a model that took as a starting point development, I was there at NIMH with Dr. Ivell (ph) years ago, and we started actually research at the Mental Health Study Center, a laboratory out in P.G. County, which I had a chance to do, and we studied babies, high-risk babies. And we came from the bottom up looking at normal healthy development and at-risk babies, and we saw a lot heading in the autistic direction and developed strategies to build healthy developmental foundations.

So the fundamental difference in philosophy is instead of looking at discrete behaviors, making a child compliant or making a child attend to a particular stimulus, we said what are the characteristics that distinguish the healthy children from the at-risk children from kids heading on different kinds of at-risk or special needs trajectories. And we found that there were six cornerstone capacities or six developmental essentials that accounted for millions of separate behaviors. And we found that when you focus on these bigger forest issues as opposed to the trees, you actually got generalization immediately, not second or third step.

Now, with that kind of an approach that builds these healthy foundations, we now have a group of kids--and I'm going to show you one in a few minutes--who are teenagers, a subgroup of children we've worked with for many years, who are doing things that children who were diagnosed originally with autism or on the autistic spectrum are not supposed to be able to do. They have not only a high-level theory of mind, but they have better empathy and understanding of other people's feelings than most of their peers. They're very social and they are happy to be social. I mean, some of them their parents describe as wanting to be with them too much. They're very creative in their language, and they make inferences.

So there was research done a number of years ago in many places on the core deficits of autism, and when they match for IQ, they find that what distinguished autism from non-autism is not language when you match for IQ per se, but the ability to make inferences, to have empathy, social reciprocity, reading the social cues of kids.

So when a child can learn to read the cues of others, you don't have to teach in a more mechanistic way, "May I come and talk to you?" The child does it the way you do working a cocktail party: makes an overture; if the other person looks away, tries a different one, until they find a successful overture; they become seductive, flirtatious, sense of humor.

So we believe that the promise--because we've now seen this, and we have a group of teenagers, which I'll talk about more systematically in a minute, who evidence this. Not all the kids get to this high level. But we did a review of 200 cases systematically, and all the children, all 200, became much more social and engaged and much more interactive, but we got different levels of language and cognition with the subgroup achieving these very high levels. In our sample, it was a significant percentage, but it was not a representative population.

Now, the six cornerstone milestones we identified had to do with wanting to pay attention, so we try to attract the baby or the child into wanting to look at mommy. The baby is preoccupied with toys or objects, we put it in our mouth, we put it on our head, so the baby merges the object with the person and pretty soon is looking at you and wanting to look you in the eye, as opposed to, you know, wanting to look away.

We then work on engagement and the depth of intimacy. We then work on two-way social reciprocity, again, off the child's natural interest. The child's [inaudible] opening and closing a door, we get stuck behind the door. Pretty soon they're going, "Ah, ah, ah," to get us away from their door. Well, now they're social signaling and problem solving.

We want to work on creative language so we get involved in pretend play with the children. It starts off with a little imitation, and then we work on logical language. You know, the child says, "Open,

open. Go out." "Why? Why?" Can't answer. "Play or go sleep?" The child says the last thing, "Go sleep." "Okay, let's go sleep [makes snoring noise]." Okay. But within the same session often the child is picking the first one. "No. Play, play." And now has an understanding they go out and play. It generalizes immediately. They know what play is. So this is the developmental foundation.

Now, we found there were two other things that needed to be done. One was identifying these foundations, which we identified in both normative studies and at-risk studies, and we just validated with a naturalistic population of 1,500 families in collaboration with the Psychological Corporation of America that produces the Bailey Scales. They now have the Greenspan Social/Emotional Scale as part of the official Bailey Scales, which is the most widely used developmental scales worldwide. And it validated the existence of these six milestones. These six milestones separated typically developing kids from kids with different high-risk groups, and they occurred at the ages that we had been hypothesizing they occurred. And we had done smaller studies but never on a representative population of 1,500 families from around the country as this. So this was very nice to see.

They also found, as we had predicted, and also had shown in shorter studies, that at the early stages, if a child mastered engagement and attention, they could go on to social reciprocity and read signals. But if they didn't master the early ones, they couldn't master the next one. And the sequence had to be mastered like you would build a house, with a strong foundation, the basement, and then the first floor and then the second floor. You couldn't skip to floor five or teach a particular thing in isolation from something else. And so there are strong correlations between the early levels and later levels, and what was even stronger was you had to master the early levels to get at the later levels. And this also was done with a brief 15-minute questionnaire which can be administered and pick up differences as early as three months of life. So we now have a screening tool that has been somewhat validated that will pick up a whole wide range of at-risk children and that is predictive. So the early stages predict later language and symbolic functioning, for example, on this scale.

Now, the two other features, in addition to these developmental foundations, are individual differences. We have tried to capture how each child is unique in terms of the way their nervous system works by looking at how they react to things like sound and touch. You all hear about unusual behavior of children with autism. Well, some are over-reactive to things like smell and taste and touch, so they shy away from it and they get very scared and panic. Others, however, are sensory craving, just the opposite. They can't get enough of it, and they're roaming around the room looking for more sensation. They're under-reactive and sensory craving. Well, these are very different biological patterns. They probably have different pathways.

Some children have very good auditory memory. That's why they become echolalic. Other children have very weak auditory memories, and it's very hard to have them even imitate one sound. Some children have very good visual memories, others weak. Even the ones with good visual memory often have weak visual problem solving seeing the forest for the trees. Many of the children have motor planning problems in sequencing, which means they can't plan a complex, ten-step action or five-step. Some can only do one or two steps, so they bang the toy because that's the way they can interact with the world, and we have to work on their motor planning.

So by looking at the sensory reactivity, the auditory processing, the visual special processing, and the motor planning, we profile each child, which we assume has different biological routes, and we profile their developmental level in terms of the six milestones and later ones that have been outlined as well. And then we use one other thing we profile. So the milestones are called the D, the I is the individual differences I just mentioned, and the R, the third feature we profile, is the relationships in the child's life. What are the family relationships like? What are the school relationships like? And what works and what doesn't work for the child? Because an over-reactive child with an operatic Italian mommy may be overwhelmed. On the other hand, an under-reactive child with low muscle tone with that same operatic Italian mommy may thrive. So we try to help the environment, the parents, which are critical, and this approach is parent-directed. We work with the parents as our primary agents of the intervention, not having to want someone else, they're doing the work, and they’re on the floor with the kids. And if they can't be, it's grandma or aunt or someone they bring in who becomes like a part of the family.

But we try to then adapt the R, the relationships, to the child's individual differences and their developmental level. What are we working on? Engagement or reciprocity or problem solving or two-way, higher-level communication with ideas.

Now, I'm going to show you two children on videotape to bring this alive, and then I'm going to show you some of our data that we have on this approach. But it offers, I think, a promising new opening for the future, and the key thing I want to say about interventions are I had Ivar Lovaas to one of our early meetings, and he and I shared a day together, sharing information with the audience, and his work was pioneering. But we can't be static in the intervention field. We can't simply stay with methods that started our optimism. We have to use new neuroscience, a new understanding about development and the brain to move the interventions forward, and many of them are integrative.

So, for example, we know that the deficit biologically is more in the pathways connecting different parts of the brain than one part of the brain for autism. We also know that when you use affect and relationships in teaching, more parts of the brain light up on PET scans and you get more integrated circuitry going on. So that suggests again these more naturalistic developmentally based models for the future.

I'm going to show you two children. Can we show the first tape? This is a child getting started. This is all happening in one session as we mobilize the child's affect. Now, what we're doing here is working off the child, off his natural interests, to try to get him cooking and master as many of these fundamental foundations as possible right in that first session because we feel you've got to see what the child can do with a little coaching to see the best the child is capable of, or else you won't be assessing what that child--his true starting point.

[Videotape playing.]

DR. GREENSPAN: You can see there he was very unengaged.

[Videotape playing.]

DR. GREENSPAN: So here you see right in the first session--this is all within an hour and a half--and this is part of a training video series where parents volunteered so that anybody can get these tapes. We have a parent version on DVD and also a professional version. So anyone can order from our website, which I'll show you in a minute. But we like to bring out the best because you wouldn't know from the first few minutes what this young guy could do right at the outset, and that's because we got that affect going, we got his relationship going. And so we believe the starting point is to get the attention and engagement based on affect and get reciprocity, and then we bring the structure in a little later if needed. So if to learn a particular academic or language task we need structure, we bring it in. So it's the opposite sequence that you heard about with the historically important behavioral approaches, and all the approaches suggest good results now, but there are differences in the social/emotional gains and the ability for things like empathy and reading cues reported by the developmental approach.

Now I'm going to show you the next video. This is a teenager who's one of our group that did very well. I want you to see what--he's talking politics, so this is his own ideas, so I can't--it doesn't represent Brookings or me. But this is a teenager now who's part of our group that did very well.

[Videotape playing.]

DR. GREENSPAN: Okay. We can stop this now.

[Laughter.]

DR. GREENSPAN: Thank you. So, you see, he's got his own opinions. He's at a very demanding private school in D.C., regular, very demanding, you know, program. Has lots of friends, plays some sports, and is one of the kids who's done very well.

Some of the kids that I'll show you in a moment in our follow-up group are superstars in the sense of at the top of their classes. Others are average students. Others have learning disabilities. Others are anxious and depressed. But they're all empathetic, warm, interactive, social kids with very, very good language.

Now, first PowerPoint. This is the model just systematically, so here you see in this model the biologically based individual differences express themselves through the child and the child-caregiver interactions. Then you have the family and community and culture also expressed through the family and through the caregivers in the interactions. Then these interactions lead to the mastery or lack of mastery of these six fundamental core capacities. And we feel we've got to get these six capacities in there as best we can, and, again, then build trees on top of that. This is the forest. We've got to build the forest first. We've got to build good foundations for the house.

Next. This is just to emphasize that here--no, next slide, please. Can we have the next slide? Stand up here with me. You can work it. Okay.

So here this is just to emphasize, again, that in this model we don't want to look for a one-to-one between a biological difference and a behavior. We want to see it as a complex developmental biopsychosocial system.

Now, we've emphasized the biopsychosocial model in psychiatry, but we haven't emphasized the developmental biopsychosocial model. So this is the developmental biopsychosocial model where there are many points of transformation and many steps between the biology and the outcome behavior later on. For subtyping, we think it's essential to understand this type of dynamic process, or else we're not going to have adequate subtypes, and then we're going to waste millions of dollars searching for a magic biological bullet when it's really a complex dynamic system.

Next slide.

To do a proper assessment means assessing all elements of our DIR model. I distinguish our DIR model that looks at this complex developmental biopsychosocial system from our Floortime techniques, which are intervention techniques of a particular kind. So this is a model of analysis where we can incorporate structure and we will use ABA and other structure techniques as needed on the way to mastering the core milestones.

Next?

This leads to a developmental profile for the child which helps us develop an intervention plan that is individually tailored, but not just around, again, changing this or changing that, but has a reason for why we're working on what we're working in a developmental framework.

Next slide.

Now, this is the social/emotional growth chart I was talking about. We have a questionnaire that can be administered in 15 minutes to parents, and here you see the curves. The dark line is the normative curve for age expectations. The line above is precocious development. And the lines below it are different levels of problems. The worrisome sign is when it starts curving away from the 45-degree angle, and that's what we characteristically see with the autistic spectrum disorders where we don't get early intervention there working properly.

Now, I'm hopeful in the future, picking up on what Cathy Lord was saying, that when she redoes her study five years from now, if we intervened earlier with more kids in a comprehensive way, it will even be more encouraging, that the data at age nine--there will be more kids with language and more kids also who are empathetic and can read social signals.

So I see the evidence for this one that these approaches are already working is evidenced by Cathy's current paper, and if we can show in five years if she goes back into the field, even better, then it will show that we're making progress in getting the best methods out to people. But now we have a simple questionnaire, again, that has been validated in 1,500 families where you can ask the parents questions about their kids for screening. We don't have to wait. Mostly the questionnaires we use now are in that second year of life between 12 and 24 months of age. That's too late. We also are doing a study on videotapes, and we're finding the same data on the videotapes of kids who were later diagnosed with autism as babies. At three months, we can see the lack of these first milestones coming in, and we're going to publish that very soon. The 1,500-family data is published in a paper that's on the Brookings website that will be out in February. It's already been accepted for publication. So that you can access on the Brookings website. It's called "Developmental Pathways"--blah, blah, blah.

Next slide.

This just shows regression and early onset autism, the different curves we see, and even for kids who regress, we see weaknesses in some of these early milestones, but they're very subtle and they have to do with the ability of the child to take initiative and to initiate the social interaction. And we have a theory called the Affect Diathesis Hypothesis where we think, even though the kids are all different in terms of the way they process sound and sight and movement, that there's a commonality here. We think the commonality that will provide a pathway for the biological understanding is that all the kids we think have a difficulty in connection affect or emotion to other parts of the central nervous system functioning, especially motor planning and sequencing, and then emergent language development. So by not connecting the affect system early to these other systems, the child beats to his own drummer, lines up the toys as opposed to goal-directed, uses language repetitively rather than meaningfully.

Now, the evidence for this we have in that 1,500-kid study and also in the videotapes, and we're now doing some research over at York University in Canada with a $5 million grant from Milton and Ethel Harris to nail it down in terms of monitoring what's going on from a central nervous system perspective as the systems are developing. But we believe the core deficit psychologically that will be a clue for the biological understanding is this ability to connect affect to other parts of the central nervous system, and we call that the Affect Diathesis Hypothesis, and it's in that article on developmental pathways --[tape ends].

--next one. We're just about done.

A comprehensive intervention model flows from this where we work with all the different elements, and next slide? It has a home program, and this is critical. This is where the parents are in charge. We may bring in helpers, volunteers, paid consultants, but the parents have got to be good floortimers, and that's where they work on these six milestones like you see in that first tape.

Next one.

A school program, too. We want to gear towards the same basic goals.

Next slide.

When we implemented this program, we studied 200 children. This is from our clinical records. This is a chart analysis. We found that 58 percent were good to outstanding. They were similar to that teenager you just saw. Twenty-four percent in the median group were related, warm, and active, but had less well developed language, and 17 percent were, again, engaged but still less language.

Next slide.

Then we looked at 20 of the children in depth. We compared them to a typical group of age-matched peers and found no differences on the Vineland and on the Functional Emotional Assessment Scale.

Next slide. Same--I already said that.

Next slide.

We did some short-term studies in the same session and at a year and two years later and found changes in these six milestones, even in the same session like you saw with the first little boy, by coaching the child. And these were changes we'd be proud of if they were intervention changes, but we know they're not intervention changes. They were just coaching parents to bring out the best in the child.

Okay. Next slide. Next slide. Next slide. Next slide. Just to show the same data in different form.

Ten- to 15-year follow-up we did. On the 20 kids who we selected for the more intensive work, we were able to get to 16 of them, and all 16 continued to maintain their progress into their teen years and were very much like that child you saw on the videotape. We were very pleased to see that because most of them had completed their formal intervention. Some of them needed psychotherapy for anxiety or depression. Some of them needed help with tutoring. Some of them were academic superstars and very popular. So a wide range, but they were all social, empathetic, all had good theory of mind, and were all cooking much better than anyone had anticipated and surprised us that a subgroup would do this well. While in our sample it was over 50 percent, that I think has to be discounted because it wasn't representative. But I think we can say there's a subgroup of kids who can do exceedingly well. We need to identify that group and not be surprised by anything that they show us.

Next slide.

Here are just some resources. "The Child with Special Needs" is out there now, describes this developmentally based approach. A new book, "Engaging Autism," will be out this spring. We have training videotapes.

Next slide.

We have also some websites where more information can be obtained, et cetera.

Okay. That's it. All right. I want to thank you all very much for, again, letting me share this with you, and together I think we can make this hope into a reality.

[Applause.]

MR. O'HANLON: Thank you, panel two.

We are going to make a quick transition now to panel three. We appreciate your endurance through these fantastic presentations, and I know it's going to take some time to digest a lot of data. Again, it's going to be on our Brookings website, many of these papers, much of the information, brookings.edu.

I also want to make a one-sentence summary of the way I see things at the moment, which is this has been a fantastic set of presentations about method, and you've gotten a window--those of you who haven't already--into the degree of vigor that remains in this field looking for better methods, but no one should confuse the ongoing debate over optimal methodology with the fact that we have a lot of consensus, that intensive intervention is much better than the alternative, frankly, regardless of which of these methods or combinations of them you choose. And to me that's a very important policy message from which we now proceed into panel three, because we're going to be talking about various ways of making these treatments more accessible and affordable at early stages of life.

I'm just going to say a half-sentence on each of our panelists, and I apologize for not doing them justice.

Eileen Costello is a pediatrician from Boston who's written a fantastic book called "Quirky Kids" and knows a great deal about this spectrum of problems, as well as the specific approach pediatricians needs to be involved in in dealing with this set of questions.

David Mandell is at the University of Pennsylvania, studies a great deal about the nature of the problem in our country of autism spectrum disorders and how they are treated and how that varies from region to region, which method may be most effective, and also which ones are financed in which places and which are not.

Lou Vismara works in California, and he's from the California State Senate. He's a medical doctor, I believe cardiologist by training, but he got into this field and has been working a great deal on these questions. So we have between him and our final panelist, Stuart Spielman, California and Maryland as two case studies because these two individuals know a great deal about these two states.

Stuart Spielman lives in Maryland. He's an attorney. He's been an important drafter of the Combating Autism Act of 2005, works with not only CSAAC but with Cure Autism Now.

And so we're delighted to have all four of you. I'm just going to get out of the way, and we're going to have to be a little bit prompt in our discussions, but we appreciate your patience, and we'll try to be done not too long after 6 o'clock.

I'm looking forward to your thoughts, Eileen.

DR. COSTELLO: Thank you. Hi, everybody. I'm in awe of everybody's ability to sit still this long.

I think one thing that distinguishes pediatricians in practice is that none of us can sit still for very long, which is why we're well suited to our job. I think we all have a certain level of ADD.

Okay. Now I'm going to try to see if I can open this. A lot of what I had planned to say has basically been said before, so--can you help me out here? That's great.

So I'm Eileen Costello. I am a pediatrician in practice in Boston, and together with a friend, an old friend and pediatric colleague, I wrote a book called "Quirky Kids," which is about kids on the autistic spectrum, broadly defined. Perri Klass and I decided to write this book after being in practice for a number of years, seeing patients together on Monday evenings, late into the night sitting down, doing our charts at the end of the night, and realizing that even though we had trained in some of the best pediatric training programs in the country, we were seeing a new population of kids that we knew nothing about, and we were learning from parents about kids with a variety of disorders that we had never heard of before in our pediatric training. And we decided to call them "quirky kids."

And why do we call them "quirky kids"? Because we think it's an affectionate term, because it's not a euphemism for something else, it's not pejorative or judgmental. It's acceptable to many parents. It's also not completely acceptable to all parents, and some people think it's just another way of saying "eccentric," but we don't agree with that. But it includes the fact that there's such a huge range of what these kids can and cannot do that there's no one word that can sort of encompass all of that. It has no prognostic significance. Many of the diagnostic terms themselves have no prognostic significance. We can't tell a parent at a certain age, well, your child has such-and-such a diagnosis and what this means is in six years he'll be able to do this or not be able to do this.

So what are the features that are shared by our quirky kids? Developmental differences, not always delays. Indeed, many of them are delayed, but some of them actually have these remarkable splinter skills. I didn't mention it earlier, but I have a 14-year-old son with a diagnosis of Asperger's syndrome who could tell time using a regular watch when he was three. And, you know, all his pictures from two and a half to three and a half, he has multiple watches going up both of his arms--the analog, the military time, all the different ways.

[Laughter.]

DR. COSTELLO: By the time he was five, he had about 70 clocks in his room because he collected clocks, and he sort of continued with that number theme throughout his life.

But, you know, there were many things he could not do. He could barely speak, but he could tell time. And I remember coming home from work and his saying to me, "You said you'd be at home at 3:00, and it's 20 after 3:00." And I'd think, "What did I do to deserve this in a three-year-old?"

Temperamental extremes that other people referred to earlier. Some of these kids are profoundly difficult to deal with. It's an enormous stress on their parents. So they can be temperamentally extreme both in the sort of overdoing everything department or needing to be, you know, really strongly stimulated in order to get a response out of them. They can be, you know, on either end of that spectrum or anywhere in between.

Dr. Greenspan referred to the sensory defensiveness that we see in a lot of these kids, and that's often something that we see very, very early in life. Since I've gotten interested in this and I see a number of kids on the autistic spectrum in my practice, and many younger siblings of those children--and, of course, my antennae are up and so are those of the parents, and I watch the babies when I put them on the exam table with that crinkly white paper that we pull out for each new patient. And some babies love the feeling of the paper. They can't wait to squeeze it, put it in their mouth. And then, every now and then I see a baby who, the minute they hit the paper, they can't stand the feeling of it, they can't stand the sound of it, they have to be picked up immediately. And that may be a subtle signal that we can see very early, this is a child who's going to have some sensory issues. They're going to be sensitive to sound, to touch, to texture, to lights.

The hallmark of all of this population of kids is their social difficulties, so I think that's been well described today. They have poor theory of mind, and theory of mind refers to the ability to take another person's perspective, to see that we're all in the same room but you're looking in this direction and I'm looking in that direction, and our experience of being here is not exactly the same.

A typically developing child will develop that very early in life, maybe at two, two and a half, or three. Kids who develop typically and have normal language, they'll be able to say, "I know that he thinks this, but I think that," or "It's his turn, not my turn." They can give us evidence that they understand that the world doesn't see everything exactly the way they do. A child on the autistic spectrum may not develop that ability until they're 12 or 13.

So what that means is they spend all of elementary school kind of clueless, not getting it, which makes elementary school so painful for so many kids on the autistic spectrum, and it's a place where some of our interventions can make an enormous difference.

I put this slide up here because I just wanted--I'm not exactly sure who all of you are and, you know, what your knowledge is or why you're in this room. But I just wanted to list this because, in my practice as a pediatrician, you know, parents come in sometimes to see me and they say, "Oh, well, my child has this or this or this." And all of these terms that are on this slide could be applied to the same child depending on who did the evaluation, what the age of the child is when they're evaluated, because all of the specialists who see these kids--most of the kids that I see are not followed by one of the researchers in this room. They're not part of a study. They don't get the best possible evaluation. They get what I can get for them, who I can refer them to, or sometimes they come to see me after they've already been evaluated by any of a huge number of people with varying degrees of skill and expertise in this population of kids.

So sometimes the youngest kids are just told--the parents are told they have severe colic, you know, and the pediatric training is it's colic, the arching, screaming, miserable, hard-to-console, impossible-to-feed baby. Well, you know, as pediatricians, we say 12 weeks it's going to go away. Well, when they're back at four and five and six months and the kid is still arching and still impossible to console, impossible to have fun with, well, it's not colic anymore. It's something else. And sometimes the first thing that they'll be called is sensory integration dysfunction because an OT might do that evaluation. Or depending on the age of the child or the lens of the specialist who evaluates them, they could be given any number, any one of these and sometimes all of them over time. And I have a huge number of kids in my practice who start with one and then morph into another, sort of depending on what aide they're evaluated by early intervention, and then they go and get a school evaluation. Sometimes they're lucky enough to be covered for one of our multidisciplinary clinics where many specialists will see them at the same time, but not every kid in my practice can get that.

So what does this mean for families? Well, everyone gives as a baby present now these "What to expect when you're expecting." I hate those books because quirky kids don't follow the guidelines. You know, there's nothing in those books that applies to this population of kids.

It's enormously stressful for families, and even as I've been sitting here this afternoon, I know this, I live this and breathe this in my life and in my office. I'm watching these thinking, Does anybody realize, like who has 40 hours a week to sit on the floor with their kid? Nobody, right? And who's going to quit their job? I mean, this has enormous implications when you think of the number of kids that we're talking about.

In the families that I take care of, the lucky kids, one of the parents can quit their job, and the vast majority of the time it's the mother. But, you know, these mothers are pediatricians, lawyers, Ph.D.s in various fields. You know, it has incredible implications for our society that these parents are just taking themselves out of the workforce. And those are the lucky ones. And the unlucky ones are the families who don't speak English or who have no insurance, who are working multiple jobs. And I say to them, you know, if one of you could work less, that would be huge for your child. Well, impossible.

What if you have a few other kids? I'm watching this thinking, "Right." You know, a typical family with two or three kids, you want to meet the needs of the child with special needs, but not at the expense of the other kids in the family. And how does the family manage to do all of the things that they're expected to do and follow all of the recommendations that we make for them? Virtually impossible.

So what else? We've heard a lot about the language delays, how that can lead to frustration and behavioral difficulties, school difficulties, occupational difficulties, longer-term dependence on parents than we expect from our kids. And Dr. Greenspan was talking about the sort of higher-functioning end of the spectrum, some of these kids, and I think the sort of stereotype of the Asperger's child is that they're all going to go to MIT and be Bill Gates and start Microsoft and be millionaires, and who cares how weird they are, they can be as weird as they want. And, you know, that's true for a small segment of this population, but it's just too appealing to think that that's where they're all going, because it just isn't true. We wish it were true, but it isn't.

You can be a genius, you can have two Ph.D.s and no job, if you don't have theory of mind, if you don't understand that the rest of the world doesn't see things the way you do. And when Perri and I were writing the book, we had a number of poignant interviews with families who would tell us about the odd relative in the family. One story I remember in particular, the aunt who had gone to law school, was on the law review, was clearly brilliant, and then was just fired from every job she ever had because she got into arguments with people. She could not understand that the whole world didn't see things the way she did.

And what does this mean for our communities? That there are increasing numbers, which I'm going to talk about in a minute, and huge implications for school districts. And this comes up a lot. I was happy to hear that there's a lawyer on this panel because, in many ways, I'm beginning to feel like lawyers are more important than pediatricians in the lives of our kids. We need lawyers. In Boston, I refer to a--we have a legal aid program in our Department of Pediatrics because many of the ills that ail my patients, the only way I can really help them is by calling a lawyer. And we have a family advocacy program of lawyers, and the lawyers work for the Department of Pediatrics, and they sue school districts for special education for our kids. They talk to landlords when the kids are suffering from asthma and their apartments are infested with roaches or mold or whatever. And this is another example of kids with developmental disabilities.

The school districts are overwhelmed with this number of kids, and I don't mean to bad-mouth the school districts. I really don't, because I think they're trying really hard. But it's incredibly expensive to do a good job. Every city in the United States deserves a Help Group, but, unfortunately, every city, including Boston, does not have one. And the schools are all trying so hard to meet the needs of these kids, and it's overwhelming all of them.

This summer, I was in Marin County, the Quirky Kid Capital of the World, and the teachers there were telling me in the elementary school level that they have--you know, in a classroom of 20 or 22, you know, regular education kids, five or six of them might have an IEP, all of whom have an individual aide in the classroom. So it's like a cast of thousands, and the teacher's trying to meet the needs of all the regular ed.

kids and this small group of, you know, quirky kids with their variety of needs all at the same time. And it's an incredible stress on the regular education system. Those kids really deserve to be educated in a system that works for them. And the regular education kids deserve to be in a school where they can learn and they can thrive and they can meet their potential. And it's often there's a time and a place for these kids to be taken into another system like the Help Group and educated there at the expense of someone other than the family, because the expense is enormous.

I think we've talked enough about the prevalence this afternoon. I think a number of you have heard all of this stuff that I'm going to say.

I do want to talk about this question of whether or not there's truly an increase. My personal impression is yes, there's an increase in this population. But it's a very complicated question. There's better assessment and recognition now than there was. There's a shift in the terminology, so if--for example, the Asperger's diagnosis appeared in the DSM-IV in 1994, so, of course, there's more of those kids now than there were 20 years ago because it wasn't even there. So what did those kids--now, I can remember growing up in the '60s in Boston, you know, the special kids, and in my school we used to put them in the basement. You know, now I wonder if they got properly assessed and diagnosed.

Where would they have been? Some of them, obviously, would have been on this spectrum. We know that there's a trend away from diagnosing kids with mental retardation, and I interviewed a number of families who told me--some very savvy parents whose kids were assessed when they were very little. One in particular I remember because his mom was a psychologist. He was assessed when he was four years old. She was told he was mentally retarded. She knew enough to know that this couldn't possibly be true. She did not share it with her school district because she didn't want him tracked in that direction. And, you know, he ended up with a diagnosis of Asperger's. But he's a highly functional, now robust, beautiful teenager with perfect pitch, plays in the school band, is on an IEP, goes to summer camp, is a very functional member of his community, was diagnosed with MR at age four. So that probably--we can attribute some of this increased prevalence to that.

We're also aware of the fact that there's a lot of secondary diagnosis because the apple doesn't fall from the tree. So there are many parents that are now being diagnosed by way of their kids. So what were they called when they were in second grade, right? And there were a number of these stories, and we know it's four times more common in males than it is in females. And there are some people, especially at Yale--I think it's Ami Klin (ph) who wrote a paper and gives a talk called "Is autism an extreme form of the male brain?" And, you know, I would say in my household, since I have three sons and a husband, you know, they're a pretty quirky bunch. And what they talk about when they get together is really not what I think of as sort of fun topic of conversation. It's mostly numbers and sports statistics.

But, anyway, the point I'm trying to make is that we have a number of kids now that in the process of their being evaluated and diagnosed, their parents are being secondarily diagnosed. And almost to a family, every time I asked, "Where do you think this came from in your child?" there was something in the family history that pointed to a genetic etiology or at least a genetic component to where this came from. You know, other neurodevelopmental disabilities, seizure disorders, ADD, depression, other psychiatric illnesses, other things in the family. People did not say, "No idea. There's never been anything like this in my family before."

And there's this other concept in pediatrics called amplification through the generations, and this is something that you hear about with regard to neurodevelopmental disorders in general, that they're amplified, that, you know, each generation is a little bit more extreme than the previous generation. And that probably accounts for some of it.

My favorite theory is the theory that was in Wired Magazine a number of years ago, just before our book came out, where a guy in California, in Silicon Valley, said, you know, 30 years ago these sort of computer geek people, you know, didn't have a way to meet each other--get a job, meet each other, and procreate. But now the computer industry has been created, and they're all in their little cubicles. They're not required to do too much social interaction, but they're meeting each other and they're, you know, quirky parents having quirky babies. There is, you know, a lot of suggestion in the technology belts around our major cities that there's probably some element of truth in that.

Why do pediatricians matter? Why am I here? Because most kids meet their pediatrician before they meet any of the other people in this room. You know, I meet them when they're born, and then I see them when they're a week or two old and, then, you know, over and over again in the first couple of years of life. So a typically developing child comes in my office 11 times within the first two years of life. That's a lot of opportunities to get a look at a baby and a baby's ability to interact.

We are also the gateway to services for kids. So in the vast majority of cases, unless I sign my name on a form saying you need a multidisciplinary evaluation or I want a neuropsych test or, you know, you need an OT eval. or you need to see a psychiatrist for psychopharm, it's not going to happen. And that is the reason why my profession is so important in trying to meet the needs of all of these kids, and as parents told us over and over again, we're not doing a very good job.

I was surprised to hear Dr. Cordero this morning saying how wonderful it is now compared to a few years ago, because that's certainly not my impression or the impression of the parents that I talk to.

Children with disabilities are even more likely to come see the pediatrician. What parents say, a couple of quotes here about parents telling us how terrible we are:

"Throughout Abby's life, every time I talked to my pediatrician, he reassured me everything as fine. When she was two, something set her off, and she started tantruming. She was fearful and overwhelmed. The pediatrician said I should just ignore all this attention-seeking behavior. He told me he thought I was decompensating and referred me and my husband for counseling."

So if I had a nickel for every one of those stories that I've heard like that--I'm going to skip that one because I think you all are pretty familiar with that story, that, you know, we have a tendency--I think all of us, parents and pediatricians alike, want things to be fine. And the concept of the tincture of time that we learn in our training--which is absolutely true for the vast majority of pediatric issues that come through the door. You know, "My sister's child walks but mine doesn't." You know, the kinds of things that we hear every day, unless you're really trained in what to look for, it's absolutely true if you tell someone to come back, you know, for their next regular visit, whatever the worry is is going to be gone.

However, in this case of kids with developmental disabilities, they need to be seen sooner than whatever their next scheduled appointment would be. And if we miss the opportunity to refer these kids, you know, the earlier the better--we know that that's been hammered over and over today--then we've missed the opportunity to help them as much as we can help them early in their lives.

Here are some interesting implications. I have a very varied practice. I work in a neighborhood health center in Boston, in a neighborhood that has, you know, from one end of the spectrum to the other. And so I see this in action in my office. White kids are identified earlier than minority kids. In a Pennsylvania study, white kids with autistic spectrum disorders were diagnosed more than a year earlier than their African American or Latino counterparts. And these diagnostic ages are not early. And so even though we're talking here about how wonderful it is that kids can be diagnosed that early in life, they're often not. And, you know, in reality, in day-to-day practice in pediatrics, they're often not referred to early intervention until they're practically aging out of early intervention. And then there's that three- to five-year--which at least in Massachusetts is a disaster. It is so hard to get a child who's between three and five any services at all because they're too old for early intervention and they're too young for kindergarten, unless they're at the very, very far end of the spectrum, and then they might qualify for services. But I have a number of patients right now that I'm advocating for so strongly that are floundering at home because they were graduated from early intervention. Zero. They went from everything to nothing overnight, and they're not given a public school program because they're not bad enough, because they can talk. It's incredibly frustrating as a pediatrician.

I think we've covered this, too. I had a mom in my office this week who's a very highly educated mother who has a baby with a hearing impairment, picked up on a newborn screen, and she said, "I think every first-time parent should be referred to early intervention. I'm having a wonderful time." And, you know, her child's only deficit is really his hearing, and he's a beautiful baby, but she feels--and she's an educated, with-in parent with resources--that this has been incredibly beneficial for her as a mother and that all families should be referred to early intervention. But the outcomes we know are tremendous for early intervention. Kids do better if they get early intervention.

I think we've covered (?) . So why is it such a problem for pediatricians? Well, the nature of pediatric practice has changed, even in the years since I graduated from my training about 15 years ago. When I was in my training, I was trained to take care of kids with overwhelming infections. That's what most pediatric residents do. We're the indentured slaves of the medical centers. We take care of kids with meningitis and, you know, kids with horrible metabolic diseases. We're not doing what we're going to do when we graduate, that's for sure.

Since I graduated, many of the diseases that I spent all of my residency years training for are not there anymore because we immunize against them. So, for example, H flu type B, one of the most common infections 15 years ago, we never, ever, ever see.

So what does that mean? Parents are coming into our office with a totally different range of concerns, much more development, how they're doing socially in their friendships, how they're doing in school, academics, their learning, their attention. This is what pediatric practice is now, much more than, you know, is this meningitis, is this sepsis--the kinds of things that we spent all of our training worrying about. And parents come in with these concerns now about their child's development much more now than they did 20 years ago or 40 years ago.

I think we know that pediatricians aren't doing as good a job as they could. On the other hand, if parents are not worried, that doesn't mean their child's development is normal. And I can tell you the flip side of the coin also, which is that as a pediatrician, it's not uncommon for me to be worried about something and have the parents put on the brakes. And so I think there is a trajectory that parents go through. And I remember this from my own life of sort of my realizing something's cooking here, something is awry, something is not quite right, and being able to go through that process, which is different for different families. I mean, some people can cope with it, and they get on that wagon and they run to intensive ABA 40 hours a week, and some people don't. There are cultural differences, there are race and ethnic differences. I have a lot of Irish immigrant patients in my practice, and because that's my heritage, I recognize the Irish male phenomenon of "Not my kid." You know, "You're not referring him to any psychologist or psychiatrist. You're not putting him on any medicine." And, you know, that is a challenge for pediatricians in practice. So it can definitely work both ways.

What are the associated concerns? Well, as has been mentioned many times, one of the great satisfactions of being a pediatrician is all of the strep throats and ear infections that we see. So if a child has strep, there's a very clear thing that you're supposed to do. You write a prescription, penicillin VK, three times a day for 10 days. There's excellent evidence that you do that the kid's going to get better and you feel like a hero.

There's no script for a kid with an autistic spectrum disorder. There's no easy thing, and I think that's been promoted over and over the course of the day. We know some things that work. We know there's good evidence. We know that not all kids can get the stuff that there's evidence to promote because of, you know, the usual issues: insurance, poverty, sometimes they're hungry, sometimes they're cold. There are more sort of pressing issues in the minds of the family than getting their kid the best services that they can get.

Third-party payers are very reluctant to pay for these things. You know, I go through hoops. I call my friends that are developmental and behavioral pediatricians and say, you know, "I want this kid to get this service. What code do you think I should use?" And, you know, it's sort of sneaky and you feel like you're breaking the law, and we probably are. But, you know, when you're in an office with a child and you know he needs a certain service, you're going to do whatever you can within reason to get that service for that child. But it shouldn't have to be that way.

I put the immunization debacle on here because there's a ton of information out there and misinformation and scary things that parents, you know, have--they're just not educated enough or they're not knowledgeable enough. We aren't knowledgeable enough to know what's real and what isn't real. But this is a big concern on the part of pediatricians, and it's taking up an increasing amount of our time in practice because parents are so frightened by the possibility that we have caused autism in their kids by giving them immunizations. I have a large number of parents in my practice now who are refusing to immunize their kids, and that in and of itself has huge public health implications because now we're starting to see the diseases that we know we can immunize against and our kids don't have to be subjected to, and this is based on no data that really supports--the things that come up the most are the Andrew Wakefield body of literature that--he was an Englishman who published something in Lancet a few years ago saying there's an association between the measles, mumps, and rubella vaccine and autism. And then a bunch of people decided, oh, my God, the doctors are causing autism in our kids, let's stop giving measles vaccine. And I think if you've never seen measles and you don't know what a rotten disease it is, it's a lot easier for you to say, "I'm not giving my kid that shot." But if you have seen measles and you know how dangerous it is, it's extremely worrisome as a pediatrician that people are choosing not to immunize their kids. And the small data that I know is showing that the kids who are unimmunized are having exactly the same rates as the immunized kids. And I have a number of younger siblings in my practice of affected kids whose parents are saying, "I don't want this. I'm afraid that this might be a cause," and their rates are the same, the same recurrence rates in the younger siblings as we see without it.

Also, this whole sort of fear mentality has given rise to a bunch of alternative therapies. We only know a little bit about what therapies really do work, and we don't know anything about all of the alternative therapies. But I have parents who have got their kids on, you know, these very labor-intensive diets, on vitamins that they believe are, you know, detoxifying their baby's systems, and they're frightening. And, you know, some of these kids aren't growing because they're on diets with so little protein. So there's a lot going on out there that we need to get a handle on, and what we want to do is fund what we know works.

This was talked about earlier today, obstacles to screening. I want to make sure.

All right. Let me just close by saying, So what happens to quirky kids as they grow up? It's very difficult to prognosticate, as we know, and I think we've learned that today. There's an enormous range. One thing we do know is that as adults, we are infinitely more tolerant of the quirky people around us than kids are. We have this problem in America which is all of our children as supposed to be Renaissance men. They're all supposed to do well in school in all their subjects--English, math, social studies, and science. They're supposed to be on the travel soccer team and play a musical instrument. That's sort of our model of the perfect child.

We're starting to get all those letters from our college friends about their overachieving children. You know, you get them at Christmas. And they're so annoying. But, you know, I think that that's the model in America, and that once our kids grow up, just think about, you know, in medicine, medicine is filled with quirky people, you know, with poor social skills, terrible handwriting, unusual special interests, but valuable and functional members of society. And so I think what we need to do is help our kids grow up to be the best that they can be and to contribute and make our world a richer place.

Thank you.

[Applause.]

DR. MANDELL: Thank you, Dr. Costello. When you were talking about, you know, you're the first person that so many of these kids see, all the people--I'm the last person they see. If you're on the front line, I'm on the back line. I have the sort of 10,000-foot view. Most of what I do is look at policies and services and practices and how they affect the care our children with autism get.

I'm trained as an epidemiologist, which means--well, I guess I'm qualified to lead very large groups, but other than that, most of what I do is related to the organization, financing, and delivery of care to children with autism.

If we think about the treatments that were described today, they're all extraordinarily intensive and time-consuming and expensive and very different than the traditional educational or behavioral interventions or pharmacological interventions that we tend to provide to children with psychiatric and developmental disorders. And so it's a new paradigm for thinking about children with these disorders and how we care for them, and I'm going to argue a little bit that part of this is because--until things change at the federal level, it's not going to filter down to states and localities and practices so that these treatments can be delivered in a meaningful way.

There certainly are federal initiatives that are ongoing related to treatment provisions for children with autism. Certainly the awareness campaigns that are going on and funded through the CDC are--I mean, their fundamental goal is not to identify children as much as it is to decrease the age at which treatment initiation occurs. NIH within the last seven years has quintupled its research budget for autism, and a lot of that is earmarked not only for etiology research but also for research focused on treatment. And certainly the Interagency Autism Coordinating Council, as its mission states, "to facilitate exchange of information about autism activities, programs, policies, and research, has done a really good job of bringing together representatives from different constituencies that normally don't talk with each other to think about how we can better care for children with autism, and their research matrix, very ambitious and admittedly so by NIMH, the lead agency, is still, you know, a product of those interactions.

As part of the Interagency Coordinating Council, there was also a services subcommittee that is thinking about how we should organize, finance, and deliver care for children with autism. The goal of this subcommittee was to develop a national plan for autism services, development, and deliver, and as part of that, they created an expert working group--Stuart and I were both part of that group; it was a wonderful group of people--that developed what they called the Autism--or what we call the Autism Spectrum Disorders Services Road Map, which is available through the NIMH website, and was our attempt, in admittedly very general terms, to try and think about what the organization of that care should be, what it is now, and how we can improve it.

So those are some federal efforts that are going on, but I want to mention one thing about that report. There were about 50 challenges to the efficient and effective delivery of care to children with autism that were identified in that report. I'd like to focus on five that I think are particularly important; that we don't have professionals who are trained to deliver these interventions that we've been discussing; that we have no consistent funding mechanism for treatment, that it varies tremendously by locality, and no established standard of care--Dr. Lord's edited tome published by the National Academy is a wonderful description of what could be a standard of care, but it certainly hasn't been implemented in any meaningful way in any place that I know of--that because of the way our system is designed, we have multiple agencies that are responsible for the care of children with autism, and those agencies don't coordinate that care very well across each other; and that leads to extraordinary variation in how care is organized, financed, and delivered across localities, certainly across states, which is the unit of analysis I've studied the most, but even within states you see dramatic differences depending on the urbanicity of the area of the state, of whether there's a tertiary medical center nearby, and on the strength of the local school board.

So what I want to talk about, aside from these federal initiatives, is what's happening now for children with autism, what's the de facto system of care for these kids, and I'll argue, in some places probably more successfully than others, that it's really changes at the federal level in part that have to occur to improve the system of care.

Probably the most important system that cares for children with autism in the United States is the public education system. As most of you know, the Individuals with Disabilities Education Act, which was passed in 1976, mandated that all children, regardless of their functioning, are entitled to a free and appropriate public education. In 1990, autism was made a category within that act, and so children with autism are specifically identified as being entitled to a free and appropriate education.

In the 2002-03 school year, which is the last year for which I have data, 163,000 children were in the autism category. This is considerably less than the estimated prevalence but other than families makes this the largest part of the system of care. It should be noted, though, that the year before--that was a 19-percent increase from the year before in the number of children served, and that number continues to increase. And we also note from studies in Atlanta and one that we're completing in Philadelphia that there are many children who would meet a research diagnosis of autism who are receiving special education services but aren't in the autism category. And if you extrapolate those numbers nationally, that's probably 30,000 children, and that may be a conservative estimate.

Now, the school system is responsible for providing a free and appropriate education, but the Supreme Court has stated that that does not mean optimal. That means that the bare requirements must be met so that education can--you know, those educational goals can be attained. But the education system--and California as in many ways is another universe in this respect, and so I look forward to hearing Dr. Vismara talk. But other than California, most states have said that the education system is not responsible for addressing the core symptoms of autism or for providing treatment per se, even though we often try to shoehorn what we think of as treatment in through the education system.

So to my mind--and this is sort of an understudied area, but the second most important player in the provision of care to children with autism is the Medicaid system. I think it's the second--it's sort of the second largest number of children with autism, but because they also cover things like residential and inpatient care, as well as some of these very intensive treatments, it's possible that they may be the largest payer for care.

In 2001, which is the latest year for which I can get the Center for Medicaid Services to give me any information, there were 45,000 children served who had an autism diagnosis, and they can qualify through a lot of different ways. States are mandated to provide--to use Medicaid to provide any medically necessary services to children in special education, even if that service isn't covered through their state Medicaid plan, and the early prevention, screening, detection, and treatment program is how they usually do that. So it often supplements special education. It's often used to provide what's sometimes called colloquially wrap-around in the behavioral health system, which is one of the ways that some of these intensive interventions are provided.

Three states--Wisconsin, Indiana, and Maryland--have decided to use the waiver mechanism, which allows them to provide services to children with autism that are not traditionally included in their state plans, but that they say are required in order to prevent those children from being institutionalized, which is another mechanism that states sometimes use. In some states, by some definitions, children with autism can qualify for Supplemental Security Income, and that changes dramatically. So when the Feds change their definition for SSI, as they did in 1998, 30,000 to 50,000 children were automatically disenrolled. Most of those children were identified as having mental retardation or a mental illness, and it is quite likely that there are a number of children with autism in that number.

And then, of course, for families that meet the income requirements for Medicaid, either through Temporary Assistance to Needy Families or the state insurance programs or because they've spent down so much of their income that they now qualify for Medicaid, they can also access Medicaid-reimbursed services.

Now, most of this autism care is provided through the behavioral health system in most states, and the children's behavioral health system is used to caring for kids with attention deficit disorder and anxiety disorder and maybe depression, rarely anything we think of as a chronic condition. So they're designed to provide acute care for a limited time, so what I'm trying to point out with these two major systems is that the way we conceptualize ideal treatment for children with autism is in some ways fundamentally outside the mission of these two systems that probably pay for the overwhelming majority of care for children with autism.

There are certainly other important systems and players in the care for children with autism at the federal and local levels. Private insurance, I put that up there as a straw man, I guess. There's some recent evidence that suggests that most private insurers provide no or minimal benefits for children with autism. I just came from the American Public Health Association meeting where I was on a panel about autism costs, and someone had a large database of 45 large self-insured companies, and the average expenditures for children with autism--and this includes kids who are inpatient psychiatric hospitalization--was $3,000 a year.

Now, Stuart was telling me that for the Maryland Medicaid waiver, they have an average of $12,500 per kid per year, and I know from the Medicaid data I've looked at from various parts of the country, the average Medicaid expenditure in various states is usually between $20,000 and $30,000 a year for children, including the supplemental services that are provided through the school system. So, clearly, there's obviously incentive--and clearly it's going on--that private insurers are reducing the services that we're providing to children with autism.

The mental retardation system is a very important system. Obviously, the evidence is changing, but we know that many children with autism have co-occurring mental retardation. And until recently, it probably behooved parents to get their kids a diagnosis of mental retardation rather than autism, because at least the mental retardation system in most states, while relatively parochial or paternalistic in its approach, offers some kind of lifelong care for children. But the basic expectation is that care is going to be based on cognitive ability, and there's little expectation of improvement as a function of treatment, which we don't think is the case with many children with autism.

There's anecdotal evidence that the child welfare system and the juvenile justice systems are involved either because of a parent terminating parental rights in order to get care for their kid or kids ending up in the juvenile justice system because of their failure to understand social norms, especially in the presence of a police officer. I don't know of any substantial systematic research addressing those issues, but probably more important than those systems is primary care. And I'm glad that you spoke first and talked so eloquently about the role of primary care.

The American Academy of Pediatrics has been very forward thinking in coming out with technical guidelines for pediatricians on the identification and care of children with autism, and because there are so many systems involved and because the AAP has identified the idea of a medical home as a critical issue for pediatricians, this may be the hub of that wheel of multiple agencies--it isn't now, but it could be, as a place where while the pediatrician is not providing necessarily some of the direct care we're talking about, that care can be coordinated across systems.

So as a result of this responsibility for care being split across systems and with systems in some ways passing the buck or trying to keep their buck and pass the kid to different systems, children require multiple plans, each addressing a separate aspect of treatment need, which creates many inefficiencies. So, for example, in many states, if you have an IEP--individualized education plan--and you have a behavioral plan through Medicaid, you're required two different sets of assessments. You're required two different teams led by two different individuals. It's a lot of money that's being spent, and probably the level of care is less efficient because you're trying to coordinate it across these two groups.

It also means that states have difficulty developing standards of care, although some states have been much more successful than others. And, again, I point to California and to the three waiver states. But you can't combine funds among agencies, and each of those agencies has separate missions. So if I wanted to create a pilot, say--which I do--where I took special education funds and Medicaid funds and pooled them and tried to think about some joint effort for kids with autism, that would be very challenging for a researcher or for a state government to try to do. And you have to sort of--a part of that is working within the specific mandate of each system, and one parent of a 15-year-old with autism that

I work with a lot, actually co-chaired the Pennsylvania Autism Task Force with me, talks about shoe tying. Is shoe tying something that your educational team should address or is it something that your behavioral treatment plan should address? And there's sort of this very gray area about what should be done within what system.

MS. : Velcro.

DR. MANDELL: I'm sorry.

MS. : Velcro.

DR. MANDELL: Velcro apparently--yes, Velcro is often brought up as the solution.

[Laughter.]

DR. MANDELL: Yes, because then it's just an impairment and not a disability, right. And the Wisconsin waiver, as an example, Wisconsin had made applied behavior analysis part of their Medicaid state plan. So they said that they were going to offer habilitative services, and the Center for Medicaid Services said we don't pay for habilitative services, so you can't offer ABA through--you can't pay for it through Medicaid. It's an educational activity, and you have to pay for it through special education dollars, which costs the state a lot more because Congress has never appropriated all the money they said they would appropriate for the Individuals with Disabilities Education Act. So now Wisconsin has had to rethink how it provides services to children with autism, and with that lack of clarity around how these services are going to be funded, there's little incentive for a provider to develop quality services.

If I were a quality provider of ABA, I would move to Seattle because Microsoft has said that it will pay for three years of ABA to children of employees with autism--well, the kid has the autism, not the employee, although as you pointed out, both might be the case.

But I note--and it's going to be three years, and they have a certain standard of care that you have to meet, and you have to be trained at the University of Washington. But I haven't seen anything other than anecdotal evidence, but the number of providers of this care is growing dramatically. Stuart will talk a little bit about what's happening in Maryland with the waiver and providers, but in most states that's not the case. And so why would I hire these people at extra cost with extra expertise when the reimbursement rate is going to be the same. And without these decision rules about how this care is going to be delivered and how it's going to be paid for, these things are decided on a case-by-case basis, which means that parents get what they negotiated, not necessarily what they need.

I know that in Pennsylvania we just completed a survey of 1,000 caregivers; 19 percent said they engaged in a legal hearing with either the education system or the Medicaid system; 17 percent had moved to get better services for their kids.

Now, I live in the middle of Philadelphia, and I watch families regularly leave the city to go to a better school district, so I don't know what the comparison group is. But certainly that seems like--you know, and it's almost one out of five families that's moving to get better care. That seems pretty high.

Certainly even if they get what they negotiated, that is, if they get 30 hours of ABA approved for their kid, they can't find a provider to deliver it, and there are fascinating stories of parents becoming experts in ABA and then teaching people with associate degrees who work for one of the providers in the behavioral health system to deliver that ABA. It also means that parents become case managers.

Now, we are all case managers for our kids and all their multiple activities that you are describing and I hope mine choose not to engage in, but it means learning complex sets of regulations, and unless you're a lawyer like Stuart, that can be very challenging. It also means that as these evaluations occur and in the behavioral health system where we expect the kid is going to improve, parents often get punished for improvement. Your kid is doing better, great, you don't need the services anymore. And that means that treatment is delayed and interrupted, even if the diagnosis is made in a timely way. And it also means that families accrue considerable costs, both opportunity costs as you discussed and, Michael, as you discussed, the actual costs of implementing these programs, because how could you not do that for your kid if you can afford it?

There was an interesting study done in 1994 looking at out-of-pocket expenses for adolescents and adults with developmental disabilities, and if you look at out-of-pocket expenses for children with mental retardation, they are flat across family income. Wealth families spend as much out-of-pocket as poor families, or vice versa, but not for autism. There's a dramatic linear relationship between how much money you make and how much money you spend for your kid with autism. And I think it speaks to the lack of an appropriate system of care for children with autism.

Now, the variation in care across localities and states was discussed as a problem in the services report, and it certainly is. It becomes very challenging for families, although there are issues of market forces and whether this is not necessarily a bad thing. But from a research perspective, I think it's a wonderful thing. We don't know what the best mechanisms are for organizing, financing, and delivering care. We have a huge national natural experiment going on, both across states and within states. And we have the opportunity to identify best practices by looking at how these states are doing in caring for kids with autism and what their outcomes are, and then using mechanisms like the IACC and federal agencies to create a standard of care, as we have for other conditions for children, and thinking about creating incentives for states and school districts to implement those.

So that was the overview of federal policy in 12 minutes, a poem, and I thank you for your attention.

[Applause.]

DR. VISMARA: Hi. I'm Lou Vismara. I'm a parent of four children, three daughters ages 25, 23, 22, and a 13-year-old son who has pretty profound autism. He was diagnosed at an early age, has received a lot of interventions, is currently enrolled at the Help Group School and is making some encouraging signs.

Now, we've heard a lot about the challenges of autism, but I can tell you, among my wife, my three daughters, and my son, Mark is the only person who even listens to what I say, even vaguely acknowledges what I say--

[Laughter.]

DR. VISMARA: --and certainly responds to anything that I've said for God knows how long.

Before getting to my prepared remarks, which I will read very, very quickly--and they and the PowerPoint will be posted on the website--I want to tell you, as I was preparing to come up here, I'm really reminded that this conference is a lot like the recent George Clooney movie on Edward R. Murrow. It's incredibly compelling, it's extremely well done, and Edward R. Murrow closed his broadcast with "Good night, and good luck," which I think are also appropriate to this conference.

Do I have the clicker up here to advance the...perfect. Thank you so much. Okay. Here are my prepared remarks:

On behalf of the parents of autistic children, I would like to express my deepest gratitude to Dr. O'Hanlon, Dr. Firestone, and to the other sponsors of this landmark meeting. This conference not only brings much needed hope to our families, but your visionary leadership strengthens our resolve.

In preparing my remarks, I was reminded of two memorable quotes that have provided personal inspiration. Indeed, Margaret Mead may have been thinking of autism advocates when she stated that, "Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has."

Also, a Japanese proverb cautions that, "A vision without action is merely a dream, while action without vision is a nightmare."

In California, we've attempted to follow both these important messages. Therefore, I hope that this cursory review of our experiences may be helpful as we seek to establish an effective national policy on autism.

As a form of introduction, I'm an Italian immigrant that grew up in a very diverse San Diego neighborhood. I've been privileged with an excellent education. Subsequently, I not only trained with such medical pioneers as Drs. Michael DeBakey and Cooley, but also for many years practiced and taught interventional cardiology. Nevertheless, I was totally unprepared for the challenges that our family faced after our son, Mark, was diagnosed with autism. Actually, this is not the right slide, but...oh, there's our son. Okay--after our son, Mark, was diagnosed with autism.

Six years ago, I left my medical practice to spend one year working as the co-founder of the MIND Institute. Subsequently, I have been employed as a full-time policy consultant at the California State Senate. My comments today are strictly personal and not on behalf of any state entity.

Before discussing our legislative policy, I'd like to briefly review my experience as a member of our State First Five California Commission. Spearheaded by actor and producer Rob Reiner, the prop. tobacco tax initiative has distributed over $3 billion on programs to improve early childhood development. Although Prop. 10 was initially focused on typically developing children, more recently programs related to autism and other disabilities have received increasing attention and funding. This was accomplished not only by personalizing these challenges, but we have consistently labeled autism as the canary in the coal mine. Thus, we have convinced our colleagues as well as the funding sources that those systems and services that are responsive to autism will also serve the needs of all.

California has been blessed with a long-standing tradition of supporting autism and other disabilities. For example, in 1974, our state assumed the responsibility for the education of autistic students. This legislation, S.B. 3854, was specifically the work of a young staffer named Barbara Boxer.

Regrettably, more than three decades later, California is still struggling to meet the educational needs of more than 22,000 autistic students that are currently enrolled in our special ed. K-12 education.

Other important legislation includes A.B. 430 that has standardized the assessment procedures for individuals with autism spectrum disorders. Another bill that is pending, S.B. 749, would require that private insurance plans also provide coverage for and to abide by similar guidelines. Last year, the Pavley legislation prohibited the administration of mercury-containing vaccines to either pregnant women or young children.

However, the cornerstone of our autism policy is undoubtedly the Landerman Act. This bill, enacted in 1969, mandated that the state would have a lifetime responsibility for the developmentally disabled.

This act also established a Regional Center system that would ensure a full measure of dignity, privacy, humane care, and education. Each of the 21 Regional Centers is a private, nonprofit corporation that must contract with the State Department of Developmental Disabilities, or DDS. The Regional Center system is extremely complex and often entails intricate state, local, and private partnerships. The system is often controversial, and some advocates suggest that there are inadequate incentives, oversights, and expertise to provide the mandated services.

Additional allegations include that consumers and families must go through the laborious process of receiving denials from multiple other agencies before receiving these services. In addition, inconsistencies among state entities, which number over 4,000, can lead to confusion as to which agency is responsible for providing the needed services.

Our budget deficit in California poses additional problems. DDS spending, which has more than doubled in the past five years, last year exceeded $3.7 billion. These expenditures have significantly outstripped demographic indicators. During the past decade, while the state's population has increased by 15 percent, DDS caseload expanded by 66 percent. Concurrently, the overall costs for services rose by a whopping 239 percent.

Autism is at the heart of this fiscal crisis. From 1987 to 2002, the incidence of autism increased by 634 percent. The cost for autism services is far, far greater than for other disabilities.

These costs also increase dramatically for older clients. For example, last year, DDS annual spending for autistic children averaged about $8,000 as compared to $5,800 for other disabilities. The average cost for autistic adults is almost double that for other disabilities and, depending on the age, ranges from $29,600 to $35,600 per year per client --[tape ends].

--out-of-pocket payments. Presently, in California, fully 84 percent of the Regional Center autism population is younger than 21 years. The future implications of the aging out of our autistic young population overwhelms the imagination.

The autism epidemic served as the catalyst for the creation of the MIND Institute. In 1997, we secured the support of a few donors and key legislators. Our message was succinct and focused on establishing a multidisciplinary center committed to the research, understanding, and treatment of neurodevelopmental disorders. Within a short period of time, the MIND Institute has become an established leader in autism science and research. To date, the MIND Institute has received over $54.5 million in state funding and an additional $20 million from the UC Health

System. The MIND presently receives almost $6 million annually in continued state support.

The MIND occupies a two-building, 100,000-square-foot facility that provides state-of-the-art resources for basic science, clinical and translational research. In compliance with the wishes of the founding parents, the MIND is committed to promoting and providing collaboration among autism research. As a parent, I'm thrilled by the promise and hope of the science being conducted at the MIND.

This slide, again, basically--which we'll post on the Internet--reviews the various types of science and research that's being conducted.

Today's schedule allows for only a few brief highlights. For example, the MIND's Autism Phenome Project is an unprecedented effort to comprehensively characterize and, therefore, better understand and treat the various manifestations or phenotypes of autism. This longitudinal study of over 1,800 children will include multiple biologic samples, including genetic, neuropathological, and immunological analysis. By combining molecular, biomedical, and neuropsychological approaches with sophisticated bioinformatics, researchers will seek to identify potential causes as well as varying manifestations of autism. The Phenome Project is not only crucial to the understanding of autism, but may also lead to identifying prevention and maximally effective treatment. And this project is currently underway, it's beyond the planning stages, and it is engaging in active research and has enrolled a number of subjects. And I was delighted to hear that this is an important project both to CAN as well as to the NIH.

The Childhood Autism Risks from Genetics and Environment, or CHARGE, study is another important endeavor. Involving nine senior investigators and funded by both the National Institutes of Environmental Health Sciences and the U.S. EPA, the CHARGE study is seeking to discover if environmental factors are triggering the onset of autism. I'm also hopeful that California will provide additional complementary resources to combat autism. Recent legislation that was sponsored by the Help Group has created a blue ribbon commission on autism. Next month, this commission will undertake a two-year analysis to provide the governor and the legislature with specific recommendations as to how existing gaps in autism services can be identified and can also be closed.

Today's conference represents an important step in engaging our national government. However, in order to achieve an effective national policy on autism, I am convinced that we should focus on strategies that are positive, that are expansive, and that seek to provide solutions to societal challenges. Further, our advocacy must be based on reasonable assumptions and supported by scholarly and comprehensive analysis. The Autism and Hope conference represents a pivotal and crucial step in these endeavors. Let me again express my deepest gratitude to the sponsors and participants. Today you've provided a beacon of hope to parents everywhere.

Thank you very much.

[Applause.]

MR. SPIELMAN: I don't have a PowerPoint. I want to thank Mike and Barbara for having me here, and, Eileen, I'm sorry to say I'm a tax lawyer. I'm not going to help you.

What I'd like to speak about today are some political efforts to provide services to persons with autism and, as other speakers have indicated, this has been a neglected area. We just scratched the surface on research. We're even further away from providing comprehensive services to individuals with autism.

I did a search on the Thomas website, which is a website that has all of the legislation since 1989, and I searched for bills containing the word "autism" that were enacted since 1989, and I came up with nine bills. Most of those bills are bills that mention autism. There are some that are significant, such as IDEA, some iterations of IDEA, but IDEA, of course, is not an autism-specific bill. And then there is the Children's Health Act of 2000, which had a significant autism component, but it was a research component only. There has not been an autism-specific piece of service legislation.

There are, however, some promising federal efforts underway. There are two pieces of legislation that I'll mention briefly. One is the TEACH Act of 2005, which will enhance autism services, educational services, and also provide for loan forgiveness for teachers of kids with autism. And then there's my personal favorite, which is the Combating Autism Act of 2005. And we've spoken about the Combating Autism Act before, but I think there's something important to emphasize in this act in that this is not Son of the Children's Health Act of 2000. This actually goes beyond the Children's Health Act in that it has a very significant services component.

The services component authorizes the expenditure over five years of $100 million per year, a $500 million authorization for services, for identification, diagnosis, and intervention systems for persons with autism, and also for medical interventions for persons with autism. And one of the purposes of the legislation is to ensure that all children are screened for autism before their second birthday, which is a very ambitious goal, but it's one that the legislation puts into words and print, and I think this is going to be quite a sea change. If this is enacted in its present form, it will, I think, dramatically affect the rate at which children are identified.

Now, I also want to point out the efforts of the IACC, and Tom Insel is here from the National Institute of Mental Health, and Tom chairs the IACC, and he's done a wonderful job of making the IACC into a community autism forum, which is something that has been sorely lacking. What we have with autism services is the same players appearing again and again. We have Department of Health and Human Services, and the IACC is under the Department of Health and Human Services. We have the Department of Education. And then we have the agencies that are mentioned but don't show up.

Persons with autism hold jobs, persons with autism live in housing, persons with autism run into trouble with the law sometimes, and yet we really don't often see them in a service context. And I hope the day will come when we will have a broad federal collaboration so that we can not just talk about the research and not just talk about the health care needs but the broader needs of persons with autism.

The road map has already been mentioned. We've talked about various things on the road map, David did. One of the things I want to specifically mention is financing mechanisms. It's interesting to me as a tax lawyer that we have these 529 plans, which probably many of you have invested in for your kids, and, of course, our college-bound kids probably are going to succeed despite our best efforts to sabotage them. That can't be said of our kids with autism. There is no comparable legislation for kids with autism. There's no money that you can put aside on a tax-advantaged basis for kids with autism. I hope that's going to be redressed at some point.

Now I want to shift from the Federal Government, which has made efforts and is making efforts to address autism, to the states, which have been the traditional service delivery vehicle. And I want to specifically focus on Maryland since I'm most familiar with Maryland since I live in Maryland. I want to mention two pieces of legislation that I think are interesting and innovative, and one piece of legislation is the pilot program to improve screening practices, study and improve the screening practices for autism spectrum disorders.

I see Sue Cohen in the back, who is the delegate who sponsored that--thank you very much, Sue--and this is very interesting legislation because it is the only legislation that I'm aware of that is attempting to train providers, pediatricians, throughout the State of Maryland in screening practices for autism. The legislation that Lou mentioned in California--A.B. 430, I believe it was--set a high standard for screening practices in the developmental disability centers, but this legislation in Maryland, which has a three-year life span and began in 2005, this legislation will train providers in two jurisdictions, will select 30 pediatricians or more, and study their screening practices, give them the best tools, and then retest them and see how things have changed. And in order to reach the kids, of course, we've got to reach them where the kids go, and before the kids get to specialized centers, they're seeing people like Eileen. And if pediatricians are not recognizing autism, if they're waiting, then there is a public health issue that needs to be addressed.

Now, it is getting late, and I'm going to be merciful, and I'm going to skip a lot of my presentation. I made all too many points, my wife reminding me that it's about one page per PowerPoint slide, and I have all too many pages. So I'm going to just go into the waiver, which is one of Maryland's innovations. As David mentioned, we're one of three states to have a Medicaid waiver for children with autism, and I think we have an outstanding program for kids with autism. The program serves 900 children, approximately, but, unfortunately, there are about 1,400 kids in the registry waiting for services. Our school population, that is, the population that's been identified through special education census, is 4,659. I remembered the figure. So we are reaching through the autism waiver program a significant number of the kids who have autism and require services.

The Medicaid waiver is a 1915(c) waiver. It is a waiver that is intended as an institutional alternative. The kids who qualify for service under this waiver require a high level of care. And the waiver services are rather broad. One of the waiver services is intensive individual support services. This is one-on-one, after-school services.

This is in addition to what the kids receive in the school system. It provides up to 30 hours a week of one-on-one intensive care services.

Therapeutic integration is also provided. This is after-school services, expressive services, and expressive therapy services such as art therapy. One of the issues with kids with autism that we haven't discussed today is their need for recreation and to participate in the same sort of social, cultural activities that everybody else in the community participates in, because if we want these kids to be typical, as typical as possible, we have to give them those skills as well as the other skills that we want to give them.

Another service that's provided under the autism waiver is supportive employment. Residential habilitation is provided for kids who need a temporary absence from their homes. Environmental accessibility adaptations, which is an interesting service, the state will provide up to $1,500 over a three-year period to make homes safe for children with autism. I'm not aware of another program like this. Respite care, up to 168 hours a week, that translates into seven days, seven full days of respite care. Family training and service coordination.

Now, one of the things that I find very interesting is that when the waivers started in 2001, we had two service providers who were listed as service providers on the autism waiver. Now, as the years have gone by, we've gone up to 85 service providers in 2005. Now, some of those service providers were existing service providers that decided to sign up for the autism waiver. But a number of those services providers were entirely new entrants into the field. So the autism waiver in Maryland has become a mechanism to create services providers, to create an availability of services that were previously not available in the community. And these services are obviously available to kids on the autism waiver, but they are also more generally available. We're creating capacity. And not only are we creating capacity in numbers, additional agencies, additional individuals who are providing services, we're creating depth of capacity.

A number of the service providers initially were providing services to 20, 30, 35 people, and now what we're seeing in the Medicaid waiver is that they're providing services to 50 percent or 60 people or 70 people. So the autism waiver has become a significant force in enhancing service provision for kids in Maryland.

I want to talk about a couple of problems with the autism waiver that we've experienced, and one problem that we've experienced has been a provision in the law, 1915(c)(5)(C), and this is a provision--this is in the Social Security Act--that habilitation services--and these are the sort of services that we're talking about in the autism waiver. Habilitation services does not include special education and related services which otherwise are available to the individual through a local educational agency.

When the waiver in Maryland first went into effect in 2001, on our first three-year cycle, the school systems were able to get reimbursement for some of the specialized autism services that they were providing. But when the waiver term expired, CMS, the Centers for Medicare & Medicaid Services, informed us that they would not allow us to get that in the future. So since IDEA is funded at, I think, about 18 percent and the rate for the federal contribution for Medicaid is much more significant, this meant that the State was out-of-pocket a great deal more.

So this is one of the areas that concerns me, and this is where being a lawyer actually probably helped. And I'm struck by how so many of the services that are provided to kids with autism are in this nether definitional world between education and health. You know, the example you used about tying your shoe, if my autistic son doesn't know how to cross the street, is he being educated to cross the street, or is he being provided health care service in order to save him?

I know that smoking cessation classes are covered under many insurance policies. I know as a tax lawyer that that's a deductible medical expense. So how is it that teaching my child not to get killed when he crosses the street is an educational expense? I find this to be rather puzzling.

Just in concluding, I think that this is a wonderful topic you've picked, Autism and Hope, and I think that there's a lot that can be done on an advocacy level. There are changes that can be brought about in the laws at the state level and at the federal level and at the community level, and it takes the effort of meeting with people and explaining the situation.

We have a very compelling story to tell as parents and providers of services to persons with autism, and I think that as the story is heard more and more, we are going to get better results for our children.

Thank you.

[Applause.]

MR. O'HANLON: Thank you, everyone, for staying late. Stay tuned for further efforts at thehelpgroup.org and brookings.edu/autism. Thank you all very much for being here on behalf of Barbara and myself and everyone else. We appreciate it.

[Applause.]

[END OF TAPED RECORDING.]

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