

# The Brookings Institution and The Help Group CONFERENCE REPORT

January 2006

## Autism and Hope

The Brookings Institution and The Help Group convened leading experts on Dec 16, 2005 for a conference entitled 'Autism and Hope.' The Event was co-sponsored by Cure Autism Now and Autism Speaks with the further support of the Karmazin Foundation and Michael Fux.

Autism spectrum disorders have become among the most common and severe developmental disabilities facing children—and thus future generations of adults—in the United States today. More than 1 in 200 young children may now be affected by a neurological condition on the spectrum (which includes autism, pervasive development disorder, and Asperger's syndrome or disorder). This fact has become increasingly well reported in recent months.

### History of Autism

1940's – 1960's	Age of Denial
1960's – 1980's	Age of Defeat
1990's – present	Age of Hope



But less well known are two other key facts, which were the main focus of a policy conference held at the Brookings Institution on December 16, 2005. First, over the course of the last 20 years, and particularly the last 10 to 15, early intervention regimens for autism spectrum disorders (ASD) have become much more effective. Children with ASD are learning to speak, and going to school, in significant and increasing numbers. We are also now seeing many adolescents that, while not cured in the strict sense, are in many cases no longer exhibiting the types and the severity of symptoms that led to their diagnosis in the first place. Whether or not they can be described as truly recovered, their prospects for leading fulfilling lives—including friendships and meaningful careers—have greatly improved. Even those children who are more severely challenged can make marked strides in more fully realizing their potential. Dr. Barbara Firestone, President & CEO of The Help Group, emphasized in her introductory remarks that these advances demand the establishment of a comprehensive public policy to ensure that all children in the United States with ASD have the benefit of intensive early intervention.

The second key fact, underscored among others by Senator Hillary Clinton in her taped remarks to the audience, is that the availability of such intensive early intervention is highly limited in our country. Most parents cannot afford it—and neither government nor the health insurance industry pays for very much of it either.

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## FACTS, FIGURES, AND HISTORICAL CONTEXT FOR UNDERSTANDING AUTISM

In addition to initiating discussion of the above key themes, the conference's first panel provided context for understanding the nature of the autism challenge. As documented by Dr. Thomas Insel, Director of NIMH, and Dr. Jose Cordero of the Centers for Disease Control, autism spectrum disorders are growing rapidly in prevalence. The incidence may have increased by a factor of ten or more since the 1980s (though there is admittedly some uncertainty over the extent to which more sensitive diagnostic techniques are finding cases that would in the past have been missed—or perhaps misdiagnosed as a problem such as mental retardation). The problem appears comparably prevalent overseas, and varies little from one ethnic group to another (though boys are roughly four times as likely to be afflicted as girls).

As Dr. Insel pointed out, the recent rapid growth in ASD suggests an environmental cause of presently unknown type, though clearly genetics have a good deal to do with susceptibility to autism as well. But little can be concluded about specific causes at this point. He reported that federal funding for autism-related research is now estimated in the range of roughly \$115 million a year, mostly through NIH (including NIMH). Some of the resulting efforts are focused on multiple neurological or developmental problems, however, and not only ASD.

Dr. Rafael Castro noted that his professional group is now frequently treating children before their 3rd birthday and sometimes even before their 2nd—a highly desirable situation given the plasticity of the young brain. Getting a firm diagnosis at such a young age may require a specialist. But spotting warning signs, and referring children to more diagnosticians as needed, can generally be done by the second birthday after going through a 10-minute developmental checklist. This process should be carried out much more commonly than is the case today. Dr. Cordero pointed out that pediatricians have become more likely to correctly spot the early signs of autism in young children—which often include failure to point and otherwise try to gain another person's attention, lack of eye contact, highly repetitive behaviors, and sometimes a regression in certain language or motor skills. However, as Dr. Eileen Costello, herself a pediatrician, subsequently argued, many pediatricians still do not sufficiently understand the signs of ASD as well as the importance of quickly getting diagnosed children into intensive treatment programs. For example, less than half conduct the simple developmental checkup tests that often give early indications of ASD.

Peter Bell, CEO of Cure Autism Now, one of the largest ASD-related advocacy organizations in the country, pithily described the history of autism. He labeled the period from the 1940s to the 1960s the age of denial. The ailment had been identified by then, but few recognized it—and those who did had



outlandish theories about what caused it, for example blaming “refrigerator moms” for showering insufficient attention and love on their children (in fact, ASD is now known to have biological causes). The 1960s through the 1980s Bell described as the age of defeat, since even though the causes of ASD were more accurately recognized to be biological, next to nothing was known about how to treat the associated set of conditions.

Since the 1990s, said Bell, we have lived in the period of hope—the hope that a cure will someday be found, and the hope that can already be given to individual children and their families from much-improved treatment methods. But we have certainly not begun to reach what might be termed the age of victory over autism, for two main reasons.

First, a cure remains elusive. Scientific research funding has increased roughly tenfold since the 1990s (largely due to the Children’s Health Act of 2000). Today’s research is overseen by NIMH and the CDC and their eight national centers of excellence. The Combating Autism Act of 2005, now before Congress, would roughly double those research funds, while also increasing funding for early detection efforts. These developments give reason for hope. But a true cure for ASD—if one can even speak of a single cure—is probably still a considerable distance in the future at current funding levels.

Second (as the day’s last panel discussed in depth), treatment remains very

expensive and funding remains generally unavailable. Even the Combating Autism Act would make only modest steps towards increasing public resources for the treatment of children currently affected by ASD. The Act would provide some \$100 million a year for treatment; by contrast, up to \$5 billion a year may be needed for the nation’s preschool autistic population alone.

### TREATMENT METHODS— DEBATE CONTINUES, BUT MUCH IS AGREED

Panel 2 emphasized the promise of modern treatment methods. It underscored that debate continues in the field over optimal approaches. But there is broad consensus, as reflected as well in previous studies by the National Academy of Sciences and American Academy of Pediatrics, that early and intensive intervention—at least 25 hours a week—is critically important. The core of most intervention plans, it is generally agreed, should be a cognitive method engaging the child’s intellect and emotions and sociability. Applied Behavior Analysis (ABA) and Floortime are probably the two best-known and best-studied methods. Given the evidence that has now been accrued through numerous studies, the argument often used by insurance companies and others to deny coverage—that treatment methods are experimental—no longer holds water.

A simplified history of highlights in autism treatment might read as follows. A

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method described as intensive behavior intervention or IBI (sometimes called ABA) was first used in the treatment of ASD children in the 1970s and 1980s. One of its key methods is to break down learning into simple steps with one-on-one tutoring, in a manner somewhat akin to how Helen Keller was taught. It has been found to be effective at working on specific behaviors and skills. Beyond this so-called discrete-trial method, other IBI approaches involve approving and reinforcing appropriate behaviors when they arise in daily life. They also include creating opportunities for social interaction, often with “shadows” present to help guide the child to interact appropriately to the extent necessary.

Dr. Christine Caselles, a psychologist and practitioner of the IBI approach at a clinic in Maryland, pointed to the original 1987 study by Lovaas suggesting that roughly half of the children participating in this treatment method wound up mainstreamed in school without aides. Some recent analyses, she said, have confirmed comparable success rates, including a new Wisconsin study.

In the early 1990s, a method called Floortime (formally referred to as the DIR model) was developed to focus on core autism deficits—emotional, social, and imaginative abilities—by harnessing a child’s natural interests and tailoring interactions to his or her specific skills and challenges. It involves not only interactive play, but activities such as varying a child’s environment to teach language concepts in a realistic way.

Dr. Stanley Greenspan, the creator of this method, carefully explained the developmental philosophy behind the Floortime/DIR approach. But he first acknowledged that IBI methods also make notable positive contributions to an autistic child’s development. He was also gratified to see that many IBI practitioners have adopted developmentally-based concepts into their own methodologies. He showed video clips of strikingly improved children. Greenspan also presented data suggesting that over half of children who followed a DIR/Floortime approach eventually achieved a mainstream level of competence—not only in attending school, but in demonstrating emotional and social skills as well. Indeed, in his most recent study Greenspan followed a subgroup of these children for 10 to 15 years. This subgroup displayed, on average, comparable social and emotional abilities to those of a neurotypical group. (Another method called relationship development intervention or RDI is based on similar theory as DIR/Floortime, but employs a more structured curriculum.)

Dr. Laurie Stephens of The Help Group explained how a combination of the above methods is used in The Help Group’s special education and treatment programs that serve more than 500 students with ASD on a daily basis. The programs use ABA, Floortime, and other approaches as appropriate, enrolling children as young as three years of age in intensive programs with high staff-to-student ratios. Children spend 30 hours a week in school even in the preschool years, with parents actively involved in



reinforcing and complementing the school's efforts after hours. The HELP Group demonstrates what is possible when programs are specifically designed and properly resourced to meet the needs of each child.

Dr. Catherine Lord showed extensive data from studies conducted in North Carolina and Chicago confirming the arguments of Greenspan and Caselles. Among her striking findings was the conclusion that virtually all children improve through early intervention, even those for whom the goals of being mainstreamed in school or "losing the diagnosis" entirely remain unrealistically high aspirations. She also explained the highly heterogeneous nature of ASD disorders, and the resulting need for individualized treatment strategies that often feature more than one main methodology.

To be sure, some ancillary therapies are more established than others. But the main cognitive methods described above all received emphatic support at the conference—as they previously have in reviews such as those by the National Academy of Sciences and American Academy of Pediatrics.

### MAKING TREATMENT ACCESSIBLE AND AFFORDABLE

But despite this hope, enormous public policy challenges need to be overcome if interventions are to be optimized and made available to every child on the spectrum. To begin, as underscored by

Dr. Eileen Costello on panel 3, many of the recent breakthroughs in treatment are not yet widely understood among pediatricians, other key specialists, or school system administrators. In particular, we now know, by practical experience and by neuroscientific research, that it is critically important to begin intensive intervention as early as possible in a child's development. Yet diagnosis often does not occur today until children reach the ages of 4, 5, 6, or more.

In addition, even where available, the major autism therapy methods are generally not affordable. Costs can reach or exceed \$50,000 a year, and are not routinely covered either by health insurance or by federal, state, and local programs, as documented by Dr. David Mandell and Stuart Spielman. Some localities provide coverage. And California is an example of a state where therapies are more frequently available, as discussed by Dr. Louis Vismara, one of the founders of the MIND Institute at UC Davis and consultant to Senator Don Perata of the California State Senate. But even in California, there are often long delays in providing appropriate service. As Dr. Vismara pointed out, a legislative blue-ribbon commission has recently been established to make recommendations on how California might close existing gaps in services. Across the nation, coverage of intensive intervention is woefully lacking, reaching only some affected children or providing perhaps 10 to 20 percent of the recommended intensity of intervention (which should optimally reach 30 to 40 hours a week).

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Existing federal legislation, notably the Individuals with Disabilities Education Act (IDEA), requires the “free and appropriate” education of children with special needs—but does not require optimal education, specify what appropriate education would be for children on the autism spectrum, or provide adequate funding for early and intensive treatment. And Medicaid funding for treatment varies enormously from state to state. Part of the problem is the fact that ASD has biological causes but is treated primarily through educational means—meaning that autism treatment methods fall uncomfortably between the traditional purviews of the educational and medical professions. Given this situation, conference participants noted, the country needs a major federal effort to inform relevant specialists about how to diagnose and treat ASD, to develop more national capacity for treatment, and to help parents finance the catastrophic costs associated with effective treatment.

### LOOKING BEYOND THE CONFERENCE—AND TO THE FUTURE

Against this backdrop, several types of policy initiatives are possible, and in fact some combination of them is probably optimal. One option, simple to describe but potentially difficult to implement, could be a new federal entitlement in the form of an autism treatment and education voucher that draws in part upon existing Medicaid and special education funds. A more likely approach is to try to extend existing vehicles for health insurance to cover autism treatments as well. This could include the following (these ideas are illustrative and highly preliminary):

- Support for ongoing efforts to have the Office of Personnel Management mandate that federal health plans cover intervention programs carried out by qualified professionals—with the hope that the idea would then spread to the broader insurance market. In addition, the military health care system, which has recently adopted unrealistically high thresholds for professional certification for all tutors working with ASD children (demanding that each and every tutor be professionally certified, rather than simply those in charge of a given program), could return to more appropriate (yet still high) standards of care.
- Federal legislation mandating coverage by all health insurance plans (akin to the federal legislation on parity for mental health conditions of the 1990s, as well as federal mandates on minimum length of hospital stays after childbirth). Even if not passed promptly, proposed federal legislation may have a very useful role as a model for state by state legislation.
- Efforts to ensure that, under the IDEA legislation and/or the EPSDT provisions of Medicaid, a diagnosis of an autistic disorder leads to assurance of available services for any afflicted child (even if the amount of government support might depend on parental means). At present, these laws and regulations often do not have their promised effect.
- A clear definition of what is required to establish an autism spectrum diagnosis and thus qualify a child for services.





- A clear definition of what type of treatment is considered acceptable for purposes of coverage (as certified by major professional associations or a special federal advisory board).
- A clear definition of what types of providers may qualify for coverage (for example, a tutor team might be permitted to include college students or graduate students provided that it was overseen and directed by a psychologist, psychiatrist, developmental pediatrician, or neurologist and at least one full-time credentialed lead tutor).

generally focused much more on research into the causes and early indicators of autism (as reflected for example in the Combating Autism Act of 2005). But there is growing support for a policy agenda that would increasingly include treatment and funding issues as well.

Autism and hope are no longer mutually exclusive. While we press forward to find causes and cures, we must also emphasize the compelling need to ensure that effective treatment strategies are made available as soon as possible to all children with autism spectrum disorders across the United States.

At present, most public policy efforts of the broader autism community are

*“Autism and hope are no longer mutually exclusive.”*

## POSTSCRIPT: CONFERENCE AGENDA

### Introductory Remarks

Michael E. O'Hanlon, Senior Fellow, The Brookings Institution, Conference CoChair  
 Barbara Firestone, Ph.D., President & CEO, The Help Group, Conference CoChair  
 Senator Hillary Rodham Clinton (D-NY) (by video)

### PANEL 1: The Nature of the Autism Spectrum Problem

Moderated by Thomas R. Insel, M.D., Director, National Institute of Mental Health  
 Jose Cordero, M.D., Director, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control  
 Peter Bell, B.S., M.B.A., CEO, Cure Autism Now  
 Rafael Castro, Ph.D., CEC Partners, Boston

### PANEL 2: The Promise of Modern Treatment Methods

Moderated by Barbara Firestone, Ph.D.  
 Catherine Lord, Ph.D., Professor, Department of Psychology, Director, Autism and Communications Disorders Center, University of Michigan  
 Laurie Stephens, Ph.D., Director, Autism Spectrum Disorders Program, The Help Group  
 Christine Caselles, Ph.D., Director, Community Services for Autistic Adults and Children, Rockville, MD  
 Stanley Greenspan, M.D., Ph.D., George Washington University Medical Center, creator of Floortime Method



PANEL 3: What's Wrong with Current National Policy And How To Fix It

Moderated by Michael E. O'Hanlon

Eileen Costello, M.D., Pediatrician, co-author of "Quirky Kids," Boston University

David Mandell, Ph.D., Assistant Professor of Psychiatry, University of Pennsylvania  
School of Medicine

Louis A. Vismara, M.D., Policy Consultant to Senator Don Perata, California Senate

Stuart Spielman, Esq., Cure Autism Now

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