

## **AUTISM AND HOPE**

(11/04/05)

A conference presented by Brookings and the HELP Group of Los Angeles, co-sponsored by Autism Speaks and Cure Autism Now, with the further support of the Karmazin Foundation and Michael Fux

**Friday December 16, 2005**

**2:00 p.m. – 6:00 p.m.**

**1775 Massachusetts Avenue, NW**

**Washington, DC 20036**

[www.brookings.edu/autism](http://www.brookings.edu/autism)

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.

But less well known are two other key facts. 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 not only speaking, and going to school, in significant 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 a fulfilling life—including friendships and a meaningful career—have greatly improved. Even those children who are more severely challenged can make marked strides in more fully realizing their potential. Second, the availability of such intensive early intervention is highly limited in our country, among other reasons by the fact that most parents cannot afford it—and that neither government nor the health insurance industry pays for very much of it either.

In one paragraph, an oversimplified history of highlights in autism treatment might read as follows. A method described as applied behavior analysis (ABA) was first used in the treatment of ASD children in the 1980s. It breaks down learning into simple steps in a classroom-like setting, 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. In the early 1990s, a method called Floortime (formally referred to as the DIR model) was developed to focus more on what we now know are the core autism deficits—emotional,

social, and imaginative skills—by harnessing a child’s natural interests and tailoring interactions to his or her specific abilities and challenges. Another method called relationship development intervention (RDI) is based on similar theory as DIR/Floortime, but employs a more structured curriculum, and like Floortime is also showing great promise in addressing the core autism deficits. In addition, there are a host of other strategies that can be effective in the education and treatment of children with ASD, some more established and others still more experimental.

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, 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.

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. Some localities provide coverage, but it is often incomplete, 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). Given this situation, the country needs a major federal effort to inform relevant specialists about how to treat ASD, to develop more national capacity for treatment, and to help parents finance the catastrophic costs associated with effective treatment.

Against this backdrop, Brookings in conjunction with The Help Group of Los Angeles and the organization Cure Autism Now will hold a conference on the subject of “Autism and Hope.” The ultimate purpose will be to work towards policy proposals for expanding the availability and affordability of early intervention for autism spectrum disorders. 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. 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.

- 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).

Follow-up activities will surely include dissemination of the conference's proceedings and findings, electronically and by other means, with a focus on audiences on Capitol Hill and in pediatricians' offices and around the country more generally. At present, most public policy efforts of the broader autism community are 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 eventually 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.

PANEL 1: THE NATURE OF THE AUTISTIC SPECTRUM PROBLEM

PANEL 2: THE PROMISE OF MODERN TREATMENT METHODS

### PANEL 3: WHAT'S WRONG WITH CURRENT NATIONAL POLICY— AND HOW TO FIX IT

Panelists: Mr. Peter Bell (CEO, Cure Autism Now); Dr. Christine Caselles (CSAAC, Rockville, MD); Dr. Rafael Castro (CEC Partners, Boston); Dr. Jose Cordero (Director, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control); Dr. Eileen Costello (pediatrician and author, Boston University); Dr. Barbara Firestone (President and CEO, The HELP Group, Los Angeles); Dr. Stanley Greenspan (Inventor of Floortime Method, George Washington University); Dr. Thomas Insel (Director, NIMH); Dr. Catherine Lord (University of Michigan); Dr. David Mandell (University of Pennsylvania); Mr. Stuart Spielman (Cure Autism Now); Dr. Laurie Stephens (The HELP Group); Dr. Louis A. Vismara (Policy Consultant to Senator Don Perata, California Senate)

Co-Chairs: Dr. Barbara Firestone, The HELP Group; Michael O'Hanlon, Brookings