



EARLY INTERVENTION IN AUTISM:
FORGING THE ARCHITECTURE
FOR CHANGE

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Hello everyone. I'd like to begin by thanking the National Association of State Directors of Developmental Disabilities Services and the other sponsoring organizations and Dr. Ron Huff for their kind invitation to speak with you today. I am especially pleased that the conference organizers decided to make autism a topic on this year's agenda.

The number of children being identified with autism spectrum disorders continues to increase at a relentless pace. At the same time, we are in a new era of breakthrough research, earlier identification and diagnosis, increasingly more effective early intervention and treatment and greater public awareness. The race is accelerating to find the causes, cures and interventions that hold promise for children with autism. It is a race that can never be fast enough for the parents who are engaged in their own marathon to find the programs and services and funding that can make the critical difference.

I know that at The Help Group we can not mobilize program expansion quickly enough. Today, we serve more than 500 students with autism spectrum disorders in our four specialized day schools on a daily basis.

Over the last 10 to 15 years, early intervention approaches for autism spectrum disorders have become much more effective. Given intensive early intervention, ideally beginning before the age of three, children with ASD are making more significant strides in the various areas of their development. Their prospects for leading more productive and rewarding lives have greatly improved. Even those children who are most severely challenged can make substantial progress in more fully realizing their potential. That's the good news.

But there's also bad news — the reality that access to early intervention remains limited in our country. We must continue our efforts to accelerate awareness, early identification and diagnosis, but, as importantly, we must 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. Nationally, the major autism therapy methods are generally not affordable to most families. Costs can exceed \$50,000 a year and are not uniformly or routinely covered either by federal, state and local programs or health care insurance. And there is tremendous variability from state to state.

We have a collective responsibility to address these issues; the need has never been greater. It is imperative that we work in collaboration with governmental entities, private third-party insurers, parents, advocacy groups and philanthropic partners to develop policies to significantly expand early intervention and education services and make them affordable to every family with a child or children with autism.

One of the important goals must be to bridge the significant gaps that exist between the parents' first suspicion that their child is developing differently and diagnosis, which may not occur until 3 or 4 years of age, and the long delays that exist between diagnosis and intervention. We must also address the inaccessibility and in affordability of services for many families.

The scope of this challenge was the focus of an Autism and Hope policy conference presented by the Brookings Institution and The Help Group in Washington, D.C. on December 16th. Additional sponsorship was provided by Cure Autism Now, Autism Speaks, The Karmazin Foundation and Michael Fux. I had the privilege to co-chair this conference.

I'd like to tell you about this important meeting where we convened some of the leading experts in our nation. It was a watershed day — a collaborative national dialogue to work towards the goal of making intensive early intervention available to all children with autism spectrum disorders. The conference was successful in stimulating an important dialogue and planning has already begun to hold Autism and Hope Part II.



As a member of the Congressional Autism Caucus, Senator Hillary Clinton opened the conference with videotaped remarks that were clear and unequivocal. She expressed concern that the availability of intensive early intervention is highly limited in our country. She also stressed that significant resources, including a strong health care infrastructure, are needed to make sure children and families dealing with autism get the support and care they need and deserve.

Governmental funding at the federal level for autism research has increased roughly tenfold since the 1990s, at about 115 million per year currently. Research is overseen primarily by the National Institute of Mental Health and the Centers for Disease Control and eight university-based autism centers of excellence. UCLA is one of the eight centers of excellence.

Dr. Thomas Insel is the Director of the National Institute of Mental Health. He is at the forefront of autism research and chairs the Interagency Autism Coordinating Committee. The creation of this Committee was mandated by the Child Health Act of 2000. It comprises federal partners including the CDD, the Department of Education, the FDA and other groups as well as parents. The committee has developed recommendations that require a coordinated, collaborative and aggressive effort.

At our conference, Dr. Insel moderated a panel discussion on the nature of the autism challenge. He said that it will take a very broad community effort to make the changes that are needed.

The CDC's director of the National Center on Birth Defects and Developmental Disabilities, Dr. José Cordero, confirmed that the number of children identified with autism spectrum disorders is growing rapidly. The incidence may have increased by a factor of 10 or more since the 1980s.



He reported that there are comparable demographics overseas, and that the prevalence varies little across ethnic groups and that the ratio of boys to girls with ASD is about 4 to 1.

He cited the study by the National Academy of Science attesting to the power of early intervention. You may be familiar with the CDC's campaign launched one year ago to increase awareness of early developmental milestones and the understanding of the benefits of early intervention. Main target audiences were the health care community and child care and early education providers and parents. Dr. Cordero said that the message is clear: the child who is identified with autism at 4 is the same child with autism who could have been identified at 3 and the same child with autism who could have been identified at 2. He was pleased to report that the program has made significant strides.

Last year, The Help Group launched its autism public awareness campaign. One of the components is an ongoing public service announcement campaign. Here are two of the PSAs that are part of the campaign. One is with KABC medical correspondent Bruce Hensel and the other features actor Gary Cole, who is the parent of a child with an autism spectrum disorder.

[PSAs can be viewed on The Help Group Web site at www.thehelpgroup.org]

I'm glad to report that we have had an excellent response to the PSAs and have received numerous inquiries from parents, educators, psychologists and other professionals.

In tackling the awareness and early identification issue, Boston pediatrician and co-author of Quirky Kids, Dr. Eileen Costello, emphasized that pediatricians are the gateway to services for young children. She stressed the importance of continuing efforts to educate pediatricians and family practitioners about the importance of identifying developmental differences early and referring for diagnostic services.



The reality in daily pediatric practice, says Dr. Costello, is that children are often not referred to early intervention until they're practically aging out of this time period that can make the critical difference. Parents should no longer accept the pediatrician's all-too-often statement, "don't worry, your child will grow out of it."

Being on the front lines of providing services to children with autism spectrum disorders, as The Help Group is, can be heartening and exciting as well as frustrating and disheartening. On the positive side, we are in an age of breakthrough research, earlier diagnosis and increasingly more effective intervention and treatment.

Early intervention, ideally beginning before age three, holds great promise for children with all forms and degrees of autism. The neuroplasticity of the developing brain during this window of age greatly enhances a child's ability to make gains in the various areas of development. While there is an ongoing debate about which treatment and education strategies are most effective, there is consensus that early and intensive intervention of at least 25 hours per week is necessary. This intensive behavioral intervention includes training on attention, language, play skills and sociability, reduction of maladaptive behaviors and academic readiness.

At The Help Group, we have seen the incredible progress that preschoolers have been able to make in our program that Dr. Laurie Stephens will tell you about in her presentation.

Allow me to show you a short video clip of Carson and his mother, Joanne. This clip is part of The Help Group's overall video that is narrated by *Good Morning America's* Diane Sawyer. Although Carson's mom is thanking The Help Group, in essence, she is thanking the field for the progress that her son has been able to make with early intervention.



[video clips]

Current research is confirming that autism can be reliably detected at age 2 and as early as 18 months in many cases. According to Dr. Geraldine Dawson, director of the University of Washington Autism Center, “research has identified behaviors you can see in a child as young as 12 months. The hope is one day to have the ability to identify children at birth.”

Autism and Hope presenter Dr. Catherine Lord’s research reinforces the benefits of early intervention. A professor at the Department of Psychology and Director of the Autism and Communications Disorder Center at the University of Michigan, Dr. Lord has made extraordinary contributions to this whole area. She points out that almost all children with ASD can make progress with early intervention, even those for whom the goals of being mainstreamed to losing the diagnosis are unrealistically high goals.

Dr. Lord also concluded that autism spectrum disorders involve complex problems that affect different children and their families in different ways. Solutions to these problems must recognize this complexity, the need for individualization of treatment, and that effective treatment must incorporate more than one main methodology.

The evidence is mounting regarding the positive outcomes associated with early detection and early intervention. Unfortunately, only a fraction of children on the autism spectrum — perhaps 10 percent to 20 percent — receive the rigorous therapy that the National Academy of Sciences, American Academy of Pediatrics and other professional groups have documented are required. Families living in underserved or rural areas have little or no access to these programs.

Dr. David Mandell, Assistant Professor of Psychiatry at The University of Pennsylvania School of Medicine, is an epidemiologist who has analyzed how treatment and financing



for those interventions vary greatly across the nation. He asserts that until policy changes are made at the federal level, treatments will not be delivered in a meaningful and equitable way.

Dr. Mandell was a member of a Services Sub-committee of the National Institutes of Health Interagency Autism Coordinating Council. His working group developed an autism spectrum disorders services road map that attempts to define what care is now, how we can improve it and what it should be. Dr. Mandell said this road map identified 50 challenges to the efficient and effective delivery of care to children with autism. He focused on these five major challenges:

- There is a lack of trained treatment professionals
- There is no consistent funding mechanism for treatment
- There is no established standard of care that has been implemented in any meaningful way
- Care is fragmented across multiple agencies that do not coordinate well with one another
- There is great variation in the organization, financing and delivery of care across localities

We all recognize that the public education system plays a major role in this area. Existing federal legislation, the Individuals with Disabilities Education Act, requires the “free and appropriate” education of children with special needs — but does not require optimal education. The act does not specify what appropriate education would be for students with autism nor does it provide adequate funding for early and intensive treatment. Dr. Mandell pointed out that in most states, the education system is not responsible for addressing the core symptoms of autism or for providing treatment per se. He pointed out that California has made significant strides in this area. He further addressed the



complexity and variation of Medicaid funding, the issues of behavioral health care system delivery of service, and the fact that most private insurers provide no benefits or minimal benefits for children with autism.

The impact of these unresolved challenges is profound. Parents must become tireless advocates for their children. In effect, they must become care managers, spending countless hours learning complex regulations and managing their child's care across multiple agencies. Parents have difficulty finding appropriate providers. They must face the frustration of treatment often being delayed or interrupted. And when they are able to find services, they must often bear considerable costs themselves or otherwise forego services. The extent of the problem is exponentially magnified for children and families in underserved communities.

Dr. Mandell concluded that we are in the midst of a national autism experiment. This variation in care provides us with the opportunity to create a federally approved blueprint for services and funding. We can look at how states provide autism care and examine their outcomes to identify best practices. From this, we can create a standard of care and the necessary incentives for states and school districts to implement this standard.

Ron Huff outlined the alarming statistics for California in his remarks. Dr. Louis Vismara, consultant to California Senate President Pro Tem, Don Perata, reviewed the California landscape at our Autism and Hope conference. Dr. Vismara is a parent of son with autism, a founder of the MIND institute at UC Davis and a passionate advocate for children with autism.

California has a long-standing tradition for supporting autism and other disabilities and is recognized as being at the forefront of this area. However, even with the efforts of the Department of Developmental Services and its network of 21 nonprofit Regional Centers



and the system of public education, there are still gaps in autism services.

He described the system of care as complex, confusing and often difficult for families to navigate, resulting in long delays in provision of mandated services.

As we look for ways to solve the challenges, we must develop innovative, out-of-the box solutions. One such solution was the development of the state First Five California Commission. Dr. Vismara, who serves as a commissioner, explained that this commission was created as the result of the successful efforts of actor and producer Rob Reiner to have a tobacco tax initiative passed in the state of California. The passage of this initiative has resulted in over \$600 hundred million dollars annually and over 3 billion dollars of funding since its inception to improve early childhood development.

This initiative was initially focused on typically developing children from the ages of zero to 5. More recently, the commission has broadened its scope to fund programs related to autism and other disabilities. Several years ago, The Help Group was awarded a major grant by First 5 Los Angeles to establish our therapeutic preschool for children with autism. Through this collaboration with First 5 LA, The Help Group has been able to develop an effective model of education and treatment that is funded on an ongoing basis by local school districts.

In 2005, Dr. Vismara arranged a press conference with the Senate President Pro Tem, the Speaker of the Assembly, and The Help Group at the state capitol to address the importance of early identification and intervention and to announce the Pro Tem's and the Speaker's plans to develop the Legislative Blue Ribbon Commission on Autism. The commission will begin its work in the near future. Its mandate is to conduct a two-year analysis to identify gaps in autism services and provide the governor and legislature with recommendations on how to close them.



Improved quality of life for affected children and their families should be a compelling argument. But policy makers can also consider this beneficial economic impact overall: the fact that children with autism spectrum disorders who receive comprehensive and intensive early intervention are likely to need costly support services later on.

With the boom in numbers of children identified today, consider the implications as these children become adults. Early investment is optimal for the quality of life of these children and their families and will reduce the level of services and associated costs throughout their lifetime. Of course, nothing in this platform is intended to undermine efforts to optimize and improve education and treatment throughout their lifetime, but rather to foster maximal growth and potential by intervention beginning at the earliest age possible.

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. According to Peter Bell, CEO of Cure Autism Now, the Combating Autism Act of 2005, now before Congress, would roughly double those research funds, while also increasing funding for early detection efforts. 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 population alone.

The agenda of finding causes and cures is a compelling one, worthy of all our support. However, equally compelling 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 intensive early intervention, and for comprehensive and innovative public policy at the national, state and local levels.



Our Autism and Hope conference clearly illustrates that the pressure to expand education and treatment research efforts, reshape public policy, and mobilize education and treatment resources is increasing exponentially.

Autism and Hope Co-Chair Michael O’Hanlon of The Brookings Institution, who is also a parent of a child with autism, outlined ideas for policy reform. He suggested several types of initiatives and said that some combination of them is probably optimal. One option he suggested could be a new federal entitlement in the form of an autism treatment and education voucher that draws in part from existing Medicaid and special education funds.

Another approach is to try to extend existing vehicles for health insurance to cover autism treatments. This could include everything from federal legislation mandating coverage by all health insurance plans to the creation of clear definitions to establish an autism spectrum diagnosis and thus qualify a child for services.

A commitment to helping all children realize their fullest potential should be at the heart of this national, state and local effort. We can no longer delay; there is a generation of children who need our help now.

Access to help is the right of all children with ASD, not just a fraction of them. Accelerating awareness, identification and early diagnosis without a concomitant acceleration of early intervention services is an incomplete and seriously flawed strategy and policy. It denies many children the benefit of treatment during the sensitive window of opportunity in the early years of development. Let us work to fill the gaps so that we may provide a seamless system of early intervention for all of the children throughout the United States.

Over 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.

Autism and hope are no longer mutually exclusive. We are at the crossroads of forging the architecture for change. It is a very complex process with tremendous sociological, educational, therapeutic research, political and economic implications. Most of all, it holds the promise of brighter futures for children with autism spectrum disorders