

U.S. HOUSE OF REPRESENTATIVES
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July 14, 2008

Secretary Michael O. Leavitt
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Leavitt,

The Combating Autism Act of 2006 called upon the Department of Health and Human Services (DHHS) to establish an Interagency Autism Coordinating Committee (IACC). I understand that the IACC has been appointed and has begun work. A key task of that Committee is to develop a strategic plan that will guide research investments.

In the Combating Autism Act, Congress directed DHHS to conduct research into screening, diagnosis, treatment and medical care for individuals with autism. These areas of research are essential to a balanced approach. In addition to these areas, I strongly encourage the IACC to promote a balanced research portfolio when examining the underlying causes of Autism Spectrum Disorder (ASD). An examination of the FY07 ASD Research Portfolio shows a strong preference to fund genetic-based studies related to autism. There is growing evidence that suggests a wide range of conditions or environmental exposures may play a role in the emergence of ASD.¹

The case of Hannah Poling is just one example that is suggestive of very important lines of inquiry.² It is becoming more clear that ASD is not a singular disorder, but one with numerous and complex etiologies. Research into the causes of autism needs to examine and differentiate the numerous biomedical causes for the similar set of symptoms, diagnosed as ASD. Without an understanding of the different biomedical causes for ASD, it will be difficult to pinpoint a genetic link and equally as important, to understand the role environmental factors play in the emergence of autism. Additionally, an

¹ A recent poster session presentation at the International Society for Autism Research suggests that research on primates is about to emerge that will provide additional evidence of environmental contributions to ASD.

² For very suggestive writings along these lines, please see: Terry Poling, "Vaccines, Autism and Our Daughter, Hannah," Letter to the Editor, The New York Times, April, 5, 2008. Jon Poling, "Open Letter to Dr. Steven Novella in Response to "Has the Government Conceded Vaccines Cause Autism," Age of Autism (web publication), March 11, 2008.

understanding of different biomedical pathways will assist other branches of research including early diagnosis and potential treatments.

The June 29, 2008 meeting in Indianapolis to examine the link between Mitochondrial Encephalopathies and Autism was a promising start to a more nuanced examination into the causes of autism. I hope that the research endorsed by the IACC would include work to further clarify these matters. This work seems so important, that I would expect the Department to undertake these efforts even before an endorsement from the IACC. Throughout the 1990s there was a dramatic increase in the number of children diagnosed with ASD. It is unlikely that this increase is entirely attributable to the more accurate and vigilant diagnosis of the disorder. During this time, the public health agencies of the Federal government were both slow to react to the increase, and slow to communicate effectively with the American public. I am disturbed that efforts to undertake and dedicate resources towards comprehensive research into this disorder, was largely forced on public health agencies by Congress and citizen activists. This delayed response has caused many Americans distrust the Department of Health and Human Services (DHHS) when it comes to ASD.

Given the fact that the Department has lost much of the public's trust, it would be to your agency's advantage to involve as many people from the activist community as possible in any decision-making process. If the Department of Health and Human Services is going to provide effective leadership in autism research, diagnosis and treatment then you need to build new relationships and repair old ones. I urge you to consider forming a Secretarial-level Autism Advisory Board (AAB). While the IACC is the primary mechanism for the coordination of research, surveillance, and early detection activities within the Department of Health and Human Services, an AAB could provide additional public feedback and serve as a liaison between parents, individuals with ASD, advocacy groups and the Department of Health and Human Services, and would assist in reestablishing public confidence. Such a board could be of whatever size and composition you found helpful and should include voices that can articulate the full range of views and concerns in the ASD-community. Since research is a key area of discussion and dispute, it is prudent to include multiple research-oriented organizations on this Board.

Groups such as SafeMinds, Generation Rescue, Autism Speaks, the Simons Institute, the National Autism Alliance, and the Autism Research Institute all have or are currently supporting research. Such groups have experience evaluating research, an in-depth knowledge of the current body of ASD research, and an appreciation of the new questions that may need to be examined in order to move our understanding of ASD forward.

Such a panel could provide an annual review of progress in autism work across the Department as well as work that is funded outside of official circles. It would also provide you with a sounding board for Departmental ideas on how best to proceed, and to communicate with the public. The work of this Board need not be duplicative of that of the IACC.

By this letter, I would ask for your thoughts on forming an Autism Advisory Board. Further, I ask that you keep me informed of the work of the IACC from this point forward, and please provide to my Subcommittee a copy of the IACC's research report when it is completed. Please direct the report and any questions concerning my request to Dr. Dan Pearson (202-225-4494) or Ms. Heather Parsons (202-225-3032) of my staff.

Sincerely,

A handwritten signature in black ink that reads "Brad Miller". The signature is written in a cursive, slightly slanted style.

BRAD MILLER
Chairman
Subcommittee on Investigations
and Oversight

Cc: Dr. Thomas R. Insel
Director, National Institute of Mental Health, and
Chair, Interagency Autism Coordinating Committee