



July 13, 2009

Interagency Autism Coordinating Committee (IACC)  
Office of Autism Research Coordination  
National Institute of Mental Health, NIH  
6001 Executive Boulevard, NSC  
Room 8200  
Rockville, MD 20852

Dear Committee Members,

The following are the scheduled remarks for Elizabeth Emken, Vice President of Government Relations, Autism Speaks, for the July 15, 2009 IACC meeting:

Hello. I am Elizabeth Emken, I'm Vice President of Government Relations at Autism Speaks. This is my son, Alex Swartz. He has autism spectrum disorder.

We are here today to show the committee another example of a person living with autism. We all know that autism is a spectrum disorder, but in meetings like these, that are very orderly with scheduled speakers and tented name cards, the environment is best suited to those on the spectrum that can express themselves. Alex Swartz, my son, is on a different part of the spectrum—and he represents a significant number of individuals living with autism. Most individuals with autism cannot walk up to this microphone and tell you what's on their minds. Most can't talk about how they feel, and discuss their hopes and dreams with you. Many couldn't be here, in this room, for more than a few moments.

Alex, do you want to say something into the microphone? (I will try to prompt him to give his name and age, and to say hello. He is not able to prepare or give structured remarks).

That's really all Alex can share with you today. He can't tell you how it is he came to be here today. He can't explain his background, his education. He will not be going to college, getting a job, getting married, and he won't be forming a 501c3 to promote his interests. Autism has left Alex profoundly disabled. Intensive behavioral therapy, provided beginning when Alex was 4 years old, has, however, enabled him to travel here today from California by plane, and sit in this meeting for quite a while, more or less quietly. Alex is happy, he loves school, he loves to travel, and he misses his family when one or more of us are away from home.

But if Alex could say this to you today, I am confident he would ask you for your help in curing his autism. Yes, **curing** his autism. I spent many years on the Board of Directors of Cure Autism Now, and I'm fortunate to currently run the Government Relations department at Autism Speaks. I do believe that

autism is a disorder that should be cured—an affliction that robs individuals of their ability to lead a productive life. It robs most of them of their ability to address you here today. It robs them of their liberty, and their ability to pursue their own happiness. Autism, for a vast majority of those that struggle with it every day, is the difference between a life of independence, and lifelong dependence.

I urge this committee to actively pursue the promotion of research into prevention, treatment, and ultimately a cure for autism. Thank you.

Sincerely,

A handwritten signature in black ink, appearing to read "Elizabeth Emken", with a long horizontal flourish extending to the right.

Elizabeth Emken  
Vice President, Government Relations  
Autism Speaks