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**TESTIMONY
RAISED H.B. NO. 7144
AN ACT ESTABLISHING A BOARD OF EDUCATION AND SERVICES
FOR CITIZENS WITH AUTISM SPECTRUM DISORDERS
MARCH 16, 2007**

My name is Stephen Mendelsohn and I am an adult who has Asperger Syndrome. I do not consider this to be a *disorder*, nor do I agree with characterizing most people on the autism spectrum as having a *disorder*. The word disorder, a psychiatric term taken from the DSM-IV, implies something is wrong and needs to be fixed or cured. If you ask autistic adults what is wrong in our lives, we will list discrimination in employment, social isolation, lack of acceptance, psychiatric coercion, sensory accommodations, and need for social supports to live independently in the community. We view our autism as giving us unique strengths and talents as well as disabilities, and we have no desire to become neurotypical (i.e., non-autistic) through any "cure." Even "lower-functioning" autistic people can be and are capable self-advocates, as witnessed by those who run the Web portal Autistics.org.

In looking at the issue this way, we have much in common with people with other disabilities. For decades, the disability rights movement has argued that disability is a natural part of the human condition and not an illness to be cured through medical intervention. To me, the very title of this bill indicates a mindset of cure and treatment instead of an independent living approach of acceptance and support.

In addition, it is widely known that the overarching problem with disability services as they currently exist is *fragmentation*. State services are set up so that blind people need to go to one agency, people with intellectual disabilities need to go to another agency, and people with physical disabilities need to go to yet another agency. For example, what will happen if someone is autistic and blind? Will the new autism agency

have a complete understanding of the supports necessary for people who are blind? Or will the person be bounced back and forth between the agency and the Board of Education and Services for the Blind (or the Department of Social Services, or the Department of Mental Retardation, or the Commission on the Deaf and Hearing Impaired, etc.), forced to endure often-conflicting services and policies? Thus far, people served by multiple agencies have not reported a high level of satisfaction. On the contrary, there is a huge outcry for more coordination, not less; and creating a separate agency for autistic people will only exacerbate this problem. Once again, there is a danger of designing services around a diagnosis instead of around a person. It would make infinitely more sense to make services that fit people instead of trying to fit people into services.

My recommendation, therefore, is that services for autistics be placed within an existing agency. The Department of Mental Retardation is changing its name to the Department of Developmental Services in an effort to leave behind stigmatizing language. While this may not be an ideal match, it would be preferable to creating yet another agency and accompanying bureaucracy. Other states now coordinate services for people with developmental disabilities this way and Connecticut would be well advised to follow suit.

As far as services being developed, I strongly encourage you to include autistic adults in every step of the planning process. Another principle of the disability movement is extremely appropriate here: "Nothing about us without us." You should also expect there to be significant disagreements between the (adult) autistic community and parents and professionals in the autism community. While some parents understand the gift that their autistic child brings into the world, many focus their efforts on trying to fix their child and even support prenatal genetic testing and eugenic selective abortion to prevent the birth of autistic children.

From the viewpoint of the autistic community, autism is not a puzzle, and it is offensive to compare us to puzzle pieces. I recently bought a sweatshirt with a slash through a puzzle piece surrounded by the words, "I am not a puzzle; I am a person." Nor is autism an appendage; rather it is pervasive and colors our entire existence. For this reason, many prefer "autistic people" or even "autistics" to "people with autism," just as I would not normally be described as a "person with Jewishness." I can no more

be neurotypical than I could be non-Jewish. Any name for a proposed agency should be sensitive to the autistic community's preferences here. And autism is not a plague. A government agency which spends our tax dollars promoting the ideology that autism is a terrible tragedy which needs to be eliminated through drugging, intensive behavior modification / aversive conditioning, and selective abortion can do far more harm than good. The last thing we need are government policies that make autistic people feel like garbage.

Thank you for your time. Please consider me as a resource as you move forward in this process.