

**Comments at March 14, 2008 IACC Meeting**

**Category : Research and Data Collection**

**Published by [Admin](#) on 2008/3/13**

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IACC Testimony:

Members of the Committee,

Thank you for this opportunity to give comment on the IACC's important work. My name is Ari Ne'eman and I am here today in my capacity as the President of the Autistic Self Advocacy Network (ASAN), a volunteer non-profit organization run by and for adults and youth on the autism spectrum. ASAN works to promote the autistic culture movement and other opportunities for individuals on the autism spectrum to interact with each other as well as work to improve the representation of the autistic community in public policy deliberations about autism and disability affairs.

I would like to take this time to reiterate and elaborate upon the comments I made at the last IACC meeting, encouraging this committee to re-orient its research agenda in a fashion that will comply with the perspectives and goals of the community of individuals on the autism spectrum. The first step towards this is to follow up on the appointment of Stephen Shore and add additional autistic representatives to the IACC and its workgroups. The concept of "Nothing About Us, Without Us" is a long time pillar of the disability rights movement and it should be respected in autism policymaking, just as it would be with the drafting of policy aimed at any other minority group.

In addition, we encourage this committee to focus its research towards measures that will improve the opportunities for communication and quality of life for autistic individuals, by funding research into Augmentative and Assistive Communication (AAC) technology, early education and service-delivery methods in areas of employment, independent living, housing and other important spheres for autistic individuals everywhere. I'm concerned by the fact that the autistic people, family members and others who make up ASAN's international membership continue to face skepticism about the very existence of autistic adults. The media portrays the autism spectrum as something new only existing amongst children. Yet, the adult population continues to lack needed support and awareness. State vocational rehabilitation agencies and other aspects of the developmental disability service-delivery infrastructure are ill-informed about the needs of adults on the spectrum. Furthermore, there is a pressing need for more research on how to best serve both adults and youth on the autism spectrum in fields like educational methodologies, restraint reduction, positive behavioral supports and other areas that take practical steps to improve access, inclusion and

respect for our community. *[Update, July 2009: ASAN has revised its policy and does not advocate the use of positive behavioral support (PBS) programs.]*

I was diagnosed on the autism spectrum at age 12, and I have been fortunate enough to benefit from a family that has been accepting of my differences and supportive of the educational services that have helped me develop. Unfortunately, not all children on the spectrum are receiving that acceptance and support. The current culture of despair and intolerance promoted by groups like Autism Speaks and Generation Rescue does not contribute to positive outcomes for autistic individuals. Statements that devalue autistic life, like those made unapologetically in the fundraising video Autism Every Day by IACC member and Autism Speaks Executive Vice President Alison Tepper Singer, do not benefit people on the spectrum and contribute to an environment of stigma and fear. Ms. Singer's comments, where she states she considered driving her daughter off the George Washington Bridge, refraining "only because of...the fact that I have another child," are of great concern, particularly given the murder of an autistic child by her mother a mere four days after her statement. The inaccurate and incomplete picture of the autism spectrum that Autism Speaks has chosen to promote for fundraising purposes contributes to the environment that makes these atrocities possible. That is why the autistic community continues to be concerned by Ms. Singer's presence on this Committee and the message her selection sends to people on the spectrum, our families and our supporters. You cannot help us by demonizing our neurology and stigmatizing our very existence.

Genetic research promoting a prenatal test for the autism spectrum is also of grave concern. It should be noted that Dr. Joseph Buxbaum, an Autism Speaks-funded researcher, believes that a prenatal test for the autism spectrum could exist as early as 2015 – in fact, genetic testing for some types of the autism spectrum is already available. There is significant evidence that such tests will and are leading to the use of selective abortion to engage in eugenics against the developmentally disabled. It should be noted that approximately 90% of fetuses that test positive for Down Syndrome are aborted. While a prenatal test for the autism spectrum is significantly more complex to develop, once it is in existence the current climate of fear makes a similar result likely. While we do not hold an opinion on the abortion debate in general, we are deeply concerned by any effort to eliminate a particular kind of individual from the gene pool solely on the basis of neurology. Taxpayer funds should not be going to eugenics.

I consider it a grave human rights concern that many autistic individuals continue to be unable to communicate because the assistive communication technology and educational methodology research that could help many more adults and children convey their needs is being ignored in favor of eugenically oriented genetic research aimed at finding a "cure" for a natural and legitimate part of human genetic diversity. The autism spectrum is not a recent epidemic but a neurological condition that has always existed, but is only now being diagnosed at incidence rates that approach accuracy.

The autism spectrum often comes with significant disabilities that require substantial support. However, rather than trying to eliminate us, we can and should be taking steps to mitigate those disabilities while empowering the strengths that we possess and respecting our legitimate place in the spectrum of human diversity. We encourage this Committee to take the first steps towards shifting the main buzzword about autism from "cure" to "communication" and ultimately, to moving the dialogue about the autism spectrum to one of acceptance, inclusion and, above all, respect.

Thank you for your time. As always, "Nothing About Us, Without Us."