

Disability Community Condemns Autism Speaks

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Over 60 organizations condemn lack of representation, exploitative and unethical practices by autism organization

Washington, DC – More than 60 national, international, and local disability rights organizations have signed onto a letter condemning the organization Autism Speaks for exploiting those it purports to help. The letter will be released on Wednesday, October 7 by the Autistic Self Advocacy Network (ASAN), the leading advocacy organization run by and for Autistic youth and adults speaking for themselves. The letter's signatories include the Arc of the United States, TASH, the Bazelon Center for Mental Health Law and the National Council on Independent Living, and it calls on Autism Speaks' donors, sponsors, and supporters—including Toys 'R Us, Home Depot, Fox Sports, and Lindt Chocolates—to end their support for the organization.

The joint letter highlights a pattern of behavior on the part of Autism Speaks beyond any particular instance, but it was instigated following Autism Speaks' most recent fundraising video, entitled, "I am Autism". The disability community reacted in horror to the "I am Autism" campaign, which presents Autistic people as kidnap victims and burdens on their families and local communities.

ASAN held a protest in Portland, Oregon on September 26 that received widespread local press coverage, including segments on the news broadcasts on two local television stations, KPTV-12 (Fox) and KOIN-6 (CBS). Additional protests are being organized for Sunday, October 11 in Columbus, Ohio, and for Sunday, October 18 in Boston, Massachusetts. ASAN is also organizing a large protest at an Autism Speaks-sponsored concert at Carnegie Hall in New York City on Tuesday, November 17. Singer Bruce Springsteen and comedian Jerry Seinfeld are headlining the concert.

"I am autism. I have no interest in right or wrong. I will plot to rob you of your children and your dreams....And if you're happily married, I will make sure that your marriage fails. Your money will fall into my hands, and I will bankrupt you for my own self-gain," proclaims the spooky announcer on Autism Speaks' "I Am Autism" video. Produced by Academy Award-nominated film director Alfonso Cuarón and Grammy award-nominated songwriter/producer Billy Mann, the video premiered at the United Nations World Focus on Autism Conference in front of a collection of dignitaries and First Ladies and was subsequently released online on September 22.

Since then, Autism Speaks has attempted to distance itself from the video, taking it down from its

website while continuing to distribute it via YouTube (<http://www.youtube.com/watch?v=HDdcDIQVYtM&feature=related>). The joint letter highlights three areas of unethical and exploitative behavior on the part of Autism Speaks:

- a) Its damaging and offensive fundraising tactics, which frequently equate being autistic to a fate worse than death
- b) The low percentage of money donated to Autism Speaks that goes towards services or support for families and individuals, particularly in light of its high executive salaries
- c) The lack of representation of Autistic people themselves in Autism Speaks' Board of Directors or leadership

"This joint letter sends a clear message to the corporate and philanthropy world that Autism Speaks does not speak for Autistic people or our families," said Ari Ne'eman, an adult on the autism spectrum and President of ASAN. "The type of fear-mongering and exploitation Autism Speaks engages in hurts Autistic people by raising fear and not contributing in the slightest to accurate understanding of the needs of Autistic adults and children."

In addition to relying on arousing fear and pity to raise funds, Autism Speaks' video repeats frequently referenced claims of higher than average divorce rates among parents of Autistic children. A study conducted in 2008 by Harris Interactive for Easter Seals in cooperation with the Autism Society of America found divorce rates for parents of Autistic children lower than those for families with no children with disabilities.

The video also relies heavily on the idea of rapidly increasing autism rates. Another new study by the British Government's National Health Service, which was released the same day as the video, found that the autism rate among adults (one percent of the population) is the same as the rate among children. This provides evidence that the popular "epidemic" claim of rapidly increasing autism incidence is likely false.

"This video doesn't represent me or my child," said Dana Commandatore, a parent of an Autistic child who lives in Los Angeles, California. "Whatever the challenges that autism may bring, my son deserves better than being presented as a burden on society. Autism Speaks' misrepresentation makes my life and the life of my child more difficult."

"Autism Speaks seems to think that parents' embarrassment at their kids' meltdowns is more important than autistic kids' pain," wrote Sarah, an Autistic blogger at the blog [Cat in a Dog's World](#). She added, "Autistic people deserve better than what Autism Speaks has to offer."

The new video is reminiscent of the December 2007 New York University Child Study Center's "Ransom Notes" campaign that used fake ransom notes claiming to be from an anthropomorphized disability that had kidnapped a child. After widespread outcry from self-advocates, parents, and professionals and the condemnation of 22 national disability rights organizations, led by ASAN, those ads were withdrawn in just two and half weeks. The Ransom Notes controversy was covered by The Wall Street Journal, The New York Times, Good Morning America, The Washington Post, and other major media outlets. ASAN is working with the cross-disability community on a similar response to Autism Speaks' campaign.

"The voices of real autistic people, and of families who do not subscribe to the presentation of their family members as something sinister and criminal, clearly do not matter to Autism Speaks," said Paula Durbin-Westby, an adult on the autism spectrum in Virginia, who serves on the Board of

Directors of the Autistic Self Advocacy Network. “Our community is furious about Autism Speaks’ continued exploitation, and we are taking action.”

About ASAN

The Autistic Self Advocacy Network (ASAN) is an inclusive international non-profit organization run by and for autistic people. ASAN seeks to advance the vision of the disability rights movement in the world of autism. Drawing on the principles of the cross-disability community on issues such as inclusive education, community living supports, and others, ASAN focuses on organizing the community of Autistic adults and youth to have our voices heard in the national conversation about us. In addition, ASAN works to advance the idea of neurological diversity by furthering the view that the goal of autism advocacy should not be to create a world without Autistic people. Instead, it should be to create a world in which Autistic people enjoy the same access, rights, and opportunities as all other citizens. For more information, visit <http://www.autisticadvocacy.org>