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Research Essay: Autism Speaks does not Speak for Autistics

There are many organizations that strive to do they most they can to support the people they advocate for, unfortunately this does not apply to all advocacy organizations. Autism Speaks is *not* a nonprofit organization, and unfortunately is the world's largest autism advocacy organization in the United States. The organization is problematic and hurts the community more than it advertises to help it as it seeks alternative goals as opposed to what the autistic community truly needs. Autism Speaks is not an organization that should be respected but boycotted instead due to its beliefs of autism spectrum disorder as a disease to be cured, discrimination towards autistics and its misuse of funds.

One of the multiple reasons why AS has controversy is due to its research goals that do not benefit autistics but seek to rid of them. An ASD expert explained exactly what AS has been doing in their research. "What a lot of the research was doing was to try and find out what the genetic component was to see if there was an indicator that they could find before the baby was born" (WROC-TV). All of AS' research funding goes towards finding out what makes people born with ASD and how they can prevent it in the first place. There are areas of improvement that AS could choose to fund and improve such as creating a system to reduce the amount of time it takes to accurately diagnose a child with ASD. James and Luiselli claim that in the U.S. and Canada, it takes around four to five professional consultations before a diagnosis can be made which causes a lot of stress and anxiety for parents who are in the process of getting their

child diagnosed (3). Improving these long wait times can ensure the safety and care of these individuals to get the care they need as soon as possible such as therapy and medication procedures (213). Instead of focusing on autistics as people who need support to find ways to improve their wellbeing as soon as possible, Autism Speaks prioritizes on funding a goal that is ignorant to the autistic community's needs and has no benefit to their daily lives.

There have been numerous accounts of neurodiverse employees leaving their job from the organization due to the individuals feeling like they aren't being listened to or taken seriously. Robinson, an ex-board member of Autism Speaks expressed his feelings on not being heard as a neurodiverse individual by AS "I cannot continue to stand up for the public actions of an organization that makes the same mistakes over and over again by failing to connect to the community it purports to represent.". One of the "mistakes" mentioned was referring to Co-Founder of Autism Speaks: Suzanne Wright's op-ed writing piece in which she unprofessionally expressed her immediate desire for a solution to "The problem" which was referring to ASD. "Life is lived moment-to-moment. In anticipation of the child's next move. In despair. In fear of the future. This is autism." (Wright). Having the founder's intense beliefs of autism being a terrible disease that destroys families and people's wellbeing is unethical and these same beliefs reflect in how the organization chooses to treat the existence of ASD. Autism Speaks does not see autism as a cognitive disability that makes an individual who they are but something that should be eradicated completely like a disease. Autism is in fact not a disease but "a range of complex neurodevelopment disorders characterized by social impairments; communication difficulties; and restricted, repetitive, and stereotyped patterns of behavior." (Shannon 3). AS' founder does not understand herself that autistics themselves are not sick, they just need support with their disabilities and are not in need of being fixed.

Autism Speaks is not a non-profit organization, meaning that they are able to profit off any donations received. Being the largest advocacy organization in the United States also means that they receive a lot of support. The amount of money that goes towards paying the people in the company is astounding as Podkul mentions that “Autism Speaks pays its high-level officials quite well, with at least thirteen individuals taking in “well into six figures.”. Unfortunately, only about 1 percent of the total money donated goes towards supporting family service grants to help autistics. AS is just an organization that does not care about where its funding goes and makes profit off people's good intentions and generosity. In the past they have had ties to the antivaxx movement in which after it was scientifically confirmed that vaccines do not cause autism, AS continued to fund research into the possibility of vaccines causing autism spectrum disorder being true. Autism speaks wrongfully spreads its funds out to areas that are not in need, yet they claim to advocate for those with ASD.

There are people who already believe that the way Autism Speaks is run is not ideal, and it needs to be known how they choose to fund their research and treat the existence of those with ASD. There are other ASD advocacy organizations that exist that are non-profit and truly aim to educate the public as well as give support to autistics. Because of its failure to fund research that will help autistics, its beliefs of autism as a disease and its problematic distributions of funds, AS should be boycotted completely. The goal is not to take away who autistics are and for them to feel ashamed but to empower them with supports that allow them to have equal opportunities in life and improve their overall wellbeing.

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