OPINION: Fix the charity that wants to ‘fix’ autism

Most autistic people want acceptance and inclusion, not a cure

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Autism Speaks is the mega-charity of the autism world. Founded in 2005, it has an annual budget of $60 million, is known for its ubiquitous awareness walks and has a handsome array of celebrity backers. In some quarters of the disability rights movement, however, it has long been reviled for silencing and shaming autistic people.

The organization is criticized for the lack of autistic people on its board of directors and among its senior leadership. Its advertising materials also present autism in the worst possible light. One video portrays autism as a terrifying stalker, saying, “I am autism … I know where you live.” Critics claim it spends hardly any money on actually helping autistic people and that it supports abusive therapies. Worst, its mission calls for a possible cure for autism, which for many autistic people is tantamount to a call for genocide.

Autism Speaks disputes all these characterizations, but well defended by its giant piles of money, the mega-charity is usually able to ignore its critics. However, when best-selling author Steve Silberman recently published a high-profile op-ed in the Los Angeles Times criticizing the group, Autism Speaks responded with a call for unity. Could its willingness to engage suggest that it is on its way to becoming a less divisive member of the disability rights movement?

Perhaps, but there are two major obstacles: its mission and the lasting imprint of its founders.

Autism Speaks’ raison d’être requires believing that there’s an autism epidemic in need of a cure. Founders Bob and Suzanne Wright started the charity after their grandson was diagnosed with autism. Bob Wright was the chairman of NBC Universal, and the couple used their media contacts and money to propel the charity into the nonprofit stratosphere. Today, they continue to promote the idea that autism rates reflect a terrifying crisis. In its “call for unity,” Liz Feld, the charity’s president, wrote, “Since 2005, the prevalence of autism has doubled.”

Silberman’s new book, “Neurotribes: The Legacy of Autism and the Future of Neurodiversity,” debunks this notion. Rates of autism appear to be steady, he argues — we’re just much better at diagnosing it than we used to be. In an email to me, he said that Autism Speaks’ rhetoric “calls to mind plagues and other mass outbreaks of disease, when Feld would be hard pressed to find a single autism researcher who believes that the true prevalence of autism has doubled in that time.”

But what if, despite the flaws in its public messaging, Autism Speaks’ call for unity signals an openness to
change? I asked autistic activists to take the call at face value and articulate what it would take to achieve. Ari Ne’eman, president of the Autistic Self Advocacy Network, a nonprofit organization run by and for autistic people, said, “Autism Speaks would have to enter into meaningful dialogue with its critics, something it has always refused to do.” It would have to shift its agenda to align with what autistic people actually want. He added, “When they’re ready to take those steps, we’ll be waiting.”

Amy Sequenzia, a non-verbal autistic, points out that she might be considered the “poster child” for Autism Speaks’ idea that life with autism is tragic, but that she’s doing just fine. She said that if Autism Speaks wants unity, they must move away from so-called “fixing” therapies and ensure that “autistics [are] part of every conversation about what affects our lives.”

Autistic advocate Lydia Brown noted that simply including autistic people isn’t sufficient, because disability identity intersects with other aspects of identity (say, race, class or sexual orientation). “Autism Speaks refuses to take any steps toward empowering autistic leadership, let alone focusing on the leadership of autistic people from multiply marginalized backgrounds,” she said.

If Autism Speaks isn’t going to listen to its critics, maybe it could learn to listen to its own employees. Change is possible, at least judging from the history of disability rights. As Ne’eman wrote in a recent essay about disability and work, “Disability policy is full of examples of yesterday’s innovation becoming today’s indignation.” Peter V. Berns, the CEO of The Arc, another disability mega-charity and a critic of Autism Speaks’ alarmist rhetoric, confirms this assessment. The Arc changed its name from the National Association of Retarded Citizens because it listened to the community it represents — people with intellectual and developmental disabilities, many of whom serve on its board. Its policy ideas have evolved from advocating for better segregated housing, education, and work to full inclusion in all aspects of society. The Arc listens to its core constituency and adapts.

Alas, Autism Speaks continues to think its core constituency is parents, not autistic people. It also suffers from what is known as founder’s syndrome, in which the original goals of the founders prevent a non-profit from evolving. They need to empower new perspectives if they actually want to change. With the news breaking that Feld is resigning at the end of the year, the charity has a golden opportunity to shift trajectory.

In fact, it might even find new perspectives internally. According to CJ Volpe, its chief of media strategy, the charity “would welcome a person with autism on our board.” It’s probably unrealistic to expect Autism Speaks to invite an autistic critic inside, but Volpe notes the organization does have staff members with autism in important positions. I asked to speak with one, and that’s how I met Kerry Magro.

Magro is a motivational speaker, author and the social media coordinator for Autism Speaks. He has autism. He got involved with Autism Speaks through awareness walks in college, received an internship from them and eventually accepted a fulltime job offer. He would be delighted to see a person with autism on the board, but is unstinting with his praise. “Everything I’ve seen with Autism Speaks,” he said,
"is a lot of embracing individuals with autism."

Then I asked Magro about whether he needed to be cured. His response revealed a pathway forward:

For a long time, when I was a kid, when I was having speech difficulties, when I was having trouble making friends, when I was having a lot of communication delays, I always wanted supports to help me progress. Autism Speaks’ mission is to help in the lives of people who have autism. Cure — in the way I’ve always seen it — is just being able to give supports to people [so that they] can live the best lives possible whether it be physical, occupational, speech therapy, etc. I hope that we are able to put supports in place to help our kids progress.

Notice how Magro isn’t arguing against Autism Speaks’ mission, but he also isn’t using the language of epidemic. If Autism Speaks isn’t going to listen to its critics, maybe it could learn to listen to its own employees.

Every movement has its center and its peripheries. It should come as no surprise that the most privileged elements — white, monied, neurotypical — dominate the center of the autism advocacy movement, or that such do-gooders find it difficult to accept as valid any criticism of their efforts. I left my conversation with Magro, however, with real optimism about the potential for change within Autism Speaks.

Organizations can evolve, but inertia and founder’s syndrome are powerful impediments. Let’s keep the pressure on.

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