

Pollsters to Networks: Please Don't Use Polls to Decide Who Appears on the Debate Stage

ASAN talks about autism very much in the context of civil rights. (“The history of America, particularly over the last 100 years, has been a history of growing recognition of diversity and acceptance,” Ne’eman, the group’s president, told me.) And it criticizes Autism Speaks for failing to sufficiently involve those with autism. “The autistic community as a whole isn’t focused on cure, but that’s what Autism Speaks is focused on,” Bascom told me. “You can see that, in about every instance, it really boils down to: There are no autistic people in positions of leadership in Autism Speaks.”

It appears to be true that no one with autism serves on the Autism Speaks board, but the organization says those with autism have substantial involvement in its work. “Every member of the Autism Speaks board is personally affected by autism,” the group said via email. “We would welcome a person with autism on our board. We have staff members with autism in important positions and serving on our board advisory committees.” The statement also noted that many people with autism contribute to the group’s website, speak at events, and volunteer at walks: “Their voices play a significant role in shaping the priorities and mission of Autism Speaks.”

In an interview, Stuart Spielman—senior policy adviser at Autism Speaks, who has a 21-year-old son with nonverbal autism—noted the importance of science and research. “We are still working towards a fundamental understanding of the biology of autism,” he said. “And that’s very, very important if we’re going to be thinking about therapeutics.” But he also said that attention needs to be paid to the sorts of issues that would help those with autism to live fulfilling lives—that is, issues like education, employment, safety, and poverty, which tend to animate more civil-rights-oriented folks. “The challenge with autism,” he says, “is that we are really talking about so many different things and so many different kinds of individuals, and what is important to one person may be less important to another.”

Robison, who was diagnosed as being on the spectrum at age 40, has been a critic of Autism Speaks. He sat on the group’s science and treatment advisory boards, but resigned in 2013 after Suzanne Wright published an op-ed saying the United States has let families “split up, go broke and struggle” because of autism. “These families are not living,” she wrote. “They are existing.”

“That’s a tagline for fundraising,” Robison told me. “But I think that, if you’re leading an organization that represents autistic people and you say things like that, you have to recognize the powerfully corrosive effect that will have on the psyches of particularly young people who are themselves autistic.”

Another divide between Autism Speaks and ASAN has to do with applied-behavior analysis, or ABA, which is meant to teach people on the autism spectrum basic skills—from learning how to make eye contact to things like using the restroom. “It breaks the learning down into small pieces and allows learning one piece at a time,” Karen Fessel, founder and executive director of the Autism Health Insurance Project, told me. Autism Speaks supports ABA, but Bascom and Ne’eman have their concerns about it. Says Ne’eman: “ABA tends to be more focused on trying to make autistic children look and act normal rather than improving quality of life.”

OF COURSE, none of these approaches are mutually exclusive. The medical model and the civil rights model can co-exist. So, too, can the notion of helping those with autism to better interact with neurotypicals, while also asking the rest of the world to do more to accommodate us.

But it’s this last idea—asking the culture as a whole to change—that may be the toughest thing to accomplish. For David Black, this would mean, in part, parents shifting their paradigm and making peace with the fact that your “16-year-old boy isn’t necessarily the child that you dreamed he would be before he was born.”

There have already been some noteworthy cultural attempts to de-stigmatize autism. In October, for instance, *Sesame Street* unveiled a new Muppet with autism named Julia. Along with the Muppet, there is also a website and app with numerous features about autism. Prior to a congressional briefing on early intervention and the new Muppet in late October, Sherrie Westin, executive vice president of global impact and philanthropy at Sesame Workshop, told me that the project was three years in the making and brought together 14 different groups focused on autism, including both ASAN and Autism Speaks. “These are groups that don’t always agree, but at *Sesame Street* we were able to convene all of these groups together because they understood this is not about cause or cure or any of the issues that may cause controversy,” she said.

Perhaps the biggest thing that people with autism can do to change the culture is to simply come out. Not only can this help to change the way neurotypical people see us, but it can help to empower a younger generation of those with autism as well. As Robison recently wrote in a blog post about autism on college campuses: “It’s time for neurodiverse faculty to come out, and stand as role models for students and staff. Everyone knows how autism, ADHD, dyslexia and other neurodiverse conditions disable us as children. What we need to balance that are successful adults who attribute their achievements in part to neurodiversity.”

The day after Donald Trump made his idiotic comments about autism at one of the Republican debates, I wrote on Twitter that, by speaking the way he did, “you are telling us we are a malady.” A parent of a 12-year-old who is on the spectrum contacted me in a direct message and thanked me. “Knowing real examples of people w/ comparable challenges who have found the kind of career she’d be interested ... in is just phenomenally reassuring,” he wrote.

WHILE I WAS interning at the White House, I found out I had been accepted to the University of North Carolina at Chapel Hill. When I returned to California, I learned I had received enough financial aid to attend.

I made few friends my first year at UNC and felt deeply isolated. It wasn’t until I became overwhelmed with the course load that I started setting up regular appointments with an academic coach, who was a specialist in learning disabilities, to map out my weeks and better manage the stress.

Returning to UNC for my second year, I made it a point that I would try and get involved with something. Since I was majoring in journalism, I joined the campus newspaper, *The Daily Tar Heel*. During the 2012 election, I dove headfirst into covering North Carolina politics. By the end of my first semester at the newspaper, I knew I'd found my niche. And thanks to the paper, I built camaraderie and friendships that persist to this day.

During college, I interned at *The American Prospect*, and eventually, I landed a job at *National Journal*. For the most part, my employers have been pretty accepting of certain aspects of me being on the spectrum as long as I deliver in my work. And journalism has, overall, proved to be a good fit for me. The nature of political journalism is asking powerful people questions to elicit answers and, hopefully, get them to say something they shouldn't have said. I have found that my penchant for bluntness and my utter inability to tolerate spin has made me more willing to be forward in demanding answers.

This isn't to say all of my problems have been solved. I still take medicine for depression and for Tourette's. And when I go back home to California, I see the same psychiatrist I saw for years for my prescription. I also regularly see a therapist here in Washington. In addition, I abstain from alcohol and do not drive.

AS I WRITE this paragraph, I am sitting in my dining room on a Sunday evening listening to Stevie Wonder's *Songs in the Key of Life* album, occasionally taking breaks to dance by myself. The night before, I'd gone to see him perform the album live in concert with Maddy, one of my friends from college who now works in D.C.

Earlier in the day, Maddy and I had brunch with three of our other friends—one of whom is my roommate and another of whom is also on the spectrum. (From what I know, most of my friends are neurotypical, though I am friends with some people on the spectrum.) We all met working on *The Daily Tar Heel*. We talked about our work, reminisced about our college days, and our trials and errors in dating, like any other group of people. There are times when I make social hiccups or I don't realize when someone is joking and I need clarification. But overall, I can't help but think how fortunate I am.

I know that my life isn't for everyone and that my version of autism isn't universal. There are many with daily struggles that are much tougher than my own. But as I reflect on my fortune, all I hope is that society can stop thinking of autism exclusively as a disease—and start paying attention to how the actual lives of those with autism are unfolding. Those of us with autism want simply to live the most fulfilling lives we can. Some of us might welcome a cure, but some of us are more than content with who we are. And we all deserve our own pursuit of happiness.