



WORDS / APART

TWO DIFFERENT ORGANIZATIONS, TWO CONFLICTING IDEOLOGIES. ONE MULTIFACETED DISORDER.

STORY DEANNA PAN / LAYOUT KATIE EVERSON / PHOTOS PROVIDED BY JULIE CECYS AND MELANIE YERGEAU



THE PROBLEM BEGINS WITH WORDS.

A loss or lack of language skills is often the first of many atypical behavioral patterns observed in children with autism-spectrum disorders (ASD), according to the National Institute of Mental Health. As infants, they might not babble or coo in their mothers' arms. As toddlers, their speech may be limited to single-word utterances, if they're even speaking at all. As adults, the problem persists; sarcasm, literalism, humor and intention may evade them. Processing, ingesting and comprehending speech may be delayed. And for some, without the use of a computerized speech-generating device, the words just don't come out all.

Among the steadily rising crescendo of the autism conversation's loudest voices, words are symptomatic of a different problem—one that pits Autism Speaks, the most widely recognized brand of autism activism in the world, against a guerrilla group of the very kind of people it's trying to cure—the autistic men and women of The Autistic Self-Advocacy Network (ASAN). While Autism Speaks defines autism as a preventable condition, Noranne Cochran, a Columbus-based autism-rights blogger, like other ASAN members, talks about her Asperger's Syndrome like it's just a quirky, though profoundly defining, personal characteristic—very much like her spiky, neon hair.

For these autistic men and women, the problem begins with the word "cure."

"Cure can mean literally anything to the individual. For some mothers with nonverbal children, cure means their child is now verbal and can speak full sentences and has pragmatic speech. For maybe a mother with an Asperger's son, for him to actually hold a job longer than a month and maybe have a girlfriend could be considered a cure," says Cochran. "For some it means a complete, utter transformation of the individual inside and out—the removal of the core characteristic of that person."

The semantics of the word "autism," including its sprawling web of cause, treatment and prevention corollaries, have changed dramatically over the past 100 years: in 1911, the disorder was viewed as a symptom of schizophrenia. In the post-Rain Man age of the '90s, it was expanded into a spectrum of low-to high-functioning variation, including Asperger's Syndrome, a milder form of the disorder characterized by the retention of normal intelligence and language development. Today, the mystery surrounding autism continues to elude parents and researchers alike.

The highly publicized autism advocacy movement surged as reports from the National Institute of Health and the Centers for Disease Control and Prevention (CDC) continued to show a spike in autism diagnoses over the years; most recently, in 2009 the CDC estimated that autism spectrum disorders affect one in 110 children in the United States—up from one in 250 in 2001 and one in 2,500 in 1985. To some parents and family members, these were signs of an epidemic—a national public health crisis was on the rise. By the time Suzanne and Bob Wright, grandparents of an autistic child, founded Autism Speaks in

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OPPOSITE, FROM TOP: MEMBERS OF ASAN STAGE A PROTEST ON OHIO STATE S SOUTH OVAL LAWN ON APRIL 20; A REMINDER OF AUTISM AWARENESS DAY MARKS THE SIDEWALK ON THE OHIO STATE CAMPUS; A PROTEST SIGN MADE BY MEMBERS OF ASAN; MEMBERS FROM THE AUTISM SPEAKS STUDENT CHAPTER AT OHIO STATE POSE FOR A PHOTO ON THE SOUTH OVAL ON AUTISM AWARENESS DAY ON APRIL 2.

2005, autism had become the disorder of the decade and the quest for the cure was already underway.

"We are out to support as many families affected by autism disorders as possible," says Kim Niederst, a regional walk director for Autism Speaks, of the organization's primary mission. "We are out to find the answers to solve this. We are searching for a cure."

The theory of causation behind ASD remains equivocal and incomplete at best, fueling a spectrum of strife and debate that's as diverse as people with the diagnosis.

"Nobody seems to have the right answer and that leads to all of this confusion and push back," says Jerrod Smalley, a father of two autistic, little boys and the anchor of NBC4's "The Autism Puzzle" special. "Without the right answer, there's a lot of speculation that other people have the wrong answer. People are frustrated and I think that leads to some of the segmentation."

In no other place in the country is this segmentation in the autism community more apparent than in Central Ohio, home to ASAN's most active chapter and Autism Speaks's only student chapter at The Ohio State University. In addition to supporting autistic university students, speaking at academic forums and rallying for statewide insurance coverage for autism treatment, the Central Ohio/Ohio State chapter of ASAN is best known for its protests against Autism Speaks. The chapter picketed Autism Speaks at its fundraising walk in October and again in April on the Ohio State campus.

Although Autism Speaks's official position is to refuse to engage in any war of words with ASAN and instead, "go on with [their] important mission," Niederst, admits that, based on her conversations with her colleagues, "it doesn't seem like anybody else is having this big of an issue as we are."

At the heart of the issue is Autism Speaks's multi-million-dollar budget for autism-related, biomedical research, which reflects, according to Melanie Yergeau, an ASAN board member and president of the ASAN Central Ohio/Ohio State chapter, the organization's "medical model" approach to disability. She says Autism Speaks places "the burden on the autistic individual rather than putting the burden where it needs to be...a very one-size-fits-all society." For the self-advocates, more disabling than the disability is the society that construes it.

"If we are only seen from a medical model, then we're seen as pathological beings," she says. "We're seen as less than human. We're seen as people who need pity. We're seen as people who need help."

In 2006, Ari Ne'eman, a college student at the University of Maryland with an Asperger's diagnosis, founded ASAN to empower autistic people to self-advocate for issues concerning their rights and welfare, and to champion "neurodiversity," a buzzword used among "aspies" and "auties" in the autistic subculture that has proliferated in the blogosphere. It's the idea that atypical neurological differences in people ought to be respected and embraced, much like skin color or sexual orientation, rather than normalized.

"The ultimate goal [of ASAN] is developing an autistic culture and empowering autistic people to be

able to represent themselves and to have the world look at us as human beings with rights, and feelings and emotions—autistic people do have emotions,” says Yergeau.

From the beginning, ASAN challenged the objectives of Autism Speaks, condemning the organization on a slew of charges, including its governance’s lack of autistic people in significant decision-making roles, the use of fear-mongering and stereotyping in its fundraising campaigns and, perhaps the most serious accusation, the eugenic implications of an autism cure: Autism Speaks funds research on the prenatal detection of autism using molecular or biological markers on the human genome. Autism-rights advocates fear the discovery of an “autism gene” will enable mothers to screen their unborn children for autism, and ultimately, terminate their pregnancies if the disorder is detected. Approximately 90 percent of fetuses diagnosed with Down syndrome are aborted, according to multiple US and UK studies. Yergeau fears autistic children could meet a similar fate.

At her office in the English department at Ohio State where she’s working toward her Ph.D. in rhetoric, composition and literacy, she cites the following Suzanne Wright quote from Parade magazine:

“We’re now playing catch-up as we try to stem the tide and ultimately eradicate autism for the sake of future generations.”

“For us the corollary to that [statement] is to eradicate autistic people because without autism there aren’t autistic people and that’s a scary prospect for us,” says Yergeau.

But for some parents of autistic children, the prospect of living without a cure for autism is even scarier. Melissa Stacey has a 19-year-old son named Christian with a dual diagnosis of Asperger’s and bipolar disorders, and the mentality of a seven-year-old child. Christian’s exorbitant medical bills forced Stacey to file bankruptcy. The stress of taking care of Christian ended her marriage in divorce. Three years ago, her then 16-year-old, 250lb son beat her so badly in one of his violent rages, she crawled to the bathroom and locked the door. The police came and took him away to live in a group home with three boys on the autistic spectrum and 24-hour attendants. She currently sits on the Family Advocacy Council for Autism and while she doesn’t believe a cure will ever exist, she thinks that medical research should continue to investigate the best tools for treating autism.

“You know, I love my child for who he is, but it had such a huge impact on my family and my marriage and my finances,” she says. “If I could go back and say I wish it would have been this way, certainly I would. I think every parent would, but he is who God gave me and that is what I have had to deal with and live with.”

Her story echoes Neiderst’s concern about autistic individuals on the low-functioning end of the spectrum—that a cure “is necessary so families do not have to struggle with any of the effects of autism.”

But for the members of the Autistic Self-Advocacy Network, their autism, regardless of the effects it’s engendered, are intrinsic parts of their distinctive identity. And in a world where they feel misunder-

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stood and misrepresented, they’re compelled to hold on to that label, subvert its stigma and turn it into something to be proud of.

“We don’t need to be fixed, altered, changed or modified to fit into an already broken society,” says Cochran. “We just need to be as is, albeit with accommodations, but be as is. And that our viewpoint, words and thoughts and opinions are valued because they are autistic viewpoints.”

Yergeau says that unless Autism Speaks, at its national level, makes systematic changes to its advertising strategies, leadership and funding initiatives, the Central Ohio/Ohio State chapter of ASAN will continue to protest regional Autism Speaks events and will likely never collaborate with Autism Speaks’s local and Ohio State affiliates. For Yergeau, it’s not simply a matter of words; “the language that you use,” she says, “is rooted in very deep ideological premises”—premises that will continue to clash unless ASAN and Autism Speaks can stand on common ground.

“It’s like a political debate where both sides have great points, but don’t agree,” says Smalley. “What I think they can learn from each other is tolerance. I think we can all learn more of that and understanding the good that they’re and all of us are trying to achieve. The only problem with that is we may not all agree on what is good.”



OPPOSITE: MEMBERS OF ASAN PROTEST ON OHIO STATE S SOUTH OVAL LAWN ON APRIL 20. **ABOVE:** YERGEAU BELIEVES POSTERS LIKE THIS ONE MADE BY STUDENTS FROM THE OHIO STATE AUTISM SPEAKS CHAPTER EMPLOY FEAR-MONGERING TACTICS.