



# Calling a Truce in the Spectrum “Wars”

Michael John Carley

**A**S BEST AS I CAN REMEMBER, the episode of HBO’s *Curb Your Enthusiasm* went like this: The main character, Larry David, meets a friend on the street.

“Are you coming to my dinner party?” he asks. The friend replies, “I can’t. We have someone staying with us who’s a survivor. I just think he’d feel out of place.”

“Don’t worry about it,” David reassures him. “I also know a survivor. I’ll get him to come, and we’ll seat the two of them next to each other.”

Comes the dinner party.

In one seat sits an 80-something veteran of the Dachau concentration camps—his tattoo still prevalent.

Sitting next to him is a 20-something male who had been a contestant on the CBS series *Survivor*.

The next camera shot has the two men standing at the table arguing.

“We were *gassed!*” screams one.

“I had to eat *bugs*, man!” screams the other.

Funny or not, hold that image for a moment.

At a recent autism event, a mother whose son has moderate Asperger’s (AS) and I were talking. We’d met long ago, had talked about our experiences as parents, and had even worked on a foundation board together. Now, we were finally meeting each others’ AS kids for the

first time. After my son had introduced himself and went back to playing, the woman turned to me and said, “Your son doesn’t look like there’s anything wrong at all.”

What caught me off guard wasn’t the words she used. The text, though slightly out of place, was harmless enough. It was the tone that was striking. It was downright resentful. And if it was resentful or jealous enough for *me* to recognize—diagnosed as I also am with AS—well then, that’s saying something.

Was I surprised by this remark? A little—maybe I was even slightly hurt. In an instant she had decided that the two of us, as parents, weren’t in the same boat anymore. Her attitude rendered the shared experience of having children on the spectrum null and void, all because our kids didn’t have the exact same functionality level. I actually felt as though I’d been accused of lying about my son’s diagnosis.

My initial impulse after hearing this remark was to *defend* my son’s Asperger’s—to *prove* to her that he does indeed have it. I was also tempted to pettily dig back with a nasty remark. Well, I don’t remember what exactly I *did* end up saying, but luckily it wasn’t offensive. Also, this was somebody I liked, and I knew deep down she’d meant no harm. But this little incident is very indicative of a new attitude that is hurtful to all of us, though especially hurtful to *adults* with AS, PDD, and autism.

As Executive Director of GRASP, I see people from all over the spectrum in our support group networks.

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## The autism spectrum is exactly that— a spectrum—with challenges that cannot be measured by functionality alone.

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Roughly, without any statistics to back me up, I'd ballpark-guess that about 15% of the people who attend our groups are mild AS (as opposed to 70% moderate, and 15% severe). Many of those diagnosed as mild are experiencing a growing pressure *not* to speak about their experiences, because supposedly their experiences aren't deemed as relevant or dramatic as the experiences of more challenged folk. To those of us mildly involved folks on the spectrum, the insinuation seems to be that we'll get in the way of funding and attention paid to the more severely-challenged folk. Three recent trends suggest that this isn't mere paranoia ...

1. There is a growing desire by the more alarmist autism groups to paint AS and autism as completely different conditions that have decidedly different prognoses: AS = You have countless Nobel prizes awaiting you. Autism = You're doomed!
2. There are hateful e-newsletters that attack higher-functioning folks on the spectrum—heck, even those characterized as moderate—because they call themselves *autistic*. Now, even if they have a point in stating that it's inaccurate for these folks to refer to themselves in this manner, why don't these newsletters go after the clinicians and book writers who encouraged the word's use? Why, instead, do they attack already-challenged individuals (who, by the way, did not diagnose themselves)?
3. There is a growing backlash against diagnosing famous, deceased individuals (in retrospect, obviously) with AS or autism. When one examines the characteristics of Einstein, Edison, Jefferson, or Emily Dickinson that are suggestive of autism, some neurotypical people get jumpy.

Back in the days when I served as a minor-league diplomat at the United Nations, we called discussions regarding who had the greater burden, *competitions of suffering*—a phrase used to give certain arguments the aura of useless waste that they deserved. The autism spectrum is exactly that—a *spectrum*—with challenges that cannot be measured by functionality alone. The problems people face aren't lessened or heightened by

“placement” on the spectrum. They are just *different*. Think about it: the higher the functioning level, the more the potential for awareness increases. So, I'm certain that when all the facts are in, the higher suicide rates will line up along the spectrum in a pattern that mirrors functioning level. Severely-affected folks aren't generally self-aware enough to want to consider suicide.

Where the functionality argument becomes a problem, is when a vocal minority of advocates for those at the more-challenged end of the spectrum seem afraid that GRASP's messages of self-worth and potential will conflict with their message that there is *only* desperation. Dumbing these complex issues down to functioning level—at the high end of the spectrum you should be succeeding, whereas at the low end, it's understandable if you don't—doesn't do the adults that live these lives any good. This is particularly true for those at the higher end of the autism spectrum, since it is precisely the unrealistic expectations for success that have caused neurotypical people to judge mildly involved AS people as failures when they don't meet those expectations. The very nature of the difficulties experienced at the higher end of the spectrum surrounds unmet expectations, not the lack of them.

In 1994 when Asperger's was entered into DSM-IV, it changed everything. And the apparent resentment that exists over the loss of pre-1994 definitions and terminology—when higher-functioning folks didn't qualify for a diagnosis—must stop. It is hurtful and divisive. Pigeonholing autism and Aspergers into opposition camps only invalidates the experiences of both sides, and gives governments and foundations exactly the excuse they need to refuse funding. (i.e., “Look at them; they really don't know what they're talking about.”)

In a competition of suffering, we'd all agree that the Dachau survivor wins. Furthermore, the CBS participant suffered his travails by choice. But who's to say that participants from the CBS series *Survivor* don't endure some very legitimate trauma?

Coming full circle, the comedy inherent in the HBO show referenced at the beginning of this article lies in the absurdity that such a competition would exist at all. And the root of all comedy, as we know, is tragedy. So I hope with everything I have that we temper this real-life absurdity, and that everyone on the autism spectrum,

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and their advocates, come together to unite in the fight to get everyone the services they need and deserve, even if the needs may differ dramatically.

At present, we are dividable and conquerable. Together, we'll all be far better advocates. The other hope I have is that I can teach my son to instantly dismiss people that push him to *prove* he has AS. Not only does that invalidate his very real challenges, but it is also no reward for how hard I see him working day in and day out to try and succeed. 🏠

## Bio



Michael John Carley received his B.A. from Hampshire College in 1986 and his M.F.A. from Columbia University in 1989. As the Executive Director of GRASP, the largest organization comprised of adults on the autism spectrum, he has spoken at conferences, hospitals, universities, and health care organizations. He has also appeared in the print media, most notably in the NY Times, Washington Post, NY Newsday, the London Times, the Chronicle of Philanthropy, and the Chronicle of Higher Education. In addition, he has also been interviewed on CNBC, and Terry Gross' *Fresh Air* as well as *The Infinite Mind*—both of which are on National Public Radio. His article, *GRASP at One Year: A Personal and Very Unprofessional Look Back* was widely circulated.

Until 2001, Mr. Carley was the United Nations Representative for Veterans for Peace, Inc. At that time, he was known primarily for his work in Bosnia, and in Iraq as the Project Director of the internationally acclaimed *Iraq Water Project*. Prior to 2001 he was a playwright who enjoyed 15 productions and 10 readings of his plays in New York. Today, in addition to running GRASP, he moonlights as a classical music host for New York Public Radio (WNYC). Along with his (then) 4-year old son, he was diagnosed with AS in November of 2000. Mr. Carley is at work on a memoir entitled, *Of Course You Are*. He lives with his wife and soon-to-be two sons in Brooklyn, New York.

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