



The OARacle



The Monthly E-Newsletter of the Organization for Autism Research
"Research and Resources That Help Families Today!"

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Dodged Bullets

Note to readers: Beginning this month, *The OARacle* will include new bi-monthly 'Perspective' column that will provide a firsthand account on a range of topics related to autism from someone affected by a developmental disorder. In this month's column, GRASP Executive Director, Michael John Carley, reflects on how his unknown case of Asperger Syndrome affected his childhood.

When it was first presented to me that my son and I might have Asperger Syndrome (AS), it didn't seem right. I was 36 years old, and I had at least enjoyed some semblance of a life. I was married, a father, and I had a somewhat ok resume—And suddenly this form of autism was being linked to me? What a crock!

That reaction was short-lived. The more I learned about AS, the more it became obvious that AS was exactly what I had, and my eventual diagnosis explained a lifetime of puzzles. As time went on I became head of the Global and Regional Asperger Syndrome Partnership (GRASP), an educational and advocacy organization serving individuals on the autism spectrum. I heard from other AS adults and it became clear to me that my experiences prior to diagnosis were something of a series of dodged bullets. I could only deduce that I had accidentally avoided traps that ensnared most other AS folks. I do not think I succeeded where others failed due to any personal strengths. Instead, my accomplishments resulted from pure and unjust luck.



Michael John Carley

When I was in 2nd grade, for example, my school demanded I undergo a psychiatric evaluation. The resulting observations were quite accurate. Today their notes would read as obvious AS qualities. Back in 1973, however, when no one knew anything about AS, they led to different conclusions. Psychiatrists summarized their observations (my obstacles) as “emotional difficulties” due to a father that had been killed in the Viet Nam war. Now, as sad as that might sound to some, this at least elicited some pity from many teachers, family members, and neighbors who otherwise would have been comfortable disliking such a supposed nuisance of a kid. Not that the misunderstanding wasn't without its drawbacks, but given how kids with autism spectrum conditions were handled back then, I was lucky that this mistake occurred. Without my father's death to mislead the psychiatrists, my behaviors likely would have been labeled as 100% antagonistic, which would not have served me well.

People with AS have difficulty picking up on the social signals (such as facial expressions, gestures, and vocal tone) that play such an important role in human interaction. Well, I was the product of a card-playing family; and to not study the bodily signals of opponents could mean losing my allowance. I therefore became better in this capacity than most folks with AS would otherwise.

By the time I was 12 I drifted to the arts. I ran desperately into the arms of an alternative high school and was thought of as a talented guitarist in many a terrible rock band. My behavioral differences were then placed into the positive category of artistic eccentricity. Others who suffered from AS without the “talent” label likely endured gut-wrenchingly different and traumatic realities. My artist mystique also gave me a pass for some of the mating games most teens and young adults engage in to achieve intimate contact with one another. In such cases, my inabilities at flirtation or small talk only furthered the artistic reputation. People misinterpreted me to be “above the banality of such stupid rituals.”

Later I became a playwright, along with which came lots of actor training. The physical work I did in these classes, such as breathing and movement exercises, helped me iron out my motor skill issues and made me much more aware of my body. Also, acting is essentially learning what it is like to be in another’s shoes. Furthermore, the arts are probably the most behaviorally accepting work field there is so my diagnosis was overlooked once again.

Until I was 27, I drank. And as hard as it is to confess, being one of many alcoholics in an Irish-Catholic lineage, I’m glad I did. I simply would not have had the social experiences I did otherwise. Even if those friendships were questionable at best, I am convinced they were better than no experiences at all. Mind you, I don’t want anyone to emulate this path. I would instead suggest that a more behaviorally permissive playing field be created. Kids on the spectrum shouldn’t have to drink in order to participate in developmentally appropriate experiences.

After graduate school, my day job had me working as a minor-league diplomat at the United Nations. Now some folks might say, “How could you do that with AS?” But the answer is very simple: As a minor-league diplomat, you don’t have to interpret anything. UN officials tell you quite clearly how you’re supposed to address this person or that person, how you’re supposed to sit in the general assembly, what clothes you’re supposed to wear...etc.

As part of the same job I often traveled and worked in places like Bosnia and Iraq. We all know 9-5 office jobs contain politics and social rules that are almost never spelled out. And since there’s such a pool of workers to draw from, how you got the job done is often just as important as completing the task itself. This did not apply to me when I was working overseas in tense and often urgent situations. No one cared how I got the job done, only that it actually got done. That was a great comfort to someone like me.

What I am today, and what too many of our folks are not, is confident. However, my life thus far can just as easily be perceived as a failure as it can a success. None of my various careers have stuck; I have not enjoyed (nor wanted) many friendships outside of work colleagues. And even though I am happily married, my first marriage ended in divorce, albeit amicably.

My biggest challenge now is the balancing of when to assimilate to the rest of the world’s way of doing things, and when I should “do my own thing.” This is best illustrated by my behavior when my son (we’ll call him “John”) first began trying to invent new games, whether the games were board games, athletic games, or card games. Having once been where he was, I knew his inventiveness was not just creativity at work. He knew somewhere inside him that he felt shut out of existing games, and that inventing new games was the most empowering option he had in the face of isolation from his peers. Even though my supposed success had been based on paving my own road, I steered him away from this. I made him instead get better at the existing games, and learn the rules. No matter how much better he may have it because of the different world he’ll enter, our way will still be the minority way. If I am to give him a chance to succeed in today’s world, then I have to teach him those rules.

Later on, no one will laugh or agree with him more than I will when he confesses how stupid everyone else’s rules seem at times. Adaptation is not a requisite in our house—I would be a hypocrite if it was. But John must have it as an option so that he really can have the life that he wants. No one should expect, or have to rely on the inexplicable luck that I had.

As the Executive Director of GRASP, Michael John Carley has spoken at conferences, hospitals, universities, and health care organizations.

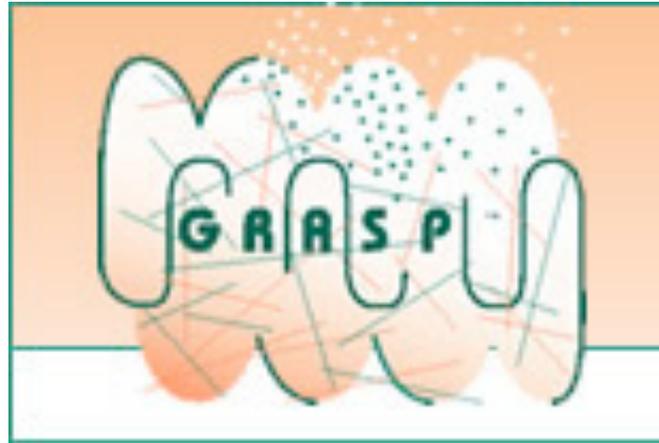
He has appeared in the media widely, most notably in the NYTimes, Washington Post, NY Newsday, the London Times, the Chronicle of Philanthropy, the Chronicle of Higher Education, on CNBC, and Terry Gross Fresh Air as well as The Infinite Mind—both on NPR. His article, GRASP at One Year: A Personal and Very Unprofessional Look Back was widely circulated. Mr. Carley also serves on the Advisory Board of the Long Island-based parents and professionals organization, AHA/AS/PDD. Until 2001, Mr. Carley was the United Nations Representative of Veterans for Peace, Inc. In 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; and under these auspices, he also hosted a monthly radio show, Progressive Radio Today. Also 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) and is currently at work on a memoir entitled Of Course You Are. He lives with his wife and soon-to-be two sons in Brooklyn.

Profile: The Global and Regional Asperger Syndrome Partnership (GRASP)

In this month's issue of The OARacle, we profile the Global and Regional Asperger Syndrome Partnership. A bi-monthly feature, the Profile focuses on the valuable contributions of a member or organization in the autism community.

The Global and Regional Asperger Syndrome Partnership (GRASP) is the only non-profit support group network of its kind.

Formed in 2003, GRASP provides educational outreach, and advocacy for persons with developmental disorders and serves as an informational clearinghouse on issues relating to the autism spectrum. Most importantly, however, GRASP requires that its Executive Director, Advisory Board, and half of its Board of Directors be diagnosed with either Autism, Asperger Syndrome, or Pervasive Developmental Disorder in order to serve.



"We, having been diagnosed with Asperger Syndrome or High-Functioning Autism, and noting the steady increase in our own population, do hereby affirm our responsibility to serve not just ourselves as a community, but all of society and the world," declares the organization's web site.

GRASP Executive Director, Michael John Carley, who was diagnosed with Asperger Syndrome in 2000, says the group's membership has already increased from approximately 300 to 2,000 in just three years. Headquartered in New York City, GRASP has developed many professional affiliations with various parents' and advocacy organizations as well as research institutions including the Center for Brain Health at New York University. In the future, Carley says the organization also plans to address issues of health, advocacy, and monitoring that face the autism community.

"The progress has been surprising to say the least," Mr. Carley said. The network has already expanded from the New York tri-state area to as far Iowa. Carley says that he anticipated that it would take at least four more years for GRASP to go national. "The growth has been wonderful in terms of the message being well received."

Carley is quick to point out that GRASP caters to all members of the autism community. He estimates that 70 percent of those who utilize the support group network are of moderate functionality, whereas higher functioning individuals and those with severe cases each comprise 15 percent. And since GRASP is the first group organized and run by individuals on the spectrum, Carley says he feels that it is incumbent upon the organization to succeed to prove that such individuals are capable of organizing themselves.

“We want to show that people on the [autism] spectrum can have the capacity to run a successful non-profit business,” said Carley. “If we turn out to be a failure, then all our messages will be for naught.”

More information about GRASP is available on their [website](#).