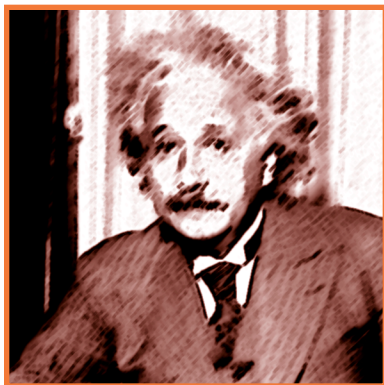


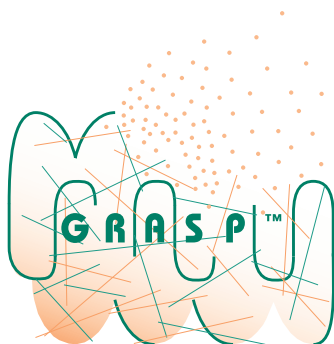
**Some people believe that Albert Einstein  
may have had Asperger Syndrome.**



**Well if he did, then amongst the world's most  
celebrated icons, we know he wasn't alone.**

**The talents of all those remarkable,  
autistic people got developed . . .**

**. . . They were the lucky ones.**



## The Problems

According to the U.S. Centers for Disease Control and Prevention (CDC), approximately one out of every 100 people—3 million Americans—has a diagnosis along the autism spectrum. Whether the diagnosis is Autism, Asperger's Syndrome (AS), or Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS), most of these individuals have untapped talents and abilities that could truly benefit society. But because of the lack of understanding and the stigma attached to these diagnoses, many people on the spectrum eventually feel unwanted. As years pass, and the negative experiences accumulate, people on the spectrum endure decreased self-esteem, increased frustration levels, and too frequently this leads to anxiety, severe depression, or worse. Few people in the general public really understand what living on the autism spectrum is like, and acceptance for the harmless (and often marvelous) behavioral and intellectual differences is still quite rare.

Since the inclusion of Asperger Syndrome as a legitimate diagnosis within the DSM-IV in 1994, the number of people diagnosed on the autism spectrum has skyrocketed. Adults especially are being diagnosed in huge numbers, as society plays "catch-up." Much of this is wonderful; for as individuals are finally given a more accurate reason why they may appear different to the outside world, it is a "why" that is centered on wiring, and not on personal fault or perceived shortcomings. Yet the outside world is still in need of education if spectrum individuals are to feel accepted and accommodated.

We all fear the unknown. And when someone's noticeable behavioral differences are without explanation . . . our inaccurate assumptions can err on the side of the negative.

### What is Asperger Syndrome?

*Asperger Syndrome (AS) is generally considered to be a form of autism characterized primarily by deficits in social interaction and non-verbal communication. More specifically, people with AS have difficulties to varying degrees with perceiving the world from the perspective of another person and in "picking up" on the social "cues" (facial expressions, bodily gestures, tone of voice, etc.) that constitute such a significant portion of human interaction. Having AS can mean having great abilities in certain areas, but it can also mean never leaving the home of one's parents, never holding down a job for any extended period of time, and perhaps never enjoying an intimate relationship.*

*Although there is no single distinguishing trait or characteristic common to all people with AS (named after the Austrian clinician, Dr. Hans Asperger, who first described it in 1944), there are numerous behaviors that are commonly observed. These include intense interests, sensory issues, loyalty, a resistance to change, truthfulness, awkward body movements (such as flapping of the hands or feet and rocking back and forth), above-average math skills, poor eye contact, and a strong literal-mindedness.*

*It is expected that in 2012-2013, the DSM-V will do away with "Asperger's Disorder" and incorporate it under the umbrella of "Autism Spectrum Disorder."*

As the prevalence numbers increase, so too rises the need for appropriate educations, living situations, and behavioral adjustments from *everyone* to help make this a truly pluralistic society. Yet as any educator, researcher, or clinical professional will attest: school boards are overwhelmed, housing authorities are swamped, and the clinical world is scrambling to keep up with rapidly changing definitions and terminology.

### **Prior to GRASP**

Before 2003 there were no truly influential advocacy or educational organizations servicing adults—certainly none that were composed of the individuals themselves. Before 2003, the focus was almost entirely on children, whose lack of life experiences made them easier to explain, and whose emotional appeal was greater than grownups (as grownups had more complicated histories that frustrated the clinical world). It was easier to feel that children could be helped, and clinicians were eager to intervene early and change the child rather than the environment. Before 2003, if an organization wanted to raise awareness, their campaigns had to begin and end with children. In children, it was thought, there existed the only potential for hope.

#### **GRASP's Boards . . .**

*. . . continue to grow. Currently, there are twenty-three individuals among the Advisory Board and the Board of Directors thus far, most notably Dr. Temple Grandin, and Dr. Stephen Shore.*

Before 2003 the vast majority of clinical, research, school, and social service professionals did not feel they could learn by listening to successful adults on the autism spectrum. Whether in the hundreds of autism conferences that had little or no input from adults, or in planning sessions for programs catering to the needs of adults, those without these conditions became more and more comfortable speaking on behalf of a people they had not adequately consulted.

Before 2003 it was not even known that the vast majority of people on the spectrum could speak. It was not known that most could hear what was being said about them, and read what was being written about them. Neither was it therefore known how much negative terminology hurt adults' chances for self-love. It was not known that words like "cure" and "disease," when overheard, put people at an even greater psychological disadvantage than that which they'd been born with.

Before 2003, it was not well known that people needed to hear about what they *could* do, not what they couldn't do.

### **GRASP**

In 2003, GRASP, the Global and Regional Asperger Syndrome Partnership was formed as a result of a generous grant and fellowship provided by the Fund for Social Change in New York City. What makes GRASP unique, other than its proven nationwide support group networks, programs, and outreach, are the stipulations GRASP must adhere to in accordance with our bylaws—that the Executive Director, 100% of the Advisory Board, and 50% of the Board of Directors of GRASP must all be diagnosed on the autism spectrum.

GRASP began with an emphasis on partnerships, and as a result, GRASP has many professional affiliations. GRASP works in tandem with many parents' organizations, service agencies, and research organizations. Since 2004, GRASP has also enjoyed a contract with the New York City Public Schools to help design and implement programs for their autistic students. GRASP also conducts outreach—either through the national office, or through its regional networks—helping to spread the perspective of individuals on the spectrum. GRASP is not solely responsible for the changes since 2003. But GRASP's willingness to engage, rather than demonize, its ideological opposites, has most certainly helped the greater collective.

GRASP has grown by degrees that few could have imagined when it began. GRASP became a national organization long before anticipated, significantly expanded its support group networks (23 in 2010) and subscriber numbers (adding about 1,000 new members per year), and has built the most comprehensive website of its kind ([www.grasp.org](http://www.grasp.org)).

GRASP enjoys an annual benefit gala bestowing three awards on our recipients; the DNA ("Divine Neurotypical Award"), the FAB ("Friend and Benefactor"), and the DSM ("Distinguished Spectrumite Medal"). GRASP is also grateful to be represented pro bono by a major Manhattan law firm; Lovells, LLC. GRASP looks forward to the day when spectrumites reach adulthood without the mistakes, anxiety, depression, and sometimes anger, that too often accompany a life lived in the behavioral minority. The adult on the spectrum that exists in 50 years may be someone we cannot even imagine.

Whether it's to join one of our regional networks, our families and clinicians network; or just to gain access to the GRASP Global online group, we hope you'll log on to subscribe. Participation in any of our programs, as well as obtaining membership, is free of charge.

### About the Executive Director . . .

Michael John Carley received his B.A. from Hampshire College in 1986 and his M.E.A. from Columbia University in 1989. As the Executive Director of GRASP, he has spoken at conferences, hospitals, universities, and health care organizations. He has appeared in the media widely, most notably in *the New York Times*, *the Washington Post*, *NY Newsday*, *the London Times*, *the Chronicle of Philanthropy*, *the Chronicle of Higher Education*, BBC Radio, on Terry Gross' *Fresh Air*; and a Peabody-nominated episode of *The Infinite Mind*. His articles have been published in numerous autism magazines, and his first book, *Asperger's From the Inside-Out: A Supportive and Practical Guide for Anyone with Asperger's Syndrome* (Penguin/Perigee) received unprecedented advance praise.



**Michael John Carley**  
Executive Director

Until 2001, Carley was an NGO Representative at the United Nations known primarily for work in Bosnia and Iraq. During this time he was also a playwright who enjoyed 15 productions of his plays, and until 2008, he moonlit as a classical music host for New York Public Radio (WNYC).

Along with his (then) 4-year old son, he was diagnosed with Asperger Syndrome in November of 2000. He and his family live in Brooklyn.

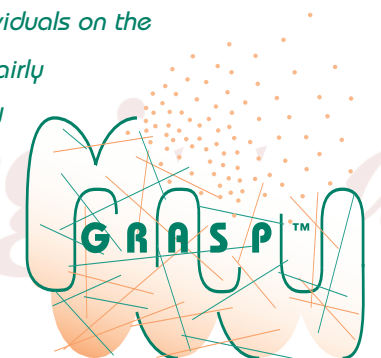
### **GRASP's Mission:**

*GRASP's mission is to improve the lives of adults and teens on the autism spectrum through community outreach, peer supports, education, and advocacy.*

### **GRASP's Vision:**

*At GRASP we envision a world where all individuals on the autism spectrum are respected, valued, and fairly represented; where appropriate supports and services are readily available to those in need; and where people on the spectrum are empowered to participate in policy and personal decisions that affect their lives.*

—Drafted; Summer, 2002.  
—Revised; Summer, 2008



*The Global and Regional  
Asperger Syndrome Partnership*

To obtain a free subscription to one our many elists  
(including one for families and clinicians)

To join any one of our free regional support groups

To join any one of our free online support groups

To obtain months of free reading and listening  
through our Articles and Interviews page

To learn about the autism spectrum

To take part in one of GRASP's events

To get help

Or to give it

Go to . . .

**[www.grasp.org](http://www.grasp.org)**

666 Broadway, Suite 830 • New York, NY 10012  
1.888.474.7277 .....(phone and fax)  
[info@grasp.org](mailto:info@grasp.org) .....[www.grasp.org](http://www.grasp.org)

Brochure and logo design © Michael John Carley • Photo of Michael John Carley courtesy of Ron Haviv

