

The Origins

By Michael John Carley
Pictures By Frank Fournier



The Global and Regional Asperger Syndrome Partnership

In March of 2001, an adult diagnosed with Asperger Syndrome (AS) was asked to take over the Adult Asperger Syndrome Support Group of New York City. The outgoing facilitator, a wonderful man named Harry Feigenbaum, was stepping down.

I was that new facilitator, and was assisted for a time by Philip Jimenez-Snyder. We saw the group rise from a list of 13 people to a list of over 300 within two years. The reason for this is arguable. But the probability was not that we were master facilitators. The better guess was that an individual with the diagnosis had a better chance of eliciting the full trust of the group members, and therefore the turnout rose tremendously.

Most of our folks have spent lifetimes trying to explain themselves to people close to them, often the people entrusted to their care. Try to imagine how frustrating it would be if you had to teach your doctor about foot pain, or if you had to teach math to your math teacher, depression to your psychologist. Who should pay who here? Well, alleviate that obstacle; let trust enter the mindset in all its relieving, happy glory and you will see a different person, trust me.

As people in the autism world started to take notice of our rising numbers, there we were (Philip and I), getting credit for this marvelous thing happening in Manhattan that really was being driven by a life of its own. Our growth was merely the repercussions of adults on the spectrum finally not having to explain themselves to others—adults discovering the joys of shared experience for the first time.

In the summer of 2002, Philip, myself, and three others from the Manhattan group spent a night in my apartment making a draft of what we considered to be an ideal national organization run by and for adults on the spectrum. Fifty percent of the board members, 100% of the advisory board, and yours truly, the executive director, all had

of G.R.A.S.P.

to be diagnosed on the autism spectrum. We had a fun time, but without funding we figured that we'd merely spent an evening clarifying our own unrealistic dreams.

Our reputation kept growing along with our numbers and in 2003, after a speaking

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engagement of mine at the NY College of Medicine, a man, who turned out to be Dr. David Tobis of the Fund for Social Change, was waiting to talk to me afterwards. He in short asked, "What's your pipe dream?" intimating we think about starting a non-profit organization.

I at first said "no," having just recently worked as a minor-league diplomat at the United Nations, where it was proven (though I could compensate in other areas) that I had no fundraising skills. But Dr. Tobis suggested I apply for their Fellowship to become a better fundraiser. I did, I got it, and they did indeed make me better. How good remains to be seen :-)

In October 2003, GRASP, the Global and Regional Asperger Syndrome Partnership, was formed from a generous startup grant provided by the FAR Fund, based at the Fund for Social Change. Dr. Peter Gerhardt, who'd arranged that fateful speaking engagement, and Dr. Tobis himself were corralled as two of the first board members. Spectrumites like Dr. Valerie Paradiz and Liane Holliday Willey, Ed.D., were soon added, and GRASP

was off and running. GRASP's subscribers now number in the thousands.

Were we the first autism organization to have spectrumites on the board of directors? Absolutely not. Far over a decade, autism non-profits had been electing adults with autism spectrum diagnoses in advisory capacities. Neither were we the first "by



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and for" organization of autistic adults, as groups like Autism Network and autistics.org (among others) had been providing a political voice for adults on the spectrum long before GRASP burst onto the scene. The next logical step in this historical context was us, a group whose very bylaws demanded the "by and for" notion be guaranteed, but who also wanted to put as huge an emphasis on fundraising, legislature, advocacy, and education as the other large, neurotypical-run non-profits. In short, we wanted:

- an organization that paid employees, contractors and vendors the same as neurotypical employees, contractors and vendors got paid in neurotypical organizations. Any non-profit is still a business, and we figured that if we just became another noble, broke, pity-inspiring organization that could write forever about what it was against, and only half a page about what it was for, then all our messages of possibility would be proven wrong.

- a website that wasn't just good, we wanted to give our adults the best autism website, period.

- the kind of clout that forced the "powers that be" to grant us a seat at those tables where decisions were made—and not just to be left protesting outside the building.

- an organization that, in its ideals, would stick to the earlier-established notions of using respectful, not to mention medically-accurate terminology (no "cure" talk) that didn't make adults feel worse than they already did.

To obtain all that, we would have to impress. And we would start strongest by serving those adults as best we could.

Through all this grand thinking, through our being vendors with the NYC Public School system (helping them design and implement full-time summer programs for their autistic students), through the educational and advocacy work we do, it is still our support group networks that are our bread-and-butter, our "raison d'être." Probably the biggest credits to GRASP are its regional Network facilitators, the all-star list of its board members, and the dynamic range of opinion embedded in its advisory board. Yet, we also succeed through a zealous belief in partnerships and committed relations with like-minded others, be they parents, organizations, service agencies, research institutions, or advocacy organizations. And we succeed because, amidst our need to separate, lies the paradoxical desire for integration into greater society—or at least to have that as an option. We do not separate for separatism's sake. We separate to become whole so that we may re-enter the world better-equipped to be our

own self-advocates, better-informed, armed with options so that we have the choice of whether to assimilate (to the majority way of doing things) or to choose not to assimilate without feeling cheated.

Spiritually we operate on old, old ideas of community. While GRASP's controlling members are predominantly at the higher-



functioning end of the spectrum, this often misleads people to thinking that the people GRASP services are diagnosed equally mild. Untrue. Ballparking such an unobtainable statistic, I'd wager the people GRASP serves to be 15% mild, 70% moderate and 15% severe. This is sometimes hard on participants, as higher-functioning folk often get scared when thinking that they mirror those with huge needs and challenges. Similarly, more

severely-challenged folk don't want to be presented with the same expectations as those who are higher-functioning. Sticking it out, both ends learn more about them-

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selves, and they learn that problems don't get worse or better the more you travel on the spectrum, they simply become different. And hopefully, they learn what it is like to take care of one another.

Funding remains a challenge, especially in the wake of the unprecedented growth that has thrown us all for a loop. But it's a wonderful problem to have. Becoming the largest organization of adults in the world in just two years has been a beautiful thing to watch, and I say "watch" because it's hard to assume credit for something you know in



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your heart progressed simply because it was time. The world was ready. **TAP**

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