

A Big, Big Transition at GRASP

By MICHAEL JOHN CARLEY

This past March, 2013, after ten years, Kate Palmer took over from as the Executive Director of GRASP, the largest organization of adults on the spectrum in the world.



Light Through Yonder Ocean Window
Embarrassingly enough, it was a moment that came to me on a surfboard ...

As I already admitted in my first book, "Asperger's From the Inside-Out," I'm a lousy surfer. I don't stand up too often on the board, and after 20 years of comic underachievement, I decided to finally ask for help and get a lesson. Through the genius of Yusef, my Moroccan sage of the waves, I was now standing with more regularity than usual... on a highly unusual trip.

I was mildly burnt out, and my wife had graciously issued me abroad to get some alone-time. So off I went: no computer, no cell phones, no ipod, and no booked hotel; with only a small carry-on containing a change of clothes, two books, and a deck of cards (though underneath the plane, dare I admit it, was a guitar).

It had been a rough period. We'd lost the fight to get the American Psychiatric Association to allow independent review of the proposed changes to the DSM-5 (the American psychiatric bible), we'd testified in the debacle that was the United States Congress' first-ever hearings on autism, and the horrific shootings in Newtown, CT had us doing damage

control (thanks to CNN's demonic portrayal of Asperger's Syndrome [AS]) in media appearance after media appearance while our day-to-day work piled up.

But more importantly, I'd struggled as a fundraiser over the prior 18-24 months — and it wasn't like I wasn't getting chances. Generously invited to the same events and circles that provide such opportunity, I was simply hearing more "no"s than I was accustomed to, and I couldn't for the life of me figure out what I was doing wrong. In addition, hating what I sadly perceive as "losing," I struggled internally, as well as externally. Granted, given all else that we were doing there was little time to spend on fundraising. But still...

My first days in Morocco settled me down as I listened to, and felt moving water eight hours a day, ate tiny sand-side lunches of rice and minced fish, and reveled in the solace of a trip that was costing a lot less than most weekends in Miami. No one knew me here — a clean slate. So I was well-conditioned for the light-bulb that went off above my head one day as I attempted to ride (what for most would be an easy) 4-footer.

What the light-bulb said was this: that I had been selling GRASP to those potential

donors with an urgency that they knew didn't exist anymore, but that I thought still carried dramatic weight.

GRASP had accomplished everything it set out to do in 2003. It had built a large membership network presently containing 28 chapters, it had removed — also with help — the negative iconography associated with the diagnosis (people forget how bad it was ten years ago), it had given thousands of spectrumites the mountain-moving power that comes with shared experience, and it very quickly shamed the clinical and advocacy worlds into addressing adult needs (beforehand... everything was all about kids). Built on old ideas of community, and new ideas about behavioral pluralism, we hadn't just succeeded... we'd flourished beyond our wildest dreams. But someone had neglected to tell me. Once you cross this figurative finish line, no one tells you — There's no checkered flag that signals the end of such a long haul. And if you've been buried in the same task-focused tunnel vision for over a decade, you're especially unable to see the signs that all has been accomplished. As I pitched to them, those donors were likely thinking, "What's he talking about? The need he's describing doesn't really exist anymore."



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After I wiped out came the more frightening stage of the light-bulb's wisdom... realizing that I didn't have the vision for what GRASP's next step should be.

At the risk of driving the euphemism of the tunnel into the ground, said underpass's darkness had conditioned my eyes so that when I emerged from so much hyper-focus, I was blinded, as my eyes struggled to adjust to the light outside. Searching with only my hands for the next tunnel I knew that my only idea for that next journey was a bigger, better version of the same tunnel I'd just been through and strategic planning can't, and doesn't work like that. Organizations need fresh ideas, not retreads, and they need to change with the times. What is summoned by the words "Asperger's Syndrome" may not be the mud it used to be, but we succeeded so well that the real problem now is in some people's perceptions that the diagnosis is a fad.

Yes, I can still identify the problems that exist today — but most of us can do that. The rare talent is the one who can identify solutions. And I have better visions for where other people's organizations should go than I have for my own, and so I needed to get out.

But I also wanted to. Given the stagnant pace of the last two years, "minding the shop" of an entity that does not grow — simply to enjoy a steady job — is agony to me. Due to the generosity of others and not to any particular brilliance on my part, I've simply grown too spoiled at top forward-moving vehicles, or figurative waves, and such fortune has created an individual too addicted to having an impact, to be ok with treading water.

My Board of Directors knew about the fundraising woes, but they were still surprised by my news once I returned and told them of my decision. Alison Alpert, our Deputy Director wasn't so surprised (more testament to how well she and I worked together) but we all were scared. None of us had ever experienced the sort of transition we were about to embark on. But one saving grace held out hope... a woman named Kate Palmer.

Kate

I honestly don't believe the light-bulb in Morocco would have appeared had I beforehand not spotted someone that I knew could replace me. As per GRASP's bylaws, the Executive Director must be diagnosed on the spectrum, and there are many spectrum-unfriendly aspects of the job (Herculean restraint is probably at the top of the list). But as I got to know Kate over the years, I saw she had the makeup. She had the smarts, she had (as an active clinical social worker) the listening ability, and most of all she had the emotional strength to take a punch, or several, and still emerge as a whole enough person who could quickly laugh off whatever insulting, threatening, or moronic experience had just transpired.



Thank goodness she wanted the job.

The Board has never worked harder than they are now at this transition — There's even more outside help that's been brought in as a result of our collective fear. Alison resigned as Deputy Director but she's agreed to take on, as a volunteer, certain aspects of website monitoring and maintenance. And Kate has dove into her work with guts, brains and heart. GRASP's members, regional facilitators, and other staff seem to like her tremendously. For my part, I'm retaining spokesperson duties until the Board decides GRASP and Kate are ready. But transitioning is still a scary place. Kate will need GRASP's friends to help her, and her fundraising ideas will have to work if GRASP is to move forward.

"Whew" . . .

During my minor-league diplomat days at the United Nations, the company I worked for, a veterans organization, went through an ugly transition whereupon their founder was forced out. The organization had changed, and was splitting in a seriously nasty manner. There were camps, and sides, fights over Board majorities, and it threatened to bring the entire, wonderful organization down.

I was enamored of this founder. He was someone who (like most of the organization's members) had experienced war, but wanted to work now to prevent or stop wars. And so simply out of loyalty, and not because I was that educated about the fiery organizational disagreements, I was in his "camp," however dispassionately. But one day I went to a meeting of the other side, just to hear what their arguments were, and upon discovering that I had attended this meeting, my clique made it clear to me that this had

been unacceptable. That their take on my inquisitiveness was comically dysfunctional was known to me at the time, and so I brushed their childishness off dismissively without hurt feelings. But that, and the founder's continued use of the term "my baby" to describe the organization, had taught me a lesson. I would later learn that this lesson is not unusual—it even has a name. It's called "founder's syndrome."

The "my baby" analogy is appropriate to describe the relationship between founder and their sired entity – I know this now for real. And if the baby in question is successful, than the reputation of the parent is naturally elevated with their peers (and in unhealthy ways, the parent can become addicted to this). But babies grow up, become their own person, and usually, they leave their parents. As Andrew Solomon wisely notes at the beginning of his masterpiece, "Far From the Tree," we don't reproduce when we have children – we produce. And after a while, it becomes time for this natural separation to occur (even if the parent wants to stay in contact, hear how well the organization is doing, and maybe even get a visit every once in a while).

Hard as it may be to believe, this experience was vividly on my mind when I started GRASP. I hoped with all I had that I wouldn't

succumb to chaining my child at home when it became time for it to sprout wings. And my current relief that this didn't happen is indescribable. From my perspective, we did everything right.

What next for me? Recharge the batteries, hopefully all summer, write, and then honor the obligations I have to my real children, and get another job. I may have left the best gig I'll ever have, and according to a lot of folks that ain't too smart these days, but I'm real good at dreaming, and trusting. All I ask is that the next challenge satisfies that addiction to change.

Funny, I used to hate change... There really is nothing more zealous than a convert.

Michael John Carley is the Founder and Spokesperson of GRASP, the Executive Director of ASTEP, and the author of "Asperger's From the Inside-Out" (Penguin/Perigee). Information on GRASP can be found at www.grasp.org ■



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