

Addressing the Needs of Adults on the Spectrum

What They *Can* Do - Not What They Can't

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Before this decade, adults on the autism spectrum were rarely considered in our collective psyche. Maybe photos of adults weren't effective fundraising devices as were photos of kids. Maybe adults were considered too damaged by life experience and/or inappropriate accommodation for us to look at them without our hearts breaking. And maybe as a greater community it was too much shame for us to confront. Even if when no one is aware, there really can't be blame.

Several factors contributed to our expanded thinking:

- We suddenly knew a lot more. Through dramatically increased knowledge about the spectrum, we gained more confidence in addressing the needs of everyone diagnosed with an ASD (i.e. there was hope!). We felt we were finally armed with the right tools to tackle the subject of improving the lives of adults.



- As the children of pioneering parent's advocacy groups grew up, their needs, as moms and dads, changed. They subsequently demanded the same alterations to greater society for their transitioning children, as they had advocated for when their kids were much younger.

- Peer-run organizations such as GRASP emerged, showing the potential inherent in adults.

Yet the most instrumental factor in our relative success has been our capacity to listen to those adults. Gone was the myth that everyone on the spectrum (even the

majority) was non-verbal. They felt, they spoke, and many listened.

Those that lent an ear heard stories about what had worked in the lives of adults (what had worked when they were children and what works now) and they also heard stories of what had not worked. Whether the subject was educational strategies, behavioral regulation, employment accommodations, or social skills training, the clinical world (and beyond) that listened benefited enormously.

Many also did not listen, and still don't. Despite the strong protests of adults, certain groups and organizations still use words like "cure" despite the medical *and* ethical problems inherent in the word's use. Vaccine theorists continue to paint people on the spectrum as chemical accidents. And it is an ongoing battle trying to convince the world that the behavioral differences of "spectrumites" are not as threatening as they might think.

Like anyone, adults on the spectrum need to know more about what they *can* do, not what they can't. They can read what's written about them, and they can hear what's being said about them. And while there is

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much tragedy in our autism/asperger world, alarmist campaigns citing only said tragedy cause psychological harm to a population already psychologically challenged enough as it is. Messages of hope, acceptance, and accommodation are not only nicer to the adults (and children) being discussed, such affirmations will be of far greater spiritual benefit to the messenger as well.

I have the privilege of running GRASP—The Global and Regional Asperger Syndrome Partnership—the largest organization in the world composed of, and run by, adults on the spectrum diagnosed with Asperger Syndrome (AS), Autism, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Before both I and my then four year-old son were diagnosed with AS in late 2000, I was a starving playwright by night, and a minor, minor-league diplomat at the U.N. by day, working on projects in places like Bosnia and pre-invasion Iraq. I was lucky. I had proof, not the faith-based



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words of self-help spin, telling me that I'd enjoyed something close to "a life" before that life-changing diagnosis at age 36.

Mine was the gift of conviction, not hope.

Quickly after making such a dramatic career change, I started to hear the plethora of stories coming from the adults that visited our nationwide network of peer-run support groups. Yes, there were stories of misfortune that paralyzed the listener. Stories of misdiagnosis leading to misprescribed pharmaceuticals, stories of consistently misinterpreted intentions... stories of giant mistakes made over the years that had irreparable consequences. One quickly could see that the depression, anxiety, and sometimes anger that existed now didn't need to be there; and wouldn't have, given a world that knew what it was doing.

But there were also tales of unbelievable heroism and resilience that taught me more than the most exhilarating war stories heard abroad in my earlier life. There were stories about learning how to trust, stories telling of smart choices concerning when to assimilate to the rest of the world's way of doing things, and stories about when not to.

I, and everyone else at GRASP, have consequently developed a rather large,

and sometimes overwhelming, sense of purpose. And yet, that sense of purpose is not to be interpreted as mired in sympathy. Given the talents, and the sometimes unreal abilities of people on the spectrum, of all the marginalized populations there are on this earth, *this* one can benefit greater society the most if better understood, if better accommodated, and thereafter more respected. Working on behalf of adults on the spectrum is clearly akin to working on behalf of everyone.

Let's be real: who in their right mind *wants* to be ignorant, scared, or in fewer cases, prejudiced against people with neurological differences? Think of the loss of anxiety we'd *all* enjoy in such a world. Binding those on the spectrum, and those off, is that we all fear the unknown.

In addition to his duties as the Executive Director of GRASP (www.grasp.org), Michael John Carley is also the author of Asperger's From the Inside-Out: A Supportive and Practical Guide for Anyone with Asperger's Syndrome (Penguin/Perigee).