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## Two Winding Parent Paths to Neurodiversity Advocacy

Carol Greenburg and Shannon Des Roches Rosa

### Shannon Des Roches Rosa: Encountering Neurodiversity as a Terrified Outsider

I came into neurodiversity activism sideways. It isn't the main reason I co-founded the online nexus and book *Thinking Person's Guide to Autism* [1]—the goal at the time was to debunk autism misinformation, and provide useful, evidence-based resources for autistic people, their families, and autism professionals—but neurodiversity, with its respect for and celebration of diverse neurologies, ended up being our organization's guiding principle.

I didn't know the word "neurodiversity" in 2003, when my son was diagnosed with autism. I wish I had; maybe I wouldn't have fallen so hard for misinformation about vaccine, causation, and autism cures. I admit

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that being exposed to that era's sensationalistic and negative media messages about autism made me vulnerable to false-hope-based cure hawkers, and that I put my son through "treatments" that were a waste of time and money.

I will never stop being ashamed of how, under the guidance of a medical doctor who convinced me and my husband that he could "treat" autism, I subjected my autistic preschooler to a full autism quackery barrage: innumerable supplements and dietary restrictions, pseudoscience "electrical field" treatments, vitamin B12 injections, and even preparation for chelation—all of which I publicly detailed at my personal blog [squidalicious.com](http://squidalicious.com) ([2]; though I was writing under the pseudonym "Squid Rosenberg" at the time).

## Rejecting Autism Quackery

Though it took too long, I eventually wised up to the fact that no child deserves to be treated as a fixer-upper rather than a fully present human being—especially the sweet little boy I was supposed to be fighting for. I will always be grateful for the frank talking-to my medical professional father-in-law gave my husband and me on not subjecting our son to chelation "treatment", as well as my guidance from generous science- and neurodiversity-minded individuals about autism origins and autistic ways of being. The only way to pay back that debt is to pay it forward.

Once I realized that we had been not only duped but fleeced by autism quacks, and were making my son miserable while autistic rather than non-autistic, since he was born with his autistic brain, I became hell-bent on helping others avoid my very avoidable mistakes. I shared my autism and parenting epiphanies publicly, not only on my blog, but in Steve Silberman's book *NeuroTribes* [3]—mortifying though it remains to detail my early fear and ignorance regarding my own child's needs.

I also founded Thinking Person's Guide to Autism (TPGA) in 2010 with Jennifer Byde Myers, Emily Willingham, and Liz Ditz. We set about gathering evidence-based autism resources presented in straightforward but supportive terms, addressing some of our community's starker realities, as well as barriers to accessing services and accommodations. We started

by publishing articles on our website, with the best going into our 2011 book. We also built vibrant social media communities.

## Learning Why Neurodiversity Matters from Insider Perspectives

One of our first published essays, sourced by Ditz, was Mike Stanton’s “What Is Neurodiversity?” [4]—also one of my first exposures to the term. Stanton emphasized the need to respect autistic ways of learning and perception as not just “different” but legitimate. We also began working with more autistic authors, and realized having an autism organization with no diagnosed autistic team members was both inappropriate and embarrassing. We invited Autism Women’s Network officer Carol Greenburg, a skilled editor as well as an autistic mother of an autistic son, to join our team. Thankfully she agreed to do so, to TPGA’s ongoing benefit as well as mine—Carol has become one of my dearest friends, in addition to being a treasured colleague.

As TPGA grew and expanded, and our author base skewed increasingly autistic, my neurodiversity education grew, along with that of many of our community members: as an autistic community outsider I can’t understand the autistic experience without access to autistic insights, and neither can other non-autistic community members—especially since autistic experiences, traits, perspectives, abilities, and personalities are multitudinous, even as autistic commonalities unite the community.

I have become reliant on neurodiversity-informed perspectives, on the insights of people who describe the reality that my mostly non-speaking autistic teenage son and other autistic people experience, and actually help make the future they deserve to happen. Without the neurodiversity concepts of respecting and supporting different minds and abilities, without the inclusiveness neurodiversity demands, autism advocacy efforts risk becoming factionalized and leaving people in need without the support and community they deserve.

Though essays like Julia Bascom’s “Dear ‘Autism Parents’” [5] initially felt hostile, with statements like “If you do indeed, as you claim, want to be *allies*, then I suggest you start *acting like it*,” when viewed through a

neurodiversity lens, it is simply a statement of affirming autistic identity and rights—and for my son, too. When I watched Mel Baggs’s video, “In My Language” [6], and saw that Mel is multiply disabled in ways mirroring my son yet could also describe that experience in writing, it destroyed my unexamined assumptions about the boundaries between disability and ability. And when the Autistic Self Advocacy Network ([www.autisticadvocacy.org](http://www.autisticadvocacy.org)) demands “nothing about us without us,” they are taking their rightful seat at the head of the autism roundtable, rather than trying to bar the concerns and questions of non-autistic parents like me from those discussions entirely.

I also had to confront flaws in my own thinking as my understanding of neurodiversity evolved. I fought against autism-vaccine disinformation because such statements are provably false. But neurodiversity activists like Emily Paige Ballou ([chavisory.wordpress.com](http://chavisory.wordpress.com)) helped me understand that not only do vaccines “have nothing to do with autism,” but framing autism as an “injury,” or even saying “don’t worry, vaccines don’t cause autism” is still making my son’s neurology into something to be feared rather than understood and accepted—and that is both stigmatizing and counterproductive.

Some neurodiversity-informed approaches have been harder to sow, due to widespread misinformation about autism and disability. We’re still working on helping people understand that it doesn’t matter how many people (and industries and lobbyists) support and promote applied behavioral analysis as a “treatment” for autism, if the goal is to turn an autistic child into a non-autistic one, because that’s an approach many adults who experienced ABA as children describe as PTSD-inducing. Instead, we need more people to understand and work with autistic children’s unique set of intellectual, visual, sensory, auditory, communication, and motor processing abilities.

Overall, I believe the team efforts behind TPGA have been successful. We hear from people every day who are grateful that we include perspectives that reflect their own experiences, demonstrate why presuming competence matters, further the shaking off of stigma, make them feel less alone, and provide insights into their children, students, clients, or even selves that they’d never considered before. And most of these efforts wouldn’t be as useful as they are, if they weren’t neurodiversity-informed.

I will always be learning more about what neurodiversity means. I now better understand the foundational drive of respecting and ensuring rights for people of diverse neurologies, and reject my initial assumption that neurodiversity advocates deny disability, but the process will always be a journey. (And not always an easy one: that while neurodiversity advocates are often the most delightful and compassionate people one will ever meet, neurodivergence doesn't protect autistic people from being capable of flawed logic, bad choices, ignorance, and outright cruelty.) But I now understand that neurodiversity is not only a fact of life but a litmus test: I can't trust people who don't support neurodiversity, not when it comes to autism best practices, or my son's future.

## **Carol Greenburg: Advocacy Rooted in a Neurodivergent Family Tree**

Before I knew many autistic adults who knew they were autistic, before I met any autistic bloggers, before TPGA existed and asked me to write a piece for them, it was about the money for me. I had helped a friend to get services for her child on the spectrum and realized I had a knack for cutting through the layers of red-tape that cordoned children like my son off from services to which they were legally entitled. I thought I could do some good and get paid for it.

So I decided to become a non-attorney special education advocate, and get paid for my work. Non-attorney advocates don't, and shouldn't charge anywhere near as much as people who go through law school and pass the bar, but even without a legal degree helping families properly prepare for and effectively represent them at IEP meetings takes knowledge and attention to detail. Processing that knowledge takes time and barrels of energy, which I think should be reflected in a paycheck.

I see the option of paid work, of contributing to my household income, as a part of adulthood I had never quite mastered. I was tired of the message that getting paid consistently with real cash for my real expertise was not a goal I was likely to reach. My first clue? Chronic under employment and unemployment in my previous attempts at paid labor, the annoying sticky

companion of so many autistics, so many women, and especially autistic women like me.

## **Suddenly My World Made Sense**

Despite my education and skills, I was fired from almost every job I held in my twenties and into the first half of my thirties. I didn't understand why, until what I had suspected was confirmed by the autism spectrum diagnosis I got when I was 44. The notion that I am autistic didn't surprise me at all. Autism doesn't just run in my family, it gallops. My son was diagnosed at 3 1/2. I called my Dad the day after we learned about my son's autism; back then Dad could still use a phone. Absurd as it now seems to me, I struggled a bit, probably more with my own internalized ableism than with any rational fear of his reaction to the question I wanted to ask him: Did he think, as I did, that there was a reason for the peculiar similarities between the three of us? To his eternal credit he didn't laugh at me, but to this day I maintain I could practically hear him roll his eyes over the phone when he gave me a definitive yes.

My Dad never got a formal diagnosis, but even before he lost most of his spoken language to a series of strokes, he has quietly carried an autistic pride banner for all of the rest of our autistic family, living and dead. In communications between the two of us, ever more halting and difficult as they are to conduct, he has expressed our shared belief that we would not trade our autistic reality for some artificial construct invented by non-autistics whose brains and experiences differ from ours so much. I did and do still check in with him periodically to make sure it's OK that I've been continually outing him as autistic and proud for over a decade. He used to tell me that he felt if I could spread that message I should, for the sake of all of us, as he dislikes how we are portrayed as having lives not worth living. Nowadays, he gives me an elaborate flourish of his hand that says to me "Carry on!"

My diagnosis took the edge off that shame and gave me some valuable context: It was now clear how much my autistic brain shaped my autistic cultural assumptions. Office politics were not only senseless, but actively offensive, built as they were on a scaffold of lies and tacky dominance

performance art. I wouldn't have participated in them even if I could have. That was only one of many social trappings of standard workplaces from which I hoped entrepreneurship would free me. The problem became not so much what, as how: I knew I wanted to start my own company as a non-attorney special education advocate. The problem was, how would I attract clients?

I had written professionally before the Internet existed, so I had some sense of what writing required, and now with the existence of blogs, I had a ready-made platform. My blogging didn't pay, but I thought my writing might help establish my expertise for clients I hoped to attract. I saw the most positive responses I got as contributing to good Karma if not immediately to my piggy bank, and tried to keep faith in the notion that getting my name out there would eventually yield some concrete results.

Paid or unpaid, advocacy by autistics for autistics is vital, but when I started this work, I felt strongly that my brand of advocacy would be linked to the economics of womanhood and autism. I was tired of lectures about the beauty of voluntarism. Women's work, autistics' work seemed to result in strikingly similar outcomes: enthusiastic praise that was supposed to somehow compensate for the lack of financial parity. Service-for-service's-sake is a principal that can stretch only so far before it becomes a burden bulging with the resentment of those serving.

However the eternal problem with a do-over in a new field still hovered over my goal. It is difficult to begin a new work life without taking a few steps backward, which in my case meant more volunteering in addition to writing. I ended up creating a DIY apprenticeship to settle myself into presenting myself as a professional. I started helping longtime friends with their children's IEP prep and meetings. In between helping individual families, I wrote, spoke, designed and delivered workshops, almost always for free. Sometimes, I had great experiences: my first clients, old friends all, treated me with respect because that's how friends act.

The treatment I got from people I didn't know, the ones who wanted me to do free workshops or write free articles: that was more uneven. Although some of these strangers eventually became welcome, enduring parts of my world, others I couldn't escape fast enough.

One workshop organizer scolded me for using the word "Autistic" to describe myself—and my own son. To her, I had no right to describe my

own personhood in the terms of my choice. Workshop participants, mostly non-autistic parents of autistic kids, often meant well, but did no better than that organizer, and thought they were complimenting me when they said I didn't "seem autistic" like their and my own mostly non-speaking kids (I speak pretty fluently, unless some upset robs me of language). I felt that thanking them for their attempts to praise me violated my personal policy of not accepting compliments at the expense of my people: It never makes me happy to hear that I'm not like other autistics—or women, or feminists, or Jews—anyone has met.

Then there were the editors, who asked for free articles, which they wanted to rewrite to reflect their own usually non-autistic biases. I like my own always-autistic biases better though, and except for minor edits for clarity, I held firm to my belief in my ability to spout my own opinions better than anyone else could spout them. I was getting discouraged. Then a new blog called Thinking Person's Autism asked me to submit a piece and my world changed again.

## **A Chance Encounter. A Permanent Change**

A month or two after I wrote that piece for TPGA, a chance encounter became a permanent part of my life. It wasn't a paying gig, but it has led to many, and at least as importantly: I finally got to get used to the kind of treatment I think all people deserve. At a panel at a BlogHer conference about busting autism myths, I met the woman who came up with the topic for the panel, Shannon Des Roches Rosa. She was there with Jennifer Bye Myers, her co-founder of the new project TPGA. Shannon had an idea that should seem pretty obvious to all of us now, but *Simply Wasn't Done* back then: She invited an Actual Autistic to join the panel.

As it turned out, the wonderful autistic advocate they originally invited was unable to attend. I volunteered to pinch-hit last-minute. I met Shannon, Jen, and the other panelists ten minutes before we went on.

I'll never forget the first thing Shannon said to me: She asked if I needed help getting up to the podium. I was amazed by the thoughtfulness of the offer. Like many autistics, I have trouble with proprioception, the awareness of where my body is in space. Although I can use stairs without



assistance, and if I try hard enough to mask the effort, I can hide how hard it is for me to just get around without falling, bumping into objects and people, or knocking things over. But when I have a problem that indicates my impairments, I'm used to people laughing at me, despite my explanations—because I just don't seem THAT autistic. So the only logical conclusion is that I'm clumsy, or I'm not paying attention or—as any autistic reading this has undoubtedly already predicted—I'm not Trying Hard Enough. Even though I am trying as hard as I can, every moment of every day of my life, even during the moments only I can see and feel. Shannon got that instinctively.

Later that day, Jen offered to let me wait in her hotel room while she grabbed something she needed for an upcoming presentation. I hesitated, because I have experienced that wrath of those who have made insincere, token offers that I accepted because I didn't know some rule (hidden to me) that I was supposed to demure. I decided to take a chance and explain that she needed to be absolutely clear with me about whether her offer was genuine, because I need spoken subtitles for social niceties. I realized her offer was real when she actually thanked me! No stranger for whom I had done a workshop or panel had ever thanked me for telling them exactly what kind of accommodation I needed. Mostly they just seemed annoyed.

## **TPGA: A Neurodiverse Ecosystem**

A few months after meeting Shannon and Jen, I was honored by an invitation to join the editorial team of TPGA. We pay our authors, but I don't get paid for my TPGA editorial work; none of the editors do. My opinions carry the same weight as those of the non-autistic editors. I want to emphasize that: The Same Weight. So if our audience likes what we publish, I may play some part in our having published it. Conversely, if they loathe what we publish, I bear as much responsibility for it as anyone else on the editorial team.

My work with TPGA remains one of the great honors of my life. Staff discussions and occasional disagreements may be blunt, but they are also respectful. While I can't define the totality of Neurodiversity even for

myself, much less anyone else, I know spaces where I can see it. TPGA is had always been one of those spaces for me.

I still do a lot of public speaking, often for money and/or at least travel expenses, and I enjoy it. How I am introduced depends upon the organization and audience. Some autism professionals and parents still feel uncomfortable around adult autistics, perhaps they expect me to judge their efforts harshly, so they soft-pedal my own autism and play up my role as the parent of an autistic son.

When I speak publicly with my co-editors at TPGA, I think it is not at all coincidental when whoever has invited us makes the greatest effort to combine all of my roles in the autism community. Those are the times when the word “self-advocate” pops up, and I do understand why, but it makes me a little uncomfortable. It is a term many autistics embrace, but I don’t find it entirely descriptive of what I do, professionally or personally. Do I self-advocate and teach self-advocacy to my autistic son? Of course, because self-advocacy means nothing more or less than insisting on one’s full rights. In my view self-advocacy is not a job in and of itself, but an expression of our dedication to living as we are. For people with disabilities in particular, the world does not approve of us accepting ourselves as is.

With the death of some in my family, and other circumstances in the lives of the other autistics whose light we can still see in this world, I’m the only autistic left who uses spoken and written languages with any fluency. Of course, I’m active in protecting my father’s and son’s rights, and I am accustomed to but continually disgusted by the efforts of many non-autistics to treat them as somehow lesser because they don’t express themselves primarily with written or spoken language.

Like all loved ones my father and my son are sometimes sources of frustration and sometimes sources of joy, but that’s a function of their humanity, not their disability. I have never been and will never be the only person in my family who has expressed agency in my own life, and my allegiance to my autistic family members’ rights stands, no matter what. Just I see myself as a full human being with all of my human rights intact I ally with my autistic family members who have fewer words when they get subpar treatment, because I am a daughter and mother of disabled men who are equally, fully human.

That is where Neurodiversity starts to gel—at least for me. Neurodiversity in my world, is the unquestioned right for all, whatever their neurological makeup, to express what they need or want. None of us get what we need or want all of the time, and that’s OK. Getting everything you request, or demand, is not the reality of anyone I know, no matter how much privilege they have, whether they own up to it or not. I don’t think any of us, of any neurostatus, should get every golden, silver, or copper ring we reach for, but everyone should have stable, level ground from which we can launch authentic discussions about what we owe and what we deserve.

## Conclusion

We wouldn’t know each other if it wasn’t for neurodiversity, and our individual journeys in understanding and embracing what that means both for ourselves and for our families. Now that our paths have crossed, we are obligated to collaborate on sharing our ever-increasing knowledge with the world. We also have the (often humbling) experience of hearing how our work, especially with TPGA, is positively influencing others’ lives—autistic people and their families, of course, yet also professionals, academics, policy makers, and researchers. I hope we’ll continue to working together for the foreseeable future, because opening people’s minds to why neurodiversity matters—both as a human rights concept and because individuals deserve respect—is a worthy endeavor.

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