

Wearing Two Hats: On Being a Parent and On the Spectrum Myself

by Phil Schwarz

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I wear two hats – my Daddy hat and my Aspie hat. I’m the father of a 13-year-old high-functioning autistic son, Jeremy, and I’m also an adult with a mild variant of AS. That has had a significant impact on how we have responded as a family to autism, and I’d like to think that it has produced some insights that are worth sharing with other families with family members on the spectrum.

Although Jeremy is HFA and has learning disabilities, and I was labeled “gifted” (40 years ago, long before anyone would have known to more appropriately describe me as AS and gifted), there is a significant number of “been there, done that” moments that dawn on me through the course of Jeremy’s development and school career. When we have the good fortune to be working with teaching staff, clinicians, and others who are open-minded and adept enough at integrating divergent perspectives, my being able to articulate those moments and convey the insight they can yield really helps.

I am probably at a disadvantage in advocating for Jeremy when the climate is adversarial – when it is too political and dependent upon the understanding and exercising of power in relationships. The kind of networking among savvy parents that functions as a unifying force in such climates is often beyond me. The syncopation and divergence in my conversational style – when I am not closely self-monitoring and self-censoring – come across as awkwardness and annoyance and work to my detriment in team meetings and teacher conferences. And there are times even in the friendliest of climates where an NT (neurologically typical – non-autistic) parent’s perspectives and instincts are just plain necessary for grounding and completeness. We are fortunate in that regard: my wife Susan is NT. When we work as a team, I think Jeremy gets the best of both worlds as a result.

But I want to focus some more on the conveyance of “been there, done that” insight. I think there is something really fundamental that underlies it. That something is the capability – and importance – of pointing out meaning in autistic behavior, sensory and aesthetic sensibilities, cognitive patterns, and emotional processing – and of asserting their legitimacy.

The purely medical model of autism, as characterized in the diagnostic manuals, dismisses these things as meaningless. But it does our kids (and adults!) on the spectrum a great disservice by doing so.

Autistic traits are far from meaningless. Autistic behaviors are often the best adaptations an autistic person can make to sensory or cognitive stress – adverse sensory stimuli, or inundations of cognitive content too much and too fast to process with the available

bandwidth. Autistic sensory and aesthetic sensibilities – however repetitive, boring, or strange they may seem to others – serve the same purposes for autistic people that conventional sensory and aesthetic sensibilities serve for NTs: to calm, to soothe, to center, to ground, to rejuvenate, to energize. Autistic cognitive patterns are often the most adaptive way an autistic person has available to integrate new information, to learn. And autistic emotional life is far from barren, once one learns to set aside expectations of emotive expression that are appropriate for the NT majority but not necessarily for those on the spectrum.

Once meaning is made clear, autistic responses and adaptations to the world around us are demystified and start to make a great deal of sense. And once that sense is understood, the door is opened to greater communication, trust, cooperation, insight, and learning – for both parties in a working relationship between autistic and NT people.

Those of us with a foot in each world – that of parents, and that of people on the spectrum – can help elucidate that meaning, and it is important that we do so.

But there are far fewer of us than there are NT parents of kids on the spectrum. And while the notion that autistic traits have meaning and legitimacy is patently obvious from lifelong experience to those of us who are ourselves on the spectrum, for NT parents of kids on the spectrum it is often initially a significant leap of faith.

Fortunately, there is a small but growing body of literature available by authors among those of us who “wear two hats” that testifies to the meaning in autistic perspectives and experience. The writings of authors like Liane Willey, Valerie Paradiz, Jean Kearns Miller and others make that leap of faith about meaning, with a parent-to-parent accessibility of narrative which I think can help many more NT parents make that leap as well.

As someone with a foot in each world, I think that is a very important goal. The more our kids make sense to all of us, not just to those of us who live the life ourselves, the better we can advocate for them. The better we can educate the larger society and work to make it less inflexible about the social, sensory-environmental, and economic conventions that, often as much as anything intrinsic to our kids, render them disabled, the better the quality of life we can help our kids achieve, both now and once they are on their own as adults without us.

Phil Schwarz is vice-president of the Asperger’s Association of New England (www.aane.org), and a board member of the Massachusetts Chapter of the Autism Society of America (www.autism-society.org).