



# AUTISM AND DEVELOPMENTAL DIFFERENCES TODAY

VOLUME 2, ISSUE 3

NOVEMBER 2008

A NEWSLETTER FOR PARENTS, EDUCATORS  
AND OTHER PROFESSIONALS

## NEWSLETTER STAFF

Jeff Fleischer  
CEO  
jfleischer@yapinc.org

David White  
President, PA and Ohio  
Director of Behavioral  
Health Programs  
dwhite@yapinc.org

Janet Crawford  
Vice President,  
PA and Ohio  
jcrawford@yapinc.org

Jessica Carlton-  
Humenik  
Pennsylvania Director of  
Autism and  
Developmental  
Differences  
jcarlton@yapinc.org

Brandon Dameshek  
Editor  
bdameshek@yapinc.org



## Do You See What I See? by Susan Oscilowski

"You know, it's funny, how you can feel like you know someone, then you find out something about them you never knew?"

Raynelle Turpin, a Southern widow in the play *Dearly Departed*, by David Bottrell and Jessie Jones, addressed her son Ray-Bud in those words after she overheard a conversation at the viewing for her late husband. The situation is humorous, as is the comedy about a funeral, but the wisdom in the statement applies to living or working with individuals on the autism spectrum.

With deficits in communication, our loved ones hide their treasures from the rest of us, whether or not they make that choice for themselves, or by means of the neurological differences. The Autism Initiative of the Youth Advocacy Program continues to remind us to seek what's hiding in the hearts and minds of those we seek to serve. Presume intellect, engage passions, and focus on the whole person, not the diagnosis---these philosophies advocated by the speakers at a parent training session I attended in Lancaster in February 2008, have long been my approach to dealing with my 8 children, including those on the spectrum, as well as my neurotypicals.

One event that has burned a memory into my other-wise sieve-of-a-brain took place on a frigid January day when I went for a trail run, and brought along my 19 year-old son, Chris, with his new 35 mm digital camera. The paper thin-ice puddles were my own stim-treat, as I've never lost the childhood sense of delight in cracking them with my footsteps to feel and hear the crunch, and admire the visual transformations the disruption causes.

My real eye-candy arrived when Chris downloaded the file from his camera's memory card. The images he discovered---along a sylvan trail he was seeing for the first time, but I knew intimately from years of running there---showed details I had overlooked in my athletic bliss. Dried purple pokeweed berries, intricate lacework sienna colored leaf skeletons, ice-encased vines, time-worn wood from antiquated properties, and other marvels of nature had caught his eye. With his exquisite talents in composition and lighting, he painted the myriad of wonders I overlooked.

When we open our hearts and minds to see differently-abled people and their perspective, and to encourage them to find a means to express themselves, we all become richer, bathed in the glow of a life we'd otherwise miss.





William  
Stillman

## Autism: A New Cultural Competency

As an adult on the autism spectrum, it is with frustrating frequency that I grapple with the misunderstanding and misinterpretation of my words and deeds; some, it seems, always rush to judgment and presume the worst in me when the exact opposite is true: I usually act out of consideration and selflessness in deference of others. It is this near-daily confluence (or clash) of ideals that can be absolutely maddening to me. And because of my forthrightness, it is a similar mindset that spurs my inability to reconcile disingenuous, duplicitous or deceptive behavior in others. I say what I mean, and mean what I say—shouldn't everyone do the same?

So, in recent weeks, when I've seen national news stories about children with autism being excluded from church, removed from airplanes, and kicked out of restaurants for "autistic behavior," I presume—not the worst—but a conflict in neurodiversity, a lack of autism cultural competency, at the root of such incidents. This culminated perhaps most succinctly when it was brought to my attention that a radio talk show host referred to autism as a hoax, a fraudulent excuse for bad parenting, and concluded that children with autism are "brats" and "idiots."

You can only know what you know—until you know better, or differently. And ignorance need not hold negative connotations if one endeavors a greater appreciation and respect. Autism is oftentimes an invisible disability, meaning, many of us get by, blend, and "pass" for normal because there's nothing particularly telling about our out-

ward appearance at first glance. It is obvious when someone is physically compromised because they are blind, deaf, or use a wheelchair—it's visible and tangible, and, in observation, we are more likely to make compassionate accommodations. So when a child melts down in the middle of the mall, screaming and thrashing, it may not be unreasonable that the average layperson leap to conclusions not unlike the radio talk show host.

Here's where autism cultural competency comes into play. A grossly overlooked and disregarded nuance of the autistic experience is the acute, overwhelming, and oftentimes painful sensory sensitivities experienced by the vast majority of autistics. For example, I filter out nothing and absorb everything around me, just like a sponge. There's very little that escapes my attention, from the distant cries of an uncomfortable infant to the whirring of an overhead ventilation system to the sudden shock of a nearby stranger's cell phone setting off. It can be exhausting to endure. Most neuro-typical or average persons *automatically and naturally* discard such superfluous sensory information and are unbothered by it. However, I can appreciate how the autistic child could overreact to a shrill church choir or pipe-organ ballistics; the blaring aircraft intercom that makes you want to jump out of your skin, though you must remain restrained in your seat; or the cacophony of voices, clattering cutlery, and swell of food aromas in a neighborhood restaurant.

The obvious response to such sensory sensitivities is to compel someone, through myriad means (like force), to be *less sensitive*; to "snap out of it" and conjoin with the real world. My reply is to suggest, "What do you think I'm doing every time I step outside my front door?" *The world hurts*. Yet I don't want to be less sensitive than I am. It serves me in my work as a consultant specializing in interpreting autistic hieroglyphics. Whereas neuro-typical professionals require hours of data collection, assessments, and observation time, I need ten minutes or less in the presence of the autistic one to know

precisely how to counsel his parents and educators in autism cultural competency; that is, fostering an appreciation for the autistic experience from the *inside out*. Oftentimes, I can intuit this information simply from looking at the child's photograph—now *that's* sensitive. My intuition *never* fails me. And I wouldn't want it weaned out of me either. It has value and purpose.

Understanding autism cultural competency includes making compassionate accommodations when and where possible in consideration of someone's sensory sensitivities. This requires not only awareness but compromise. I know of parents who insist that their children with autism go to Disney World though each child clearly protests while there—further stigmatizing others' perceptions of the autistic "brat" when, in fact, the behavior is clearly communicating, "I'm in pain and don't want to be here!"

I encourage parents, instead, to focus on prevention instead of intervention; partnering with their children *well in advance* of an activity or an environment to equip the very sensitive one with strategies, techniques, and devices to pull it off and get through it as successfully as possible, averting the assaultive irritants that conspire their undoing. And I implore the average onlooker not to jump to hasty and judgmental conclusions but to believe that we all have good reasons for doing what we're doing, and we all are doing the very best we know how to on the spot and in the moment—even the child who outwardly appears to be the product of "bad parenting."

© 2008, William Stillman

*William Stillman is an adult with Asperger's Syndrome and author of special needs parenting books. His Website is [www.williamstillman.com](http://www.williamstillman.com).*

## Project for Rethinking Autism by Pat Amos and Janet Crawford

The Youth Advocate Autism Institute, in collaboration with Wheelock College's Center for Scholarship and Research, has embarked on a **Project for Rethinking Autism** which will focus on two key activities:

1. Bringing together and encouraging research which situates autism securely within our general knowledge base on infant and child development, and adapts the principles of typical child development to guide and illuminate the developmental paths of more neurologically diverse populations; and
2. Translating this research into effective practices and strategies for everyday use by teachers, parents, therapists, support staff, community members, program providers, and all those who work directly with infants and children on the autism spectrum.



**The Project for Rethinking Autism** is a response to growing evidence that the development of infants and children with autism is neither peripheral to nor unrelated to the requirements and motivations of those considered to be developing in a typical way. By charting this common ground, the Project hopes to place the lessons that autism teaches in the center of our culture's deep concerns about how best to support the emotional and so-

cial health and potential of ALL children, and what the goals and values of our education and family support systems should be. In particular, this Project will explore the best uses of relationship and reciprocity in supporting the development of infants and children whose sensorimotor challenges can interfere with this vital component of development.

Through relationships children explore the world and become aware of the possibilities of their lives. They learn to attach shared meanings to their emotions and experiences, figure out what is and is not considered important, and test their emerging ideas by seeing how others respond. Bit by bit, they develop motivation and direction as their daily experiments receive positive and gratifying responses. Relationships shape us all – not in a coercive way, but as mutually engaged participants exploring the world together. We learn to trust, to give and take, and ultimately to empathize and “feel with” others.



These things cannot be taught in a lecture or a lesson; they can only be experienced over time, in the company of caring guides. They do not flourish in artificial and isolated settings, and their development cannot be forced or imitated. Instead they involve a mutual journey. Our cultural wisdom stresses the importance of the travel itself over the destination, urging us that “life should be a journey, not a race” or reminding us that “getting there is half the fun.” For children on the autism spectrum, it is especially important to think of the journey and the destination as a seamless whole, and start out as we wish them to end up:

- *If our vision for their future is one of friendships and inclusion in a caring community, then fostering desirable and inclusive experiences is also the way to get there.*
- *If a lifetime of nurturing and joyous relationships is our goal, then relationships must pave and power our journey toward that goal.*



## We Are Trying To Make It

By David McWade

I was looking on the Jessica Kingsley Publishers website some time back (jkp.com) and read about a woman—I guess she was a professor—who was diagnosed, like me, relatively late in life with Asperger's. I can't find the passage on the web site, but she remarked on how she finally had an explanation on why she stumbled, struggled through her entire life, to an extent well beyond what would be expected given how smart she was.

I realize this is a newsletter produced by an organization meant to focus on youth. I'm out of the box here, while my childhood was difficult at best I know that it was when I reached the age of about 24 I was out of college and I didn't know how I would pay the rent. The approximate 80% rate of unemployment for those with autism spectrum disorders has a reason, and the need to focus on those leaving the system upon young adulthood is something I hope to have the time and wherewithal to address.

It has been an incredible ten months since I was diagnosed. Having new friends (some of whom work for YAP) who actually know what I am going through, that know that some of the things I want are what other people my age already have—financial independence, fulfilling relationship(s), fulfilling work, self-actualization: the ability to change the world and give back. Maybe I'm getting closer to that.



## A Valuable Lesson: "Behavior" as Communication!

By PA ASD BSC



In consulting with Bill Stillman for several months now with the interests of young girl with autism (who we will call Emily for confidentiality reasons), I have learned one very important lesson, Behaviors ARE a form of communication! I started consulting with Bill back in De-

cember of 2007 because of changes in Emily's behaviors. She would scream, cry, stomp her feet, throw herself on the floor, and at times would push or forcefully throw herself on the TSS. Through the course of the monthly consults Bill would suggest to me that Emily was desperately trying to communicate to me and others that something was wrong! Among other things such as sensory sensitivities, Bill would recommend that I investigate Emily's home life and the people that are in it. In an attempt to find out what she was trying to communicate, I started to talk with her mom about changes occurring at home. At the time, Emily's mom had a new boyfriend and the family was in the process of moving. I had attributed all of these changes to her behaviors, but several months went by and no positive changes in Emily's behaviors/communications were seen. In talking with a friend of the family (with mom's permission), we discovered that recently the ex-boyfriend had begun drinking often and was verbally abusive toward Emily's mother. Emily couldn't tell me what was wrong, but looking back, all of the signs were there and I am sorry that I missed them. The signs were so obvious too. She at times cried and would refuse to get on the van to go home at the end of the day. Emily came to school with a bruise on her arm where finger marks could visibly be seen. Emily's communication through her behaviors could not have been clearer, but I missed what she was trying to communicate. Now that the boyfriend is no longer in the picture, Emily is happy and the crying and screaming has ceased. I apologized to Emily for not understanding what she was communicating to me. I have learned the valuable lesson not to dismiss any "behavior" as anything less than a "communication"!

