



# AUTISM AND DEVELOPMENTAL DIFFERENCES TODAY

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A NEWSLETTER FOR PARENTS, EDUCATORS  
AND OTHER PROFESSIONALS

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## Who I Am and What I Believe by Jonathan Hess

For me, autism is an advantage to gifts normal teenagers don't pursue as long as they should. Let me introduce myself. I am Jonathan Michael Joseph Hess, and I was diagnosed with autism when I was very young. I have a special ability, it seems, that most average kids don't practice: pursuing an ultimate goal to become a famous geographer. I don't let any off-topic things (as wild stuff) distract me from my goal. That means no drugs, no parties, no sex, no evil hang-outs, no sleepovers, no anything. Everyday I practice and increase my geographic knowledge. I'm not planning on hitting the IQ 140 genius level, but I'm getting very, very close! I study several reference books for statistics, geographic facts, history, government, climate, crops, religion, political statistics – anything I can have at my fingertips. Give me a book on facts and maps and statistics, and I will clutch it, flip through for possible learning areas, and stand there staring at the cover for a few minutes. I keep a bookshelf handy in case I need refreshment on other topics I study, like herbal medicine, language, gardening, geology, chemistry, and astronomy. For such a hard studier, I also keep my radio on every afternoon (or every day) to listen to Christian seminars, discussions, radio shows, gospel music, and such religious stuff. I am an expert in all utmost random scientific areas, but I have one thing young scientific experts don't often have: a strict personal Christian faith. What is Christian faith like? Well, according to all the broadcasts I listen to every day on WCRF, it is not just being a crusader to the ones who haven't heard the gospel yet. It is a strict personal relationship with God and his son, Jesus Christ. It also has special interviewers with Christian scientists (called theologians) that study the faith and have scientific experiments inquiries on Christians. They all on WCRF are really good debaters and questioners. That is why I have the faith that I do.



Along with being a highly intelligent expert, the form of autism it goes with is called Asperger's syndrome. Children/adults with this disorder are prominently intelligent, but usually they undergo anxiety and stress everyday. I too, am always anxious to learn more about the amazing world I live in. Simply put, if someone takes my books away, I get very aggravated and won't stop until I get them back.





William  
Stillman

## The Real Autism "Epidemic"

We hear so much about autism these days. In fact, hardly a day goes by without some reference to autism in the media, be it a newspaper or magazine article, a television feature, or a radio news story. The focus tends to be on the growing number of very young children—two, three, and four year-olds—being diagnosed autistic with greater regularity. Much attention is also given over to research, causes, and cures, though, to date, no definitive explanation has been put forth. As such, we often bandy about the term "epidemic" to describe what's been transpiring with such alarming frequency that the Centers for Disease Control and Prevention now suggests one in every 150 children has autism. That term, epidemic, evokes thoughts of a plague or a scourge, which autism most certainly is not. But should the word epidemic be applied to autism, the truth is, it has nothing to do with those very young and newly-diagnosed toddlers. It has everything to do with autism's forgotten people.

If the word epidemic is apt in describing an unaccountable experience that affects us in a widespread manner, it best applies to those adolescents and adults over the age of twenty-one who have "aged out." It is these citizens who have grown beyond early intervention eligibility, and burgeoned past the educational curriculum (or life-skills training) of their school years. Epidemic refers to those with autism who struggle with rejection, misunderstand relationships because of others' lack of honesty and forthrightness, and can't land a job for being different, "quirky," or unem-

ployable. Epidemic pertains to those same such individuals who have—through no fault of their own—grown up believing all the degrading epithets used to separate "us" from "them." So dehumanized are many of them, they struggle with addictions to nicotine, alcohol, or marijuana; and they all too often grapple with acute anxiety, post-traumatic stress disorder and debilitating depression. So vicious a descending spiral it may be, that some attempt to end their pain by taking their own lives.

The escalating epidemic of teens and adults with autism who experience the preceding self-fulfilling prophecy is not a by-product of autism, and is not some twisted birth-right-curse either. It is, indeed, *entirely avoidable*. Those of us who have the privilege of supporting young children and adolescents on the autism spectrum are learning the inside-out perspective: to presume intellect, practice preventative measures, and foster self-advocacy. We are conscious of sensory sensitivities, understanding of the genuine need for self-soothing (not stimming) techniques, and envisioning passionate interests (not obsessions) as relationship building-blocks. This is real, this is meaningful; and these kind, compassionate experiences will be retained well into each individual's adulthood, sustenance to counteract a culture of pandemonium. Never underestimate the power you have to forever alter the course of someone's life by demonstrating great sensitivity, pensive patience, and a comprehension of opportunities to simply be the pupil instead of the instructor. You might just save someone from becoming an adult statistic of the real autism "epidemic." You might just save a life.

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*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).*

## Autism Retreat: New Trainings, New Connections By Jessica Carlton-Humenik

In late May, many of the identified Behavioral Specialist Consultants specializing in autism/developmental differences gathered in Northeast PA for a retreat to share ideas, attend new and innovative training opportunities and to further solidify our approach as a team. I was particularly impressed with this second annual "Autism BSC Retreat" in that the folks on this team, even during their free time, managed to gather together and be actively brainstorming and sharing thoughts on how we could better serve the children and families we work with. We saw fantastic ideas unfold, creativity in thinking "outside the box" and support for one another that was beyond my expectations. Those present managed to re-arrange personal and work schedules so that they could take the opportunity to learn and grow professionally and personally. To see new relationships forming and to feel the "buzz" of excitement for the work that we do was fantastic!

The training schedule was intense for two and half days, covering "Demystifying Autism" with William Stillman, "Social Skills Development" with Pat Amos, Self-Advocate Jeremi Goike's "Personal Life-story" presentation and "Communication Insights and New Developments" with the Prentke Romich Company. Again YAP thanks our presenters for the opportunity to learn from their expertise and to those who participated so actively throughout our time together!

## Autism Arts in Action by Pat Amos

Imagine....a celebration of Autism Awareness Month that focused on the incredible talents found across the spectrum, recognizing the rich imaginations and deep perceptions to be experienced there. Imagine a day of exhibits and presentations by people with autism, their families and friends -- a day wholly devoted to people's passions and interests rather than their labels. It happened on April 5, 2008 when Youth Advocate Programs joined up with Holy Family University in the Far Northeast of Philadelphia to create an outside-the-box event called "Autism Arts in Action." Fourteen art exhibitors, from young children to teens to middle-aged adults, staffed tables to display and sometimes sell artistic creations ranging from paintings, drawings, jewelry, photographs, and greeting cards to CDs of original music. "Rebel Heart," an inclusive Irish dance troupe from the Harrisburg area, put on a remarkable precision dancing performance that had attendees clapping along and asking for more. HeARTS for Autism [www.heartsforautism.org](http://www.heartsforautism.org), a new and vibrant organization in Philadelphia, set up an arts station where children could create their own works on the spot and attendees could relax with a Reiki session.



Pennsylvania Speaker of the House Dennis O'Brien, who has dedicated enormous effort to the development of improved supports for people with autism and their families, toured the art exhibits and kicked off the event with a rousing speech about how far our community has come. Through his work, "autism awareness" is growing daily in our state. Speaker O'Brien was introduced by YAP's Board Chair, Lynette Brown-Sow, who emphasized Youth Advocates' commitment to self-determination, families, and community living. Also addressing the group was Stephen Glassman, the Chair of the PA Human Relations Commission, who urged us to work with his office whenever issues of discrimination threaten to hold us back. Nick Pentzell and his mother, Gwen Waltz, illustrated how far we can aim as they showed his award-winning video "Outside/Inside." Nick, a college student, communicates via typing to share his deeply artistic and scholarly nature, reminding viewers that "my body is not who I am" and that we each have a part of ourselves that is hidden from view.



A series of exciting break-out sessions included "Building a Bridge from Isolation to Interaction" with Mark Bottos and Christine Wineberg of the Kardon Institute for Arts Therapy; "Video Collaboration: The Inside Scoop on Outside/Inside" with Nick Pentzell, Gwen Waltz, and videographer/discussant Chris Oscilowski; "Music Communication and the Unseen Spectrum" with Stephen Mallon of GRASP; and "Coloring Outside the Lines" with the Rev. Robin Schwoyer of HeARTS for Autism. Participants ended the day by unwinding with their choice of "Yoga and Sensory Integration" with Barbara Gini, RCYT, CMBT, of BodyLogique, or "Connecting through Creativity," an interactive art therapy session with Diana Matteson, MA, ATR-BC.

KenCrest Services shared a informative table display and handouts, as did the Kardon Institute for Arts Therapy and the Global and Regional Asperger Syndrome Partnership, GRASP ([www.grasp.org](http://www.grasp.org)). Art therapist Diana Matteson, a YAP consultant, unpacked and exhibited her magical box of activities and information. Popular books on autism by the gifted writer William Stillman, founder of the Pennsylvania Autism Self-Advocacy Coalition, PASAC ([www.udservices.org/PASAC.asp](http://www.udservices.org/PASAC.asp)) and a YAP trainer, were also available.

Among the hits of the day were the new YAP T-shirts and over-the-shoulder totes, which feature the work of local artist Ted Harris. A sketch of a full orchestra in session is accompanied by the slogan "Working in concert to create harmonious communities."

Special thanks are in order to the welcoming faculty and staff of Holy Family University who donated both time and space, and in particular to Dean Leonard Soroka and Dr. Brian Berry. Once again, the power of relationships has taken us all to a new level!



## Blue Ribbon Day

By Marion Wells

A small group of dedicated YAPpers volunteered at the Crawford County Special Olympics. All of the athletes were more than ready to show off their skills at the various events. There was one young female athlete that really touched me. She placed first in her heat for the standing long jump and her excitement was very evident. She threw her arms

in the air and began yelling, "I can't believe it! I got first place!!!" I handed her the blue ribbon and tears of happiness for her began to well up in my eyes. At that moment I began to wonder...what was my blue ribbon day?



Then it hit me...Each month I get to meet new staff from Western Pennsylvania and I get to share with them our relationship-based approach and hopefully transform their thinking so they presume intellect, focus on prevention rather than intervention, engage passions and promote self-advocacy. That is my "blue ribbon day": engaging my passion for educating others about the autism spectrum.

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## Play Ball: First Annual YAP Baseball Fundraiser

This baseball season, the Youth Advocate Programs, Inc. Autism team and supporters are partnering with minor league baseball teams to raise money to support our Youth Advocate Endowment Fund, which provides scholarships to our youth to educational and vocational programs. Local teams participating in the fundraising event are: Reading Phillies, York Revolution, Harrisburg Senators, Lancaster Barnstormers, and Altoona Curve. All five teams support this event toward a great cause!

Here's how the fundraiser works: each Central PA office and its staff is paired with one of the local teams listed above. Each interested staff member in those offices may place a small pledge for the number of homeruns their local team hits during the regular 2008 season. For example, John Doe, a director from the York Office, pledges a five-cent donation for each homerun the York Revs hit during the season. The Revs end up hitting 100 homeruns. John's pledge donation due at the end of the regular season would be \$5. The goal of this fundraiser is to get as many staff as possible in different counties motivated to pledge donations for the Endowment Fund and to support their local baseball teams.

How do we sign up and get our staff motivated? The Northeast Region of Pennsylvania (NORPA) Autism Field Coordinator, Michelle Miller, has made sign-up sheets for each office for staff to make a pledge donation. Michelle, along with Dwayne Neff (Central PA Autism Field Coordinator), will monitor each office's progress per week during the season. All directors need to do is make sure the sign-up sheets are placed in their offices at a central location for their staff to observe and sign up.

Listed on each county's sign-up sheets is the local team's homerun stats from the 2007 season to give staff an idea of how much money to pledge. (Granted, the larger the pledge, the better.) Pledge donations will be collected at the end of the regular season. The Autism Field Coordinators will be in contact with directors and staff in advance, to give them an exact date to have ALL pledge donations collected and ready to turn in. All proceeds will benefit the YAP endowment fund. Creative charts, developed by the Field Coordinators, will be made and distributed to each office for tracking purposes.

Game tickets, team merchandise, and other prizes will be awarded. Thank you for your interest in supporting local baseball and the YAP endowment fund! Interested players may contact Dwayne Neff at [dneff@yapinc.org](mailto:dneff@yapinc.org), or Michelle Miller at [mmiller@yapinc.org](mailto:mmiller@yapinc.org).

