



AUTISM AND DEVELOPMENTAL DIFFERENCES TODAY

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A NEWSLETTER FOR PARENTS, EDUCATORS
AND OTHER PROFESSIONALS-SEPTEMBER 2007

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Susquehanna Baseball League and YAP Support Special Olympics



Special Olympics

As an employee of this company and representing my current position (CPA Autism Field Coordinator), one of my main goals was to eventually get YAP involved with the York County Special Olympic Organization. After two years of research and observing, we finally landed a friendly partnership in May 2006. York County Youth Advocate Programs has been setting booths up at local York County Special Olympic events. We supply water with our logos and other small supplies, games at Olympic Village, and face painting at our booth. The biggest and best support YAP provides is our clients. That's right: clients!! Thank David White for presenting the idea of letting our probation clients in our Advocate Programs participate. These clients have interacted with Special Olympians with face painting and games at Olympic village. Not only does this positive interaction build their self-concept and self esteem, but they also earn credit towards community service hours. I'm in the process with some YAP team members of expanding this partnership across Central Pennsylvania and maybe eventually across the state. From our experiences so far with this project, we all agree that the rewards with helping the Special Olympics are endless.

In May of 2006 I took another step at helping the York County Special Olympic Organization. Being involved in a competitive Susquehanna men's baseball league, I thought a league pledge would help raise money for the York athletes. The Susquehanna Baseball League this year performed its second annual league pledge to help raise money. I started with my team last year, the Windsor Cardinals, mainly to raise awareness for all special athletes. My teammates and 50+ fans pledged \$1 for every home run our team hit. Last year we hit 24 and raised \$1,200 from just Windsor alone. Five other teams (Hallam, York Township, Red Lion, Jacobus, and Felton) gave \$100 flat donations. Last year's league pledge total was \$2,500. This 2007 year 3 more teams joined the good cause. From all this support, I was appointed head coach for the York County Special Olympic Softball team.

This past June, the Windsor Cardinals Baseball Team hosted their second annual "Special Olympics' Day at Windsor." The game was between Felton and Windsor. During the game, donated prizes from 25 different businesses were raffled off. Two waitresses from Hooters restaurant came to the game to help motivate fans to buy tickets. The prize money went towards the league pledge. After watching an intense game, my softball team took the field and played a one hour fun game with the players from both sides. My athletes beat the players 17-0. My father, Nate Neff, quotes from the article printed from the York Daily Record: "Nice crowd, nice day. Hats off to Felton, they played with a lot of heart. I'm very proud of my son, doing this from his heart. We're all very proud of him. It's one of those days where you can really puff out your chest. Makes me proud to be his father."

-Dwayne Neff, Central PA Autism Field Coordinator

Quote of the Month

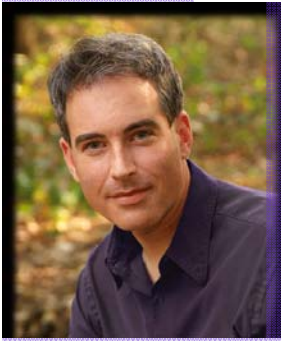
"If our vision for the future is one of friendship and inclusion in a caring community, then fostering desirable and inclusive experiences is the way to get there. If a lifetime of maturing and joyous relationships is our goal, then relationships must pave and power our journey toward that goal."

Pat Amos, Advocate, mother of a child on the Autism Spectrum

What's Happening in YAP Autism Programs—

- William Stillman and Ann Lyon presented at the AAIDD Conference at Willow Valley on September 6th.
- YAP presented at the Autism Society of America in Phoenix and at the Autism Institute Conference in San Diego in July.
- Youth Advocate Programs will be presenting at the NATTAP Conference in Columbus, Ohio on September 26th.
- Lancaster County will host a parent training on October 3rd. Brochures are available!
- Youth Advocate Programs will present at the TASH Conference in December in Seattle, Washington.





William
Stillman

WHY LANGUAGE MATTERS

Eagle-eyed readers of Youth Advocate Programs' autism newsletter will have noticed a difference in the newsletter's title between the first two issues and the copy you hold now. The first issue was called *Autism and Developmental Disabilities Today* but subsequent issues are titled *Autism and Developmental Differences Today*. Seem like a trivial exercise in semantics? Not if you're the person being labeled—not only as "disabled" but as a "disordered, stricken and afflicted sufferer." It appears so often that those who are normal or "neuro-typical" use the epitome of an optimal quality of life as the measuring stick of a successful existence; anyone falling short of that measurement is potentially dehumanized or pitied, or both.

Why does language matter and what makes it an important point of contention? Language matters because it shapes others' perceptions and makes a statement about the user of insensitive and disrespectful language. Within the last year alone, witness those high-profile celebrities who have experienced significant backlash for their offensive language; discussion via all media outlets has been buzzing over certain personas' very public use of the "N-word," the "F-word," or similar cultural and faith-based slurs. The backlash that prompted the ensuing "rehab" stints and public apologies was spurned by minority and advocacy groups vocalizing their extreme disdain for the egregious indignities violated upon them...because of language. Yet when discussing individuals with autism, there is a liberty taken in defining those very persons in terms of their labels, limitations, and perceived deficits. Remember, too, that such individuals oftentimes cannot talk, or speak reliably; as such, there is at present no autism self-advocacy group that commands enough attention and respect to hold others publicly accountable for their misuse of language or their stereotypical portrayals of autism.

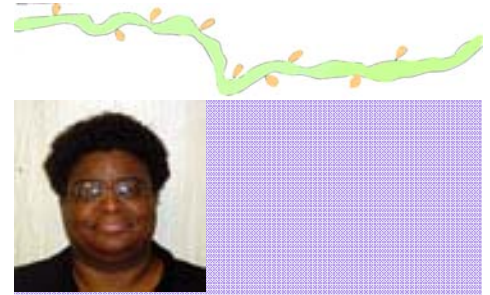
Youth Advocate Programs has made a commitment to refer to individuals with the ASD label (if necessary at all) in terms of an

Autism Spectrum Difference instead of Autism Spectrum Disorder. This is progress, but it is only a beginning. Demonstrating true respect for individuals with autism requires one to be conscious and aware of not only the language being used, but the manner in which one interacts within the context of relationships. It is gracious to employ person-first language as a thoughtful demonstration of respect by verbally valuing the individual before describing them by their diagnosis or difference. For example, instead of calling someone "an autistic" or saying "autistic child," you would value the person first by rightfully stating "child with autism." In making this point about person-first language, advocate and mom Kathie Snow asks if you would rather be described as a person with cancer, or as cancerous? It is the difference between being sensitive or insensitive, between telling about who not what.

As you learn more about autism and partner with self-advocates, you may understand that persons on the autism spectrum, themselves, are not particular about person-first language; they may, in fact, refer to one another using slang terms such as autistics, auties, and Aspies. Additionally, you will frequently hear the same individuals refer to stims, stimmies, and stimming to connote the self-soothing or self-regulating techniques they employ to calm, quell and maintain (such as twirling a piece of string, or rocking or spinning in place). This does not mean that you should follow suit and abandon using person-first language. Persons on the autism spectrum enjoy a cultural privilege, a camaraderie that permits them to employ "insider" slang if they choose to, in the same manner that other cultural groups use certain labels in jest or affectionately among themselves but consider it offensive if an "outsider" uses the same terms.

Why is it respectful to use person-first terminology even though self-advocates refer to one another as auties, Aspies, and call self-soothing actions as stimming? Responding respectfully with person-first language compels you to be conscious of your words and aware of how you use them. It also means you are far less likely to be unpresuming of someone's intellect by talking about them in front of them in ways that are hurtful, embarrassing and humiliating without a way to defend themselves—just as prominent advocacy groups have in recent times. Unless you have been specifically told differently by an individual with autism, continue to preserve the most respectful approach. You will, in no time, cringe or correct others when you don't hear them using person-first language, and that's a good habit to have.

William Stillman is an adult with Asperger's Syndrome and author of special needs parenting books. His Web site is www.williamstillman.com.



A Note from Lori Burrus—

YAP is teaming with Blue Mountain School District's transition program for young adults with autism. We are preparing individuals to go into the workforce. YAP will be providing an autism behavior support consultant who will work with traditional job coaching agencies. We will be teaching our relationship-based model to them and giving behavioral support. Direct care staff will work with job coaches in identifying obstacles that could impede a person from succeeding. They will assess job environments for any necessary adaptations, teach social skills and assess sensory inhibitors.

Case Study:

Matt is like many young people in Pennsylvania with an Asperger's diagnosis who are going through the transition of school to adulthood. He attends York County School of Technology in the commercial arts program. His goal is to attend college to become a video programmer. For Matt the difficult part of the transition is relating to others. He has difficulty in doing organizational and scheduling tasks. It is a problem for him to read facial cues. He feels that people do not understand him.

However, what makes his experience different from others? Matt and his mom agree that it's Justin. Justin is Matt's support staff through the mental retardation waiver program. Together, they work on social skills, transitioning problems, creating systems for scheduling and organizational needs. Matt has gained self-esteem through this relationship. He feels that Justin understands him. Matt and his mom describe Justin as "phenomenal, caring and willing to learn."

How did YAP prepare Justin? Justin attended the YAP autism training. He is receiving recommendations from the autism field coordinator and the developmental disability coordinator. An example of a recommendation is a PDA for organizational and scheduling needs.

CHALLENGING AUTISM'S OUTDATED PARADIGMS: BEGINNING WITH MYSELF BY MATTHEW GROMIS

When I stop to think about it, I am startled by the personal and professional transformation I have undergone in the past several years. Working with the wonderfully incredible, sensitive, and loving young people on the autism spectrum has taught me a wealth of knowledge about being of service to others, while also giving greater insight into my own life. None of this may have been possible if I was not able to reconstruct and rehabilitate what I thought it meant to work with these children and young adults.

Starting out in a behavioral health field is an intimidating and sometimes overwhelming experience. Because of this, I looked to the professionals in the autism field for help in understanding the kids that I so greatly adored but was unable to yet fully grasp. While these experiences were beneficial in many ways, I also came across many unpleasant and compromised methods, at least to my own judgment.

"You have to destroy him so that he knows who is in charge!"

This was boasted by the autism specialist who was training new staff in the classroom after grabbing a child who was "too excited," screaming at him, and forcing him into a chair.

"He is as close to a primordial creature as you will come across."

Another comment made by a professional when I was introducing a new staff member to the child he would be working with.

"He doesn't communicate. There's no intellect here."

These are the actual thoughts of someone who had worked with a nonverbal student for several years.

These comments were all said to me with the utmost sincerity and by those who thought they were doing everything possible to help children on the autism spectrum. Fortunately, I was able to find the true experts in the field to guide me and help me understand autism: those living with it.

My preconceived notions first started to fade away as I met the person who would help me put into motion a real transformation in my work and personal journey: William Stillman. Bill helps others understand autism from a first person account through his work as a consultant, author, and as someone living with Asperger's Syndrome. He began working with my agency, as a consultant, in conjunction with Temple University, to develop a curriculum for wraparound services serving

those with autism that focuses on the individual first. He was able to articulate the experience of autism from the inside-out. **I was finally able to understand many things such as the fact that self-soothing behaviors serve not only a purpose, but are actually a very important form of coping with a world that many times seems to be at war with one's senses.** He helped me to start looking past labels to the true intellect and person that lies beneath a body that does not always respond in a manner that is reliable. But this was only the beginning.

Bill introduced me to a group of individuals who have completely changed the way I look at the world and I believe would do so for anyone who spent time in their company. These individuals meet to discuss advocacy, education, and in general opening the minds of everyone around them. While there are probably many autism support groups with similar missions, this group is different in that all its members communicate through the use of Alternative and Augmentative Communication (AAC) systems. Spending time with these individuals has been both educational and inspirational. They have fought hard to overcome prejudice and stereotypes, while constantly showing love and understanding to the world which has not yet learned to understand them.

I am fortunate enough to have the opportunity to train new staff who begin at our agency by giving a three day inside-out perspective of the autism experience. As I speak to new staff, many of whom have never worked with an individual on the spectrum, I am assisted by Will Turnbull, a nonverbal adult with autism, who communicates through facilitated communication. Therefore, where people may have once looked upon him as mentally retarded simply because of his appearance and/or diagnosis, he is now able to educate and break down stereotypes of those who listen to him. This seems to be the best way for others to learn about what autism really is about, from someone living the experience.

These are just a few of the wonderful people that have assisted me in my journey of a more pure understanding of those with different ways of being. Hopefully we all continue to examine our perceptions of others and learn from those who have much to offer, but oftentimes no voice. Learning to listen in ways other than with just one's ears is an essential step to understanding the

communication of those who have difficulties in this area. Perhaps we should all start listening more with our hearts and minds to truly be of service to others.

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Matthew works in the behavioral health field helping those with different ways of being find their voice and the right to advocate for themselves while teaching staff to understand these individuals from a person first perspective. He may be contacted at: matthewgromis@hotmail.com.

A Letter from Ryland Davis



My name is Ryland. I am 12 years old. I will be starting 7th grade in August. I have two brothers and one sister. I go to James Buchanan Middle School. I like to play video games on the Xbox. My favorite Xbox game is Halo. Right now, I just got rid of my PS2 and got an Xbox like my friends. I like Yu-Gi-Oh cards and Manga. I like Jack Russell Terriers and get upset when any animal is hurt. I like to play baseball and go fishing. I see the world in pictures and I am a visual learner. However, I am a literal thinker.

I was so freaked out when I found out about autism. I didn't know what it was and I just found out that I was autistic. I was six or seven years old at the time. I am comfortable with autism now because I know that it is not a disease. I am going to let people think what they think about it because it just doesn't matter to me. I know that it is nothing bad. My friends don't look at me any different. I am glad that my brother looks at me the same way that my friends do, a normal person in their eyes. Being autistic doesn't make me un-normal. I hope that you can find the same about any autistic person that you meet.

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Sensory Issues

I have several sensory issues: certain noises especially sounds like the scratching of fingernails on the chalkboard or snapping of fingers that give me the chills; the feel of wet slimy things like jelly; crunchy things like nuts; loud noises such as screaming; the feelings of numbness in my hands and feet when I am tired; hot or cold things in my mouth; toothbrushes feel like they are scratching my teeth; and the sun beating down on my eyes makes my eyes feel dry.

I am very sensitive to strong smells like tobacco, trash, dog droppings, pollen, fresh-cut grass, sauerkraut, and broccoli, those strong smells gag me. I can smell the change of the weather in the air. I don't like the texture of canned fruit and it gags me when I eat it. I can feel sleepy dust forming on my eyes and exiting when I am drinking an e n e r g y d r i n k .

I also have motor tics. My eyelids feel like they are stuck and they pop back into place. The feeling of someone's rough skin on my skin gives me the chills. I am very sensitive to individuals body scents, a girl once touched my hand in gym class and left h e r s c e n t on me. I like to be aware of how my hands smell by frequently smelling my hands. I don't like for flies to walk on me because it makes because it makes me feel like I am being tickled. Occasionally I let flies walk on my hand because it makes me feel as if I am being tickled. Occasionally I let flies walk on my hand because I like to watch their motions.

In the shower the water feels like needles on my skin. I don't like for my fingernails to be clipped because I was cut one time and bled. I don't like disposable razors. Dog hair and dog paw feels rough on my skin but I still like to pet my dog Norah. The tops of bottles feel like they are scratching my skin when I try to open them. My mouth feels dry after I drink homemade tea. I can smell saliva on cups when people drink from my cup. I smell like my cousins because I am starting puberty. I don't like the feel of combs and brushes because it feels like my scalp is being scratched. I don't like tags in my

Clothing because they are scratchy on my skin.

Self Soothing

I have several self-soothing behaviors that make me feel better when I am anxious. I like to spin in circles in my chair, petting Norah (my dog), hanging upside down, laying my head down in my arms and sitting up when I am ready, sitting in Delilah's dog crate makes me feels safe, and playing video games.

I also feel better when I read, sit locked in the bathroom (in the shower I like to read or play video games in there), listening to music, and deep breathing. I like to leave the T.V. on in my room so that there's activity in the room. When I am playing with my brother and get upset I will leave for awhile and cool off, but I do like hanging out with my brother. I like to hang out with my mom's dog Mo (Malaki). When I am upset I like to talk to mom. (I call my mom and grandmother mom.)

Also when I am upset I will tell an adult about my problems that are occurring. I will take breaks at school and go for a walk or sit in the back of the classroom. I like to go to Mrs. Wright's classroom or the library to calm down. I take time for myself, hum songs, or repeat my dog's name to help calm me down.

Anxieties

I become anxious when I think about mathematics, language arts, art class, and cursive writing. I get upset when I am working and have to switch subjects without warning. People picking on my friends upsets me. Being under pressure, time limits, any kind of changes or transitions, counting, and 1,2,3, Magic. When my mom is gone for a long time, for example when she goes to the store, I get anxious. Being asked to do something like start my homework when I am talking my dog Norah. When I am asked to do something that is against school rules, I become anxious. Dad not giving me enough time to do something that he has asked me to do, and being rushed.

Differences between Autism and Anxieties

The difference between autism and anxieties is that you can have anxieties even though you are not autistic. If your anxieties are not as highly increased as the autistic person's anxieties you will know you are not autistic. The reason that the anxiety is highly increased in autistic people is because they are highly sensitive. I am sensitive to a lot of

things that don't bother other people.

Depression

In depression, my feelings increase a lot. I sometimes get feelings of suicide due to my feelings increasing by the amount that they do. I don't know what caused my depression, but I do know that changes increase my depression. I don't enjoy things that I used to such as soccer, kickball, basketball and drawing. I don't like playing PS2 anymore; it's not fun anymore. The depression got worse when my TSS, Miss Ashley, left. Luckily, autism is not connected to depression and you might not find some autistic kids or teens that are depressed.

TSS Requirements

I would like for my TSS to have understanding of autism, my sensory issues and my depression. He or she should understand how to calm me down and not to rush me. I need my TSS to like dogs and not be afraid of dogs. I need someone to believe me when I am telling the truth, have a sense of humor and be working to help a child and is not there for the paycheck. Someone who wants to take me into the community to places I want to go and not where he or she wants to go. Someone that is interested in the same things that I like such as video games and bikes, someone who will assist me only when help is needed, able to read my body language, able to watch for cues and give me a break when I need it and will ask me if I need a break. Lastly, someone who will make suggestions instead of telling me how to do things.

Things Not Wanted in a TSS

I don't want a TSS to judge me or touch me unless I say it's ok. I don't like for a TSS to stare at me or hover or watch over my shoulder (it makes me uncomfortable). I don't want to be told to look at you (because sometimes my eyes will lock on that person or thing and it will look like I am staring at you). Lastly, not being too serious (I like to have fun, but I do intend to get things done).

How I Show the TSS That I Need Help

I will go to the TSS or give them cues such as covering my head with my arms, throwing my arms down, looking like I am throwing a fit but I am not, laying my head down, pointing to the paper, motioning the TSS towards me with my hand and looking towards the TSS.

When working with people with autism, remember to treat them as individuals!