To invent, you need a good imagination and a pile of junk.

Thomas Edison
Inventor
1847-1931

Nothing in life is to be feared. It is only to be understood.

Marie Curie
Physicist
1867-1934
Hello from Robin Lurie-Meyerkopf, AANE’s New Associate Director
Robin.Lurie-Meyerkopf@aane.org, 617-393-3824 ext. 316

I have been involved in various ways with the New England Asperger's community and AANE for many years; I am delighted that I am now officially part of the AANE staff. For those who do not yet know me, I would like to tell you a little about my background.

For the past 28 years, my family and I have lived in the Mt. Washington Valley area of New Hampshire. For over 20 years I worked there as a classroom teacher and an environmental educator. I recently returned to school at Antioch where I applied my graduate credits I earned from the ASD Certificate program towards a Masters in education. For almost three years I have run a support group for parents in the North Conway area, close to where I live. I have been involved with my local high school’s Equity Committee, the Northern NH Autism Task Force, Valley Outreach (a coalition of agencies and consultants working to improve the lives of families), and NH Connections. I have been an active participant in the AANE NH Chapter. I have worked part time on a consultant basis for AANE, and part time as a private consultant running my own business, training parents and educators, and consulting to schools and families concerning children with AS and other similar conditions.

In my (limited!) free time I enjoy baking, gardening, walking my dogs, and spending time with my family. My twin sons are both college freshmen this year. They are very excited about my new role at AANE, and very happy for me. My husband and I have recently purchased a house in Portsmouth, NH. This will make it easier for me to commute to AANE’s office. However, I will also continue to travel to other areas of New England to help build AANE chapters.

As Associate Director, in addition to helping with the day to day operations, I will focus on chapter support and development, and on conference planning. I feel very welcomed by the AANE “family” and look forward to getting to know many more AANE members over the coming year. Please feel free to stop by to meet me, e-mail me with your concerns and ideas, or just give me a call to say hello. I look forward to doing all I can to help AANE grow, so we can meet the needs of adults, families and professionals across New England.

Hello from AANE’s New Board Member Michael Wilcox
www.qwafafew.org

I'm excited to be joining AANE’s Board of Directors. I see my role on the board as one of contributing to the strategic planning function. Of the various focuses of AANE of which I am aware, the issue of employment is of the most interest to me. I am a Chartered Financial Analyst, and for many years made my way in the world by using computers to do quantitative analysis of investment vehicles of all kinds. Not a surprising career for an Aspergian, I guess. At the peak of my career, I became a partner in a well-known Wall Street firm, but, like so many other Aspergians, when I was promoted out of technical work and into the world of office politics, I “hit the corporate wall” (as John Robison has described it, having had the same experience). So I retired at age 45 (although I didn't call it that; instead, I viewed it as going into business for myself, and in truth I've been able to make some money doing consulting and expert witness work, but I've never again earned the kind of money that I did when I was drawing a paycheck).

I was also very involved in politics and the peace movement when I was young (college age and a bit beyond), but I put that aside in order to focus on my career. In recent years, I've been very active in Massachusetts politics. I also know many other political activists and social advocates throughout the Commonwealth. I'm aware of what the "NE" stands for, and although my primary contacts are within the Bay State, my network extends throughout New England.

Professionally, I stay in touch with developments in my field through an organization I founded, called QWAFAFEW. This name is a back-formed acronym and an obvious play on words, invented by a friend of mine who is probably on the spectrum as well. The purpose of the group is to get a bunch of “quants” together in an informal setting to have serious discussions about the latest research and practices in quantitative investing. Although the London and Washington DC chapters have gone dormant, we do have active chapters in Boston, New York, Chicago, Toronto, Denver, Vancouver, and São Paulo. Our website is www.qwafafew.org. I am Town Moderator (an elected position) of Alford in Western Massachusetts. I may be the only Aspergian Town Moderator in the Commonwealth, I'm not sure.

Perhaps you're beginning to get a hint at why it was difficult for me to obtain a clinical confirmation of my self-diagnosis of AS, although I finally did. In less than a month, I'll be 62 years old; over the course of all those years, I've learned how to hide my condition and to compensate for it. All of this I did through trial and error—there was no other way for me, since I had never heard of AS until about 3 years ago. Part of my interest in helping out is to see what I can do to smooth the way for fellow sufferers, and I use that word advisedly. Although I can tick off my accomplishments, and I'm very proud of them, I could also tell you tales of my crushing defeats, bouts of depression, moments of anguish, and three divorces. Life has not been easy for me, and I still have trouble with simple things—like using the telephone. I look forward to sharing more of my stories with the AANE community as time goes by. Meanwhile, I invite you to browse my personal website, www.mfw.us, where I have posted several essays.

You have just been subjected to an Aspergian “hello.” There is nothing that can be said in one word that can't also be said in 659!
MESSAGE FROM AANE’S EXECUTIVE DIRECTOR

Dear Friends of AANE,

Thanks to your support and participation, AANE continues to grow. With our larger staff and larger space, we can offer more programs and services to meet the diverse needs of our community—including more programs for parents, teens, adults, and spouses. Some evenings AANE is humming with three simultaneous groups! In addition, wonderful volunteers—too many to name in this publication—continue to come forward to help us in every way.

Recently our Board of Directors has undergone a process of reorganization, set to take effect in July as we begin our new fiscal year. If you would like to participate more actively in AANE’s development as a board or committee member, we invite you to fill out the online form at: www.aane.org/about_aane nominate_board_director.html.

We are so glad to welcome Robin Lurie-Meyerkopf as Associate Director. Since chapter development will be one of her major concerns, many of you will have the pleasure of meeting her over the coming months. We have been fortunate to have Gail Kastorf (photo at right) as part of our Adult Services Team. Sadly for us, she now needs to cut back her hours with AANE. Fortunately, however, she will continue to facilitate our employment committee and do related trainings. We have been fortunate to find Gina Hartley to take over some of Gail’s responsibilities as part of our Adult Services Team.

We are always glad of opportunities to educate a variety of professionals about AS—please encourage organizations to contact us. This winter, Jean Stern, our Director of Children’s Services has been doing extensive educator training across Massachusetts, sometimes with Lynne Mitchell. AANE has done more police training, generously supported by the Union Church in Waban.

Among the many illuminating articles in this issue of the AANE Journal is one by writing teacher Sibyl Johnston (p.10). Sibyl teaches her writing students how to give constructive, tactful feedback—a social skill that anyone could also use in other school or work situations. Andrew Feldman speaks about his positive experience at the LABBB Collaborative (p.9). I just want to make clear that there is no single educational model that is best for all students with AS. It’s best to consider a variety of educational models, depending on the interests, strengths, and challenges of the student. Congratulations to AANE Board President Emeritus Stephen M. Shore on completing his doctorate. See Dr. Shore’s inspiring article on music education for students with AS on p.6.

Saturday, May 3rd, we will hold our second annual Matthew Dandurand Memorial Workshop and award ceremony in Holyoke, MA; we will post the winners of the Award for Special Effort on our web site. On July 26th we will hold our second annual adults only conference—we will post more details soon. I look forward to seeing you at our Asperger Connections 2008 conference on October 3rd and 4th in Marlborough, MA. We will put details on our web site soon, and send you a brochure early in the fall.

Sincerely,

Danie Feld

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The AANE Journal is published twice a year, once in the spring and once in the fall. Please submit articles or ideas, stories or poems, drawings or photos, to:

Stephanie Loo, Editor
Stephanie.Loo@aane.org

We are so grateful to the advertisers, who help subsidize the AANE Journal. For information on advertising in the AANE Journal, please contact cmeyers@aane.org.
People often ask me how I became involved with AANE. The simple answer is that I am a father of a boy who was diagnosed first with PDD-NOS, then alternatively with NLD and lastly with Asperger Syndrome. That is the simplest answer; however the truth is much more complicated.

My son with AS was the first born and my first experience as a father. My priorities were pretty much focused on how to provide for and take care of my new family by working and traveling hard. So maybe I wasn’t alarmed when he didn’t crawl, but instead scooted around in a sitting position, or even that he didn’t learn to walk until 20 months. But reality checked in when his playschool teachers, who for twenty years taught two-year-olds exclusively, told me that my boy was not reaching developmental milestones.

Thus began our journey of evaluations, specialists, special education and heartache as we tried to fix what was wrong—perhaps he would catch up and outgrow his diagnosis? My wife buried herself in stacks of books and would either read passages to me or leave the stack on my side of the bed in hopes that I too would read them. Along the way we found a social pragmatic group run by Elsa Abele, whom I quickly recognized as an expert in dealing with AS kids. She was teaching a course for AANE called “What did you say? What can I say?” which my wife had signed up for, but she had a conflict when the date occurred. Well, we both agreed we couldn’t let Elsa down by not showing up, so the conclusion was that I would attend in my wife’s place. My thoughts were, “Well I’ll go the first day and leave early to go to work,” and perhaps skip the next day because I couldn’t possibly take the time away. Well I not only attended the first day, but I stayed late to speak with Elsa more, and was most likely the first person there the next morning. I was blown away. What an amazing teacher, and what a great organization AANE must be to expose people to experts like Elsa! My commitment began there.

Our journey of course didn’t end there; my son is now only 12 years old. But we had a turbulent nine years where we called on AANE constantly as he slipped into a downward spiral despite interventions, and despite our involvement. By fourth grade he had been restrained by adults at his school, he was on multiple medications and was truant by December of that year. At home, depressed and lonely—addicted to his video games and afraid of the world—he (and we) hit rock bottom. However, once again our connection to AANE provided a window of hope. While sitting in on one of the committee meetings, I happened upon a parent who also had a son like mine. I talked about my search for a school that would make my son happy. She had an answer for me, one that I didn’t want to hear: a marvelous boarding school in New Hampshire that welcomed bright kids who could not function in typical settings. She spoke of miracles and I listened. That summer my wife and I made one of the hardest decisions of our lives—we would send our nine-year-old to boarding school in hopes of saving him and providing a chance at happiness with peers. We again spoke to our friends at AANE to give us the wider perspective needed to make the right decision, which goes against everything your gut tells you.

So I am committed to this organization, because it has helped us in three distinct ways:

♦ It educated me so that I understood my child better.
♦ It provided a network of other parents who were going through exactly the same struggles, but could provide powerful hindsight experience.
♦ When we were facing extreme difficulties, AANE offered someone to talk to, who could understand and give applicable advice.

I am happy to report that, three years later, my son is exceeding all my expectations at his very special school. He is free of medications, he is attending classes and is on the honor roll. Teachers report he is the most liked student at the school, and last weekend he sang to the entire student and parent body the song “Happiness” from the play Charlie Brown. Do I think we have overcome all our obstacles? No, in fact I am sure we face many more as he transitions into an adult who has to face the overwhelming complicated social world we live in today. But I know at least we don’t have to face it alone because we have other parents, professionals and AANE to help guide the way.

Dear Dania, Stephanie and the AANE staff,

We want to thank you from the bottom of our hearts for all of the support, kindness, understanding and generosity that you have shown to us. It is truly humbling and overwhelming to be the recipients of both the AANE membership scholarship, and especially The Doug Flutie, Jr. family grant for $500 that we just received. This grant will help with the expense of hiring an educational advocate to ensure that our daughter will receive the services and accommodations necessary for her to succeed in school.

We have been advocating for our four children for a long time to try to get their needs met through the public school system. When we came to the place where we knew we could no longer do it alone, we reached out to AANE for help. We were impressed with their immediate response. It was full of compassion and the willingness to help. We are so grateful to be a part of such a caring organization that provides so much support and has so many valuable resources.

Again, we want to thank you for your generosity and kindness, you truly have been a blessing to us!
AANE’s 2008 gala—our guests and bidders, speakers and entertainers, filmmakers and auctioneer, donors and sponsors—it is your support that gives this event its real magic—and provides a major part of the funds that sustains AANE. You allow us to grow, and meet the needs of the growing AS community.

Thank you, Gala Committee!

2008 Gala Chairs
Mary Ann Marie and Dan Gross
Grace Peng and Steve Edelstein

Honorary Chairs
Hank and Melinda Miller
Nancy Schwartz and Mike Levinger

Committee Members
Alma Bair, Natasha Chomas, Sangeeta Dey, Lynn Flaherty, Donna Frank, Alexandra Graham, Elaine Harmon, Maureen Huddleston, Yolanda Kolinski, Peggy Kriss, Karen Lewis, Stephanie Long, Natasha Miller, Jill Purpura, & Allison Sargent

with AANE Staff
Kristen White, Lisa Grafeo, Dania Jekel, Meghan O’Malley & Linda Pereira

WWW.AANE.ORG

If you haven’t looked at our web site recently, it’s worth the trip. Over the past year, Chris Burns of Fort Point Design worked closely with our staff to fully redesign the site to make it more attractive and useful. Ilya Lozovsky contributed great technical and writing skills to the project. Web Master Matt Conrad rose to the challenge of adapting to a new system for updating information on our site.

AANE members and first-time visitors to the web site can now do many things conveniently online: join, renew, make donations, volunteer, register for a conference or workshop, request information, recommend a resource, or post something on our Community Bulletin Board. We hope you will now find it easier to locate:

♦ Information, articles, and lists of books about AS.
♦ Information about AANE services and upcoming events.

Of course, AANE members and staff familiar with the old web site format have to learn their way around the new site. If you’re wondering where to find something, just give us a call—we’ll be glad to give you guided tour!

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Sam is a 12-year old boy with Asperger Syndrome. He had recently been rejected from a private school specializing in Asperger Syndrome for being “too low functioning.” His mother, a professional musician, knew Sam had much musical talent but had yet to find anyone who could teach him how to read music. At our first meeting, she also expressed concerns about the difficulties Sam would begin to face as he entered adolescence.

As with all the children I work with, I requested that a parent (or significant caretaker) join in the lessons. Not only are parents the experts on their child; the lessons give them another way to relate to their child, and they can do additional work with the child between lessons. Occasionally though, the presence of the parent distracts the child from learning. In these cases I start by working only with the child and then gradually involve the parent.

In my first lesson with Sam I made gridlines on a notebook-sized piece of paper, resulting in a 7 row by 10 column box matrix. After placing a few A’s on the first line, B’s on the second, down to G on the last line, I asked Sam if he would like to continue. Eager to do so, he quickly took the paper and started filling in the blank spaces with letters.

Many people on the autism spectrum have a strong need for order and completion. A piece of paper that looked like this...

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Sam’s need for order and completion enabled him to complete an assigned task, and in the process work on fine-motor control and penmanship. Arranging his environment to take advantage of this characteristic worked much better than treating this need for order and completion as aberrant behavior.

Later on during the lesson, I started cutting the individual squares from the piece of paper and then passed the job over to an eager Sam. While he worked on this project, I drew a treble clef and staff on a larger piece of paper along with a lighter dashed line for middle C. Then I drew a B on the middle line and asked Sam if he knew where C went. He responded with an anxiety-filled no! I drew the letter in the space above the B.

A query about where D belonged elicited the same response. I now asked if Sam could just guess where the letter D might go. Now he answered correctly, and I had him writing the letters in the right places on the staff.

With the letters’ placements marked out Sam was now able to place those lettered squares he previously cut out onto the staff in the right locations upon my request.

Soon we were spelling words such as “bag, dad, eat, and ace,” followed by simple complete songs such as “Twinkle, twinkle little star,” and “Mary had a little lamb” which I then played on a musical recorder.

Shortly thereafter we ran out of space on that sheet of paper and it was time to make another sheet of staff paper. Sam’s anxiety rose dramatically at my request to draw the staff lines and the treble clef this time. However, his reluctance melted away just as quickly when I offered him assistance in drawing the lines.

Using Music to Enhance Communication for the Child with Asperger Syndrome
by Stephen M. Shore, Ph.D.
emotions that she broke down in tears. Sam looked over at her and with just a bit of nudging from me gave his mother a big hug. Who said that those with Asperger Syndrome are emotionless?

It appeared that Sam was very anxious about failing at tasks. When he understood that he was in a safe environment without penalties for making mistakes, he did very well. I suspect that Sam’s behavioral challenges in school were a result of not feeling safe academically. During my first lesson with Sam much of the conversation centered on his concern for what an F grade meant, and that it was not good to get such a grade. But the next time I saw Sam there was no mention of grades. Sometimes Sam would immediately reject a request with “no!” only to commence the task a few seconds later. Perhaps his “no!” was in reality a bid for more processing time. Other than easily being overwhelmed with anxiety over failing, Sam seems to enjoy the continuing sessions and is a pleasure to work with.

By placing the notes on this staff in this manner Sam learned how to read music and apply it to a piano keyboard. The difference between this approach and traditional music education is that the primary goal of decoding musical notation was incidental to the activity from Sam’s point of view. In other words, a more traditional way to teach Sam music would involve spending a lot of time sitting in a chair, explaining and showing Sam the names for the lines of the staff, notes, and their relationships. Using a kinesthetic approach engages Sam in the creation of his own learning materials, which served to reinforce the physical activities of putting the notes in the right place on the staff, followed by placing them on the piano keyboard. For people on the autism spectrum, it seems important for the physical aspect of the body to be in order before attending to the emotional and cognitive aspects. Additionally, by assisting in the creation of his own resources Sam probably felt ownership of the learning materials and the activity. I was able to work with him not only on music, but on communication, taking turns, and fine-motor control.

When the time comes for Sam to get his first piano book, he will have a good background in the musical concepts presented in the text, having already ascended the initial learning curve involved in reading, understanding, and converting notation to music on the piano keyboard. He also now has a skill that will help him to interact with others. Perhaps the school that rejected Sam was too low functioning for him.

With the child that already plays an instrument, I will introduce myself into their world by sharing the instrument via turn taking. When I play the instrument the child accompanies me on the percussion. Then we will switch roles. The turns start out short and gradually lengthen to where I work on other issues such as verbal skills, writing, and motor control as needed. To establish equality between us, I must also take my turns doing anything I require of him or her. I too, for example, need to ask for permission to use the keyboard if the child is already using it.

**Music in Ensembles**

For the child at the high-functioning end of the autism spectrum, the school band may represent or provide an important avenue for development. The trombone requires a good kinesthetic sense of where one’s arm is in order to place the trombone slide in the right place for a note to be in tune. Other instruments, except for the stringed ones, require less ear-to-arm coordination as the pitches are obtained with the assistance of keys or valves. The French horn, however, demands much coordination of the embouchure. (Embouchure is French, meaning flow into mouth. The word refers to the position and use of the lips, tongue, and teeth in playing a wind instrument. Sometimes it refers to the mouth piece of a musical instrument.) Percussion may be another avenue. If complex rhythms present a challenge, the bass drum may be a good choice as the musical patterns are relatively simple. Additionally, the bass drum with its low and relatively simple sound waves is often easier for a person with sound sensitivities to handle. Finally, being at the rear of a potentially cacophonous musical ensemble may be of help, as it is less noisy there.

Location in the ensemble may have to take sensory sensitivities into account. If a student with autism insists on playing a certain instrument and it is clear that there will be problems with sound sensitivities, allowing the child to sit in a different location may be easier than rearranging the ensemble in a non-standard manner. I skipped many jazz band rehearsals in high school because the director was unwilling to let me sit elsewhere than right in front of the blaring trumpets. In addition to the purely musical benefits, playing in an ensemble is good for working on cooperation with others, coordination, and a sense of accomplishment.

This article previously appeared in spring 2003 edition of The Source, a publication of ASC-US.

**Dr. Stephen M. Shore** is a President Emeritus of the AANE Board of Directors. He lectures all over the world on autism and Asperger Syndrome, and is the author, co-author, or contributor to many books, including *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*, published in 2001 by AAPC, *Autism for Dummies* (2006) and *Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum* (2004, AAPC). To enquire about private music lessons, contact Dr. Shore at tumbalaika@aol.com. Read more at www.autismasperger.net/faq.htm.
I cannot count the number of times I have been asked (or heard others asked) whether or not parents should tell their child that he or she has Asperger Syndrome. I will give my opinion in a moment, but first I want to address how this is relative to empowering victims.

Tim and Ted are children with Asperger Syndrome, both 14 years old. They don't know each other, but they live only a few miles apart. They were both diagnosed with Asperger's at age 12 and are often bullied at school. The main difference between them is that Tim's parents have decided not to tell him he has Asperger's while Ted's parents have told him. Every day when Tim is bullied, he internalizes it and blames himself. He knows something is different about him but he can't put his finger on it. This sense of always wondering why he is different creates depression. Ted is also depressed. His parents told him that he has Asperger Syndrome, and he thinks it's a death sentence. He rationalizes that others bully him because he has a “disease” that makes him repellant to the other children.

Playing devil's advocate, I have given two entirely different arguments why it is not good either to withhold a diagnosis or to disclose it. In my professional life, I have met practitioners who strongly advocate for disclosure as well as those who are vehemently against it. One can argue reasonably either way. Withholding the diagnosis can cause much confusion and turmoil. When episodes of bullying take place, Asperger children know they are different but the lack of any real understanding can create a negative self-image. On the other hand, sharing the diagnosis may label the child as "defective," and he or she could become even more depressed after receiving that information.

However, Asperger Syndrome is nothing to be ashamed of. It is not a death sentence, nor is it a character defect. The fact is that Asperger Syndrome is a neurobiological difference. It results in perceiving the world through a slightly different lens than others. Many people have speculated that Thomas Jefferson and other notable geniuses may have had Asperger's. There is no shortage of brilliance among the population (Ledgin 2002). Along with this brilliance and uniqueness come differences from the general population. Unfortunately, those who have differences (or stick out in a crowd) are usually the ones who suffer the most from peer abuse while growing up.

Of course not everybody with Asperger Syndrome is a genius, but most people with Asperger's who I've met have some kind of unique personality traits, interests, or talents. Gail Hawkins (2004) states that these unique qualities have led to some of the greatest contributions to society. Gillberg (2002), a noted author on autism, agrees that people with Asperger Syndrome are a tremendous asset to the world. And yet, these same individuals are the ones who often suffer the most peer abuse in childhood, simply because they are different.

Children have a right to know that their differences actually have a name. The name does not define their entire being but it does serve to provide some additional information for self-knowledge. While many children resist being diagnosed and may not even want to talk about it, these same children could continue to suffer from confusion and depression simply because they don't understand that their differences come from a group of traits that they were born with.

If parents withhold the diagnosis from their child, they should expect that eventually their child will discover this truth later in life. People generally need to acquire self-understanding in order to gain greater self-acceptance. The diagnosis of Asperger's can be the information that helps to accomplish this objective. If a child is not told about this diagnosis, a reasonable assumption the person can make when learning of the diagnosis later in life is that there is something wrong with having Asperger's. For example, if I was diagnosed at age 12 but didn't learn about my diagnosis until adulthood, I would wonder why my parents withheld this information from me. Was there something bad about having Asperger Syndrome that my parents didn't want me to know?

By disclosing the diagnosis to your child, you are letting him or her know that Asperger's is nothing to be ashamed of. You are taking away the confusion and pain of not knowing the answer to the age-old question, “Why me?” Instead, you are empowering your child with the knowledge that being a little different could be the greatest gift the Asperger child can have. As my friend Michael John Carley, president of the Global and Regional Asperger Syndrome Partnership (GRASP), has stated, even if he were given the option to become a neurotypical, he would refuse to take it. He likes being different.

Nick Dubin is currently pursuing a doctoral degree at the Michigan School of Professional Psychology. He has produced DVDs on AS and is the author of the following books, published by JKP and available through the AANE web site:

Asperger Syndrome and Bullying: Strategies and Solutions
(From which this article was excerpted)
Asperger Syndrome and Employment: A Personal Guide to Succeeding at Work
Breaking through Hidden Barriers

Nick Dubin spoke for AANE in Holyoke, MA in spring of 2007. We invited him back to speak to our Maine Chapter on March 1, 2008, and in Newton, MA on March 2, 2008.

References:
Ledgin, Norm, Asperger’s and Self-Esteem: Insight and Hope through Famous Role Models, Future Horizons, 2002
Hello everyone, and thank you for coming. Accepting other people with differences is an extremely difficult thing to do, especially in high school, and especially when the difference is a disability. I know from first-hand experience, because I was diagnosed with Asperger Syndrome (AS) in 7th grade. AS, a neurological and biological developmental disorder, is often characterized by difficulty understanding social and communication pragmatics such as: understanding facial expressions, understanding sarcasm as well as other jokes, using appropriate eye contact, or reading body language. Neurotypical children tend to acquire such everyday skills without formal instruction, whereas people with AS have to put in a lot of time, effort, and determination to develop them.

I will now tell you about my experience growing up and dealing with AS. Since I was very young I always had a lot of anxiety. Going through elementary school I had a lot of friends and play dates, and seemed to be progressing like every other kid my age. There’s one interesting memory that my parents and I have. (My parents remember this more then I do.) At my 4th grade birthday party I took 15 kids to a Red Sox game and it was a great time. Just one year later, for my 5th grade birthday it was hard for me to find more then 3 people who would attend. I’m sure you’re wondering how this drastic change in friendships can happen in such a short one year span. I will tell you that the way kids interact with each other in 4th grade is a whole lot different than the way kids interact in 5th grade. By the time 5th grade rolls around kids begin to joke around with each other and form groups of friends to hang out with. Once these jokes started to happen I didn’t understand that they were jokes and I would take them seriously. For example, if someone called me a loser in a joking way, I would not interpret it as joking and would say something really mean back. Throughout 5th grade my friends kept on disappearing one by one due to my lack of understanding of this type of “fun.” By the end of 5th grade my parents began to think that something else was going on that was more then anxiety.

Middle school was hell for me, the worst years of my life. I would come home crying and saying, “Everyone hates me,” and even wondering what the point of living was. As you move through middle school the teasing and joking around only gets worse, which made my situation worse as well. I was constantly teased and picked on. I did not understand why this was happening to me, and at this point I don’t think my parents did either—I was always blaming someone else.

I got through my 7th grade year in the Needham public schools and I had had enough and so did my parents. They knew that I needed some support, although I didn’t want to accept it. Starting off 8th grade I went to a private school, but right from the start we knew this wasn’t the right place for me. I was reprimanded and punished for things I didn’t know were wrong such as saying inappropriate things. (At the time I didn’t know they were inappropriate.) I only stayed at that school for half a year. On February 3, 2003, half way through my 8th grade year, I started at the LABBB program in Belmont. The LABBB program has opened my eyes and helped me acknowledge the support I needed, and that is the reason I am so successful today.

The LABBB program has saved my life! I know that for everyone in the audience that might seem like one giant leap, but it is true. If it wasn’t for all the work LABBB and my parents have done to get me the correct support, I don’t know if I would be standing up here talking to you today, or even living for that matter.

None of this drastic change happens without extreme hard work and determination from myself and my whole support team. When I first came to LABBB I was a kid with no friends, called out in class and couldn’t fit in socially anywhere. I thought it was all one big joke, that there was nothing wrong with me, and I didn’t need to be here, and everyone else needed to change. It took me probably a good year and a half to realize that I had struggles, but everyone had struggles and it was ok. I would hide behind doors and in offices when “regular” high school kids would walk by, because I didn’t want to be seen as a LABBB kid. I knew the other high schoolers thought that the LABBB kids were losers, and I was determined not to be one. Today I am not afraid to talk about my struggles, and definitely do not hide in the LABBB classroom anymore. I have worked for the past four years on accepting my disability, and that is the biggest thing anyone can do: accept your struggles, because everyone has them and no one is perfect. Once I accepted my disability I was determined to change and make myself feel socially acceptable. I sat in social group after social group, learning what sarcasm was, and what things to say to people, and how to make small talk and just simply interact with peers. Once I was taught things, I began storing these skills so I could take them out when needed. If I can say so myself, today I feel that I can successfully navigate social situations—but I still go back to the little things that LABBB has taught me about how to have appropriate eye contact or whatever it is. I want you people to realize that everyone struggles with something, but if you put your mind to it you can conquer your challenge and improve. I look up to everyone in the LABBB classroom, because some of those kids struggle with things that none of us could imagine dealing with everyday. They have inspired me to succeed, and I think they should inspire you, too.

After hearing me speak up here for 10 minutes or however long it has been, I do not want you to leave this lecture hall feeling bad for me; that is not the goal. I love my life. I continue to move on to bigger and better things, and I will never stop trying to improve. What I want you to take out of my talk is to realize that everyone struggles and has difficulty with something—everyone! So next time you go to make fun of someone who struggles with different things than you do, I want you to stop and think about how it would feel if you were made fun of for something you struggle with, however small that thing is.

Andrew delivered this speech at the Belmont High School in February of 2007. The LABBB Collaborative primarily serves students in the towns of Lexington, Arlington, Bedford, Belmont, and Burlington. Andrew impressed AANE staff when he appeared on the Channel 2 program Greater Boston in January of 2007. He is currently completing his freshman year at Endicott College.
I am a professional writer who has taught neurotypical teenagers, college students, and adult writers. I first taught fiction-writing at Emerson College, beginning in 1993; for the past five years I have been teaching college students at Tufts University. I am also the author of The Longman Guide to Fiction Writing for Beginners, available through amazon.com.

When a talented teen with Asperger Syndrome (AS) showed up in one of my adult education classes a few years ago, I became especially interested in working with this population. Since then I have been lucky enough to work with several students with AS who are prolific and talented writers of fiction or poetry. I hold some classes in my private writing studio in Lexington, and others at the Community Education Program at Minuteman Regional High School. I generally work with small groups that meet monthly or bi-monthly. Groups can also access an online discussion board for exchanges between face classes. At other times I may work with a student individually.

In my classes, students with AS may learn both writing skills, and also social skills. For example, giving and receiving criticism can be challenging for any student. In many of my early writing classes I immediately saw a great need for social skills training in this area! Accordingly, I developed a few tools to help students improve their skills. (The exercises below, along with others, are explained at more length in my book.)

- Exercises demonstrating the skill of describing concretely (through the senses) rather than abstractly (by means of intellectual or emotional judgments).
- Hands-on criticism exercises using examples of poor writing from published fiction. First we criticize freely, and then we “translate” our criticism into tactful language we could use to give feedback to the author if s/he were actually present.
- See my tip sheet on giving concrete criticism below.

Giving Concrete Criticism:
What Do You Need When You Read?

**Objective:** This handout will help you to give specific, constructive criticism.

**Giving Helpful Criticism**

Writers need readers. Part of your job in a writing workshop is to help others improve their work by making suggestions. Ideally, your suggestions should be complete—that is, they should be clear and specific, and should include ideas for improvement. Here are some guidelines:

- **Praise:** Everyone likes to be told when they’re doing well. Honest praise is encouraging and builds confidence. Here are a few hints about how to praise other writers helpfully:
  - **Be sincere.** Praise the parts of the story that you think worked well.
  - **Be concrete:** “It was good,” or “I liked it,” are nice things to say outside the classroom, but they are too vague to be helpful in class. Try instead: “The paragraph/sentence/word on page (number) is effective, because…” Telling the writer what exactly is working well, and why, builds confidence and helps the writer to improve.

- **Suggesting Improvements:** Giving suggestions is a positive way of helping the writer to improve areas that may not be working yet. Here are some ideas about giving this kind of criticism:
  - **Be honest.** Pay attention as you read to any parts of the story that are not as effective as they might be. List these on your Reader’s Chart.
  - **Be precise.** Take the time to carefully identify problems. Instead of saying, “I didn’t like it,” say specifically what you didn’t like, and why.
  - **Offer possible solutions.** Think about your reactions—what did you, as a reader, need more/less of? Always try to include more than one possible solution to a problem. This shows respect for the writer by giving him/her a choice, and it acknowledges that we are reading a work that is in progress, and so we don’t expect perfection.
  - **Use “I” statements, not “you” statements.** Focus on your needs as a reader, rather than on what’s wrong with the story. Example: “As I read the first scene between the two main characters (page number), it was hard for me to tell who was speaking which line.”
  - **Use time well.** Choose one or two important points to bring up in class. At least one of these points should be positive. Write minor criticisms, such as word choice, punctuation, and other details, on the manuscript, rather than using time in class to discuss them. Be sure that you leave time for others to contribute.

- **Good Communication:** Think out your remarks before class. Here are some tips on how to express criticism helpfully:
  - **Be polite.** Consider the writer’s feelings; avoid unnecessarily harsh expressions such as, “I hate that,” or “your story is really bad.”
  - **Don’t make fun of anyone’s work.** Avoid laughing at someone else’s story—unless it’s clearly supposed to be funny. Never make jokes about someone else’s story.
  - **Don’t be sarcastic.** Sarcastic remarks can easily cause hurt feelings and misunderstandings.
  - **Don’t overload the writer.** Everyone has limits. Stop after making one or two points, even if you think there’s more to be said. There will be time in another workshop to suggest other changes.
  - **Be honest.** Good criticism balances honesty and sensitivity. It won’t help to tell someone that an unsuccessful story is brilliant. On the other hand, if you hurt another writer’s feelings by insulting the person, s/he will be discouraged, and may not be able to listen carefully to your feedback. The most important thing is to think about your remarks before class. That way, you can plan how to express yourself clearly, effectively, and tactfully.

If you or someone you know would like to participate in one of Sibyl Johnston’s groups, contact her at sibyl@rcn.com.
If you missed seeing the exhibit
Seeing with A Different Eye: Art by Adults with Asperger Syndrome
at the AANE fall conference or at the Cambridge Multicultural Art Center, here are more opportunities:

The Concord Free Public Library
129 Main Street, Concord, MA
April 2, 2008 - April 30, 2008
Library hours: Mon - Thurs 9 - 9, Fri 9 - 6, Sat 9 - 5, Sun 1 - 5

The Honan-Allston branch of the Boston Public Library
300 N. Harvard Street, Allston, MA
Reception: May 3, 2008 2:30 - 4:30
Library hours: Mon & Wed 12 - 8, Tues & Thurs 10 - 6, Fri & Sat 9 - 5

The Massachusetts State House - Doric Hall
Beacon Street, Boston, MA
June 2, 2008 - June 13, 2008
Reception: June 3, 2008 10 am - 12 noon - Nurses Hall
Gallery hours: Mon - Fri 9 - 5

The exhibition catalogue is available at www.aane.org.
For further information contact Kathy Clark at ktheclark@aim.com

The positive impact of the exhibit just keeps growing:
♦ We want to congratulate Jamie Maxfield and John Williams, AANE artists who also exhibited this winter at the gallery of the Concord Art Society.
♦ Instrument-maker Gary Hudson performed with two friends at AANE’s first ever Irish music concert this March.
♦ At the exhibit opening at the Cambridge Multicultural Art Center, some of the talented poets in the AS community read aloud. On this page we offer a few of their poems. We’ll print more in our fall 2008 issue.

Child in the Attic
I am the child you locked up years ago in your "attic"
I am the one who embarrasses you and makes you frantic
You'd like to pretend I just got up and went away
When in fact I was inside you every single day

You have become an adult and started a family of your own
You forgot all about me and left me in this "attic" all alone!
It's been years since I've seen the blue sky, the sun, a flower or a tree
And all I've ever wanted was just to continue being free...

I am the child in you that you keep under a lock and a key
I am the one who is trying to get out of this small dark "attic"
And show the world you are really a part of me!

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Beyond The Silence
From beyond the silence I'll emerge
My way of thought, my feelings
I'll tell the world
No longer will I hide behind my mask,
I'll take it off, allow people to ask...
I'll be the spokeswoman for people like me,
Who can't share their feelings
And about them can not talk
I'll be the one, who teaches them how to stumble first,
Then how to walk
From beyond my silence I'll emerge
And show them how it's done
I will open the door
And reveal my world to everyone!!!

This is who I am, Who I was meant to be
This is what has brought me all this way
And made me into ME.

This is what I am- I'm an Aspie!

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Michal Maoz is a 35 years old Israeli-born poet and artist, who has AS and is a mother of 2 Aspie boys. She has been writing poetry in Hebrew since early childhood, and started writing in English after her move to the US in 2000. Michal is about to publish her first poetry book with PublishAmerica in 2008. Learn more about Michal, her company, art, and vision, at www.auristic-spectrum.com.

Gorgeous Tomorrow
The anticipation, the exhilaration, the relief,
runs like wild horses along the Oregon Coast,
right through my heart
The glorious future,
lke a breathtaking copper sunset with a touch of violet,
seeps through that gloomy hive of jaded cynicism,
hovering above and drips all over us.

by James Williams
For the past several years Middlesex Community College (MCC), like many other colleges throughout the United States, has seen a steady increase in the number of entering students with Asperger Syndrome (AS) and other diagnoses on the autism spectrum. Countless students with AS have the intellectual capacity to be successful with college-level academics. However, their difficulty with change, poor ability to read/learn unwritten rules and procedures, and frequent concomitant anxiety—all hallmarks of their AS—exacerbate the already daunting task of transitioning from high school to higher education—even at a nonresidential, commuter college. In my position as a Disability Support Specialist at MCC, I have worked with many students with AS, and had noted that many seemed to struggle most during their first semester. I was looking for ways to address this problem, when a new opportunity came along.

In 1998, Middlesex Community College launched a Carnegie Academy for the Scholarship of Teaching and Learning group. Pat Hutchings, Vice President of the Carnegie Foundation for the Advancement of Teaching, says that the goal of the Carnegie Teaching Academy is to “put forward new models of teaching that will foster deep and lasting understandings by students,” and “to raise the status of teaching by underlining its character as intellectual, scholarly work.” Since 1998, the MCC group has expanded its members and the focus of the work on campus. Faculty representing both campuses (Bedford and Lowell, MA) and a wide range of disciplines have proposed, researched, and shared results of projects to further the scholarship of teaching and learning. In the spring of 2006, the MCC Carnegie group extended their annual invitation for the first time to include not only faculty but also professional staff at MCC. Accordingly, I proposed researching and designing an orientation program for new, incoming students with AS. My proposal was approved, and I was invited to join the group.

During the 2006-2007 school year, I interviewed three groups of people in order to explore their perceptions of initial challenges in transitioning to higher education: students with AS currently enrolled at MCC and finding academic success, disability support specialists at community colleges across the state, and several experts in the disability and higher education field. Based on these results, I designed and implemented a four-session orientation program for students on the spectrum. In August 2007, five students were invited to take part in the pilot orientation program, and four chose to participate. Some of the activities and the topics in our orientation sessions included:

♦ Explicit teaching of the vocabulary of college, e.g., what does “three credits” vs. “four credits” mean? What are the differences between lecture, hybrid, and online courses? What does it mean to add/drop a course vs. withdrawing from a course?
♦ Initial explanation of some common unwritten rules of the MCC campus, e.g., how to access adjunct faculty vs. how to access full time faculty; where do students go when they have down-time between classes; room numbers that start with a “2” are generally on the second floor, etc.
♦ A campus tour including looking inside a classroom in each academic building.
♦ Several guest speakers, e.g., someone from the student activities office discussing how to get involved.

Initial results appear promising. Answers on the pre and post-orientation surveys reflected students’ increased understanding of some of the systems of the college, as well as increased awareness of where to go and how to ask for help as needed. All four participants independently sought me out during their first days of class, and were able to reiterate information covered during the orientation program. Although they may still have felt anxiety about the transition, they appeared to have the information they needed to begin to navigate a post-secondary environment.

As the Carnegie Group is equally committed to the dissemination of supported scholarly work, my charge for the 2007-2008 academic year has been to compile, document, and report the results of my research and the pilot orientation program. In this way, other colleges will have an opportunity to create orientation programs to increase the comfort and success rates of incoming students with AS.

In September 2007, Korinne Hertz participated in AANE’s panel discussion for prospective college students on the spectrum, their parents, and service providers. For more information on Middlesex Community College’s Carnegie Group, please visit their website at: www.middlesex.mass.edu/carnegie. To contact Korinne Hertz directly, call 781-280-3640 or email hertzk@middlesex.mass.edu.
Two Sides of Jason

Jason Brodsky, age 25, is an anime and manga fan. Jason goes to several anime conventions around New England and is always in costume. He tends to like characters that are cats mainly because of his love of cats. Having earned an Associate Degree at NH Technical Institute, he works as a Network Technician and computer repair person for Arcomm Communications in Hillsboro, NH.

Left: Jason as Meowth, costume by Jodi Scaltreto.

Right: Jason at work.

Brittany Finds Her Vocation
by Donna Litterio

My daughter Brittany is 17 and in the 11th grade. When she was younger, she was convinced that she was going to own her very own bistro, with bakery items. I couldn’t imagine it, but I worried needlessly. In the 10th grade, a year later than normal, I got her into the vocational exploratory program: kids try out a number of vocational experiences for about 10 days each, and then get to pick up to three vocations ranked from first choice to last. Culinary work was her first choice, but cosmetology was her second. She got into the cosmetology course. I was frantic: a people job—how is this going to work? Her educational team was worried, too: “She’s got AS, this isn't what she wants,” etc.

However, I was asked to please let her give it a try. To my amazement, she loves cosmetology. The other day her instructor spent 40 minutes on the phone with me because I expressed a concern about why she was moved from the hair cutting program to the facial program. The instructor reassured me that she was making an amazing adjustment and settling in just fine—even though she is the only high school junior there, the rest are seniors and two post-grads in their late 20s! She is under the instructor’s wing, and I can’t be any happier! I suggest, if I may: If your teens have dreams or ambitions, let them take the classes that they will need, or give them experiences that show them what that career would take, or try a vocational program. Sometimes you might get a good surprise!

Brittany was chosen as a final selection for the celebration of quality writing done during the third annual “Weymouth Writes” to be displayed in the Humanities Center at Weymouth High School during the month of April as part of the community celebration. There was one winner per grade. Brittany also was chosen the first year 2006, in grade nine.

After High School: Alternate Routes
The Destruction of Manglestron
by Richard Zicko

Long ago, in the Narpe galaxy, there was normal planetary action. Then, out of nowhere, came a huge starship called the Ark. As long as the planet Earth is wide, it was carrying half of the populations of an entire star system. This ship was headed for a system called the Triplet Suns. They were bringing a huge machine of some sort. All you could see from the outside was a giant green sphere emitting a blue light. This machine was dropped into orbit around the Triplet Suns and the entire space-time continuum itself began to warp. Around the machine formed a huge bowl of rock with the machine in the middle. After that, a huge deformed planet formed. This planet would come to be known as Manglestron. The Ark landed on the base of a half-sphere completely covered in sand. The Ark became the government building and would house the sub-government (led by a species called humidrak), the lower government (led by a species called dracoslyths), and the upper government (led by a species called darsk, and more specifically, someone named Zyke, who just happens to be immortal). The rest of the people (builders, army, and civilians) spread across the land and settled on the planet permanently. To help be protected and make sure what happened to the planet would not happen to the last planet would not happen to this one, the builders created a new semi-robotic species; the kilodroids had been born. A cross between wareesp and darsk, with a nanotechnology brain, they proved too aggressive and powerful to control. Consequently, they were imprisoned in the core of the lava ring for all of eternity...or so they thought...

23,666 years later, the planet is thriving. So far, in all of these millennia, the Manglestronian army has never been defeated.

“Zyke! There has been a disturbance in the lava ring! A hole is opening on the far side! Strange creatures that look like huge darsk are pouring out!” It was Zyke’s advisor, Scalaab Girogen (a humidrak). “Shall we take any action?”

A hissing voice came from under a glowing blue cloak and two glowing green dots appeared under the hood. “Send a group of engeron to check them out. They will be able to tell if these things are what I think they are. If they are, then I fear the contents of the prophecy.” “The prophecy that foretells the destruction of the planet? Run! Ahhhhhhhhh! Ahhhhhhhhhhhhh—” A large ball of fire was launched from the hand of Zyke.

“That was getting annoying. Ah! Here is the report on the escapees. So, they are kilodroids...” He pushed a button on the computer console in front of him. “Deploy the army to the lava ring, and deploy the skyfighters between the lava ring and rock shell. THE KILODROIDS MUST NOT REACH THE ROCKSHELL!!! I will be joining the battle as soon as I can.”

The scene at the lava ring was one of violence and destruction. “Zyke! They are ravaging our troops! Did you know they can fly?”

“Of course they can fly!” said Zyke. “They got their wingspan from wareesp, not darsk! I guess I will have to take care of this myself.” He joined a line of darsk and they started throwing fireballs simultaneously. A line of kilodroids assembled across from them and they volleyed back and forth, picking each other off until it was just Zyke and Lord Kiloron fighting back and forth, dodging each other’s blasts. Zyke started blowing a huge stream of fire, sweeping from left to right. He hit every kilodroid on the ground, including Lord Kiloron, but it did no damage.

The battle in the sky was no better. Wareesp were flying around breathing massive spouts of fire while clawing and biting the enemy. Tiny engeron were latching on to the kilodroids and using their extremely powerful breath to their advantage. Even though all of this would have destroyed an ordinary army in minutes, it was not working against the kilodroids.

Zyke shouted “Deploy the last resort!” At this command, an orange cloud came out of the building, floating in the middle of the lava ring, and bright orange lines started to form between the rock shell and lava ring. Between these lines flew the entire Manglestronian army, the flightless riding on wareesp. Unfortunately, so too did three kilodroids, including Lord Kiloron himself. The lines then formed into an impenetrable orange wall. Another cloud, this time silver, came out of the building. This time, silver lines appeared around each kilodroid. When the shells dispersed however, there was nothing in them. The Kilodroids had been destroyed once and for all...except for the three that got through the barrier, who promptly entered the hollow side of the rock shell. Zyke, riding a wareesp named Splain Superion, chased them in.

Zyke said in a hissing voice, “Only darsk and kilodroids are not affected by the slowing of time that occurs as you enter the shell. You will have to wait at the rim.”

“Yes sir,” replied Splain. Zyke then walked towards the center of the shell where a large green sphere emitted a blue light.

“Halt! Do not destroy the sphere! If you do, the entire planet will be destroyed!” The three kilodroids positioned themselves around the sphere and started breathing large amounts of fire at it. The sphere stopped emitting light. It turned red. A screeching sound filled the air. There was a huge explosion. The sphere was destroyed, taking the planet with it. However, before it exploded, many members from every biological species boarded the Ark and took off. It then teleported to a new system. Hopefully they have learned their lesson.

Rich Zicko, age 15, loves building incredible lego structures, playing Wii and other video games, and reading and writing science fiction.
“Hello, Mrs. Thompson, this is Ms. O’Conner, Jacob’s teacher. I’m calling today because there was another incident in class. Jacob is struggling with listening to directions. We were at morning meeting and, as always, he was jumping up and down and calling out. Another student asked him to sit and be quiet because he couldn’t hear. Jacob screamed at him and ran down the hall. Can you come in for a meeting on Friday so the Principal and I can talk with you about what our plan is from here?”

If you are a parent, you’ve probably gotten some phone calls like this, and you probably wish you could do something to make sure you’d never get another one. If you’re an educator, you would probably be happy if you never again had to make such a call. Well believe it or not, your wishes can come true!

What is behind the disruptive, impulsive, seemingly irrational and inexplicable behaviors of children with Asperger Syndrome (AS), and how can adults intervene to diminish such behaviors? Let’s first quickly explore why children with AS may exhibit difficult behaviors, and then we will devote the rest of this article to quick and easy-to-implement recommendations.

Children with Asperger’s tend to have specific traits which fall into three broad categories:

1. **Difficulty with Executive Functioning Skills** Executive functioning skills enable us to create a goal and a plan for reaching that goal, and then to initiate, sequence, sustain or inhibit behaviors to work towards and finally attain that goal. Executive skills also enable us to reflect upon our behavior, assess our progress, and make adjustments as necessary.

2. **Difficulty with Sensory Processing, Regulation, and Modulation Skills** or "the ability to attain, maintain, and change arousal appropriately for a task or situation (Kranowitz, 1998). “Self-regulation” also refers to the ability to control one's emotional, mental or physical responses to sensations.

3. **Difficulty with Social Skills and Social Rules** Social skills include all verbal and nonverbal skills that are required to have fluid interactions with others. This can encompass reading and giving nonverbal cues (such as body posture, eye contact, tone of voice, etc.). Social skills also involve taking another’s perspective, knowing what to say and what not to say, and when, and to whom.

Because many children with Asperger Syndrome have difficulty understanding the subtleties in life, the interventions below are designed make the subtleties obvious. Additionally, there are interventions to help children regulate their bodies and provide creative ideas for social interaction. The interventions are grouped to target specific areas of difficulty. There are many interventions listed here; not all will work for everyone. Choose and try out what you think will work for your individual child or student.

Some interventions listed below are just good teaching practices, whereas others were created specifically for our kids with AS and related conditions, by Milestones staff or by other professionals. An asterisk indicates that a professional from outside our agency created the specific strategy.

### Executive Functioning Interventions

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post the Daily Schedule</td>
<td>By writing out the daily schedule (at home or school), we make the child’s day more predictable, and help the child be more prepared to meet each challenge. At school, make the schedule large enough so the child can see it clearly. Post it at the child’s eye level, somewhere so that it is in view at all times. When a subject is completed, erase it or check it off, so the child can easily see what is coming next.</td>
</tr>
<tr>
<td>Oops Board</td>
<td>Post a list of daily events that are unexpected changes (i.e., “Surprise math test today” or “No Gym today”). Usually, students do better when they know in advance to expect a change, rather than learning about it two minutes beforehand. Keep this list in a consistent place. (Some students may perseverate on these changes, in which case this is not a useful technique.)</td>
</tr>
<tr>
<td>Physical Boundaries</td>
<td>Because children with AS have difficulty inferring, they may miss cues about where to stand or where they can and can’t go, or place or move their bodies or body parts. Create a visual support by adding shapes by the door so the children know where to stand when they are lining up. If the child tends to bump into people while in line, have him/her be the leader or caboose so there are fewer kids to bump into. If the child is fidgety and pokes people when seated at his desk, move his/her desk a little further away from people, or put tape outline on the floor around the child’s desk, so the child has a physical marker and knows where the boundaries are. During meeting times, use carpet squares, shapes, or desk chairs so the children know where to sit, and do not invade each other’s personal space.</td>
</tr>
<tr>
<td>Intervention</td>
<td>Rationale</td>
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<tr>
<td>Bin System &amp; Graphic Organizers</td>
<td>Instead of having children keep their work in their desks, provide the children with a set of clear plastic bins in which they can keep their work for each subject. This will limit the chaos of having all subjects in one binder and will also increase the likelihood that papers will stay sorted. Graphic organizers can help children focus and guide them in a good direction. Giving children a system to use also frees up their brains for other tasks!</td>
</tr>
<tr>
<td>Consistency</td>
<td>Whatever rules you create, stick with them and be consistent with follow-through. Sudden changes which might seem logical to the teacher or parent may go right over the head of a child who has difficulty making inferences. While all the other kids have caught on, the child with AS is still following the old rules. By only picking a few rules, but always following through consistently, you will achieve success with these students.</td>
</tr>
<tr>
<td>Point of the Lesson</td>
<td>Although it may seem obvious to you, it is crucial to tell children the main point of the lesson and write it down on the board. Children with AS often retain only random facts from a lesson. By making clear the main point of the lesson, you are giving the child a framework to attach the facts to, and helping them create a whole picture. Additionally, if the student’s attention wanders, it is a great tool to pull the child back and help him/her refocus.</td>
</tr>
<tr>
<td>Be Specific</td>
<td>Always tell the child what you want him to do, not what you want him to abstain from. If you say, “Stop that!” (which is too vague) or “There’s no talking out in class!” (all negative), it doesn’t tell the child what he should do. By saying, “Write down your questions,” or “Hold your questions until 11:00 am and then you can ask me,” you are giving the child tools for what is appropriate, and curbing the child’s anxiety.</td>
</tr>
<tr>
<td>Reciprocal Teaching</td>
<td>To assure that a child really understands the concept you are teaching, first teach the group and then have individual children re-teach others. One fun method is also to provide an assignment for homework or in small groups, and have the children then teach others what they have learned. This also helps children with AS learn perspective-taking, since they need to take their audience’s reactions to the lessons into account to determine whether the audience needs more information, or if they have given too much information.</td>
</tr>
<tr>
<td>Decrease Clutter</td>
<td>Organize the environment so everything has its place and is labeled. Decrease any extraneous stimuli (i.e., nothing hanging from the ceiling, cover shelves with sheets, taking down old class work from the walls). Use privacy boards (screen that goes around the top of the child’s desk, minimizing distractions so s/he can concentrate on his/her work) as necessary. For many children with AS, all stimuli seem equally important; therefore the teacher is competing with objects dangling from the ceiling. Decrease visual clutter so that the teacher can be the most important thing to focus on (or at least the child will have fewer distractions). This can really help with sensory regulation as well.</td>
</tr>
<tr>
<td>Transition Warnings</td>
<td>At 5 minutes, 3 minutes, and 1 minute prior to ending activity, give children warnings. If you are teaching, set a timer to go off 5 minutes before the lesson is over, or assign this task to a student. This technique slowly prepares the child for the upcoming transition to a new activity or task.</td>
</tr>
<tr>
<td>Ignoring Points</td>
<td>Have children earn points (tally marks) when s/he ignores inappropriate or irrelevant information in the environment (such as peers who are acting inappropriate or something s/he is perseverating on). This is a helpful way to “train your brain” to ignore unimportant things.</td>
</tr>
<tr>
<td>Thought Boxes</td>
<td>Provide a box on the child’s desk so when s/he has thoughts that are inappropriate (wrong topic, wrong time, wrong person), s/he can put them in the box, close it, and put the thoughts away.</td>
</tr>
<tr>
<td>Math</td>
<td>If children who have difficulty with visual organization, have them use graph paper to write out math problems. Use one box per number. This can help keep numbers in line.</td>
</tr>
</tbody>
</table>
Classroom Warm Ups
Have kids up and moving every 20-30 minutes. They can do simple things such as ten wall pushups, ten jumping jacks, get up and run around your desk three times, etc. This physical activity break will help children switch gears and calm their fidgety bodies.

Reduce the number of problems on a page.
For children who become overwhelmed easily by work. Take the 20 math problems you have assigned, and instead of giving the child one page with 20 problems, give 5 pages with 4 problems each. This will help decrease anxiety.

Auditory Interventions
Close the classroom door to decrease noise, permit the child to use an iPod when working on individual quiet assignments, place tennis balls on the bottoms of chairs, have a one-person-talks-at-a-time rule, or place a rug on the floor to muffle sound.

Tactical Interventions
Have a fidget box filled with small manipulables such as modeling clay, play dough, pocket koosh balls, lotion, and other small things that kids can use to fidget with. Offer the option of working on the floor or standing, instead of only sitting at a desk. (This can help with low muscle tone as well.) Use weighted blankets to provide sensory input to students.

Scheduled Frequent Breaks
Provide the child with frequent, regularly scheduled, short breaks. Think of breaks like food; if you wait too long between breaks, or don’t give them until the child absolutely needs them, the child will be distressed, just as s/he would be if s/he had to wait too long between meals. If you provide regular, predictable, short, frequent breaks, the child can remain regulated.

Keep furniture placement the same.
For children with motor planning and sensory issues, for whom it is a struggle to remember where things are and how to avoid furniture, keeping furniture placement the same all year reduces anxiety. This includes where the children sit. If you need to move furniture, have the child help you move the furniture; this way there is some participation on the child’s part, which may help with visual memory.

1-5 Scale
The 1-5 Scale, created by Kari Dunn Buron and Mitzi Curtis, provides a visual representation for the range a child can be experiencing. This range was originally created for sensory regulation. At Milestones, however, we often use it to represent ranges of behavior or social appropriateness as well as for sensory regulation. (See below.)

Below is an example of a 1-5 scale that I used with a child who had difficulty understanding how much of an emotional response he should have. This child often catastrophized, becoming very upset with others or himself over small things. This chart provides an idea of what a “1 problem” is vs. a “5 problem.”

<table>
<thead>
<tr>
<th>Using the 1-5 Scale for Sensory, Volume, Inappropriateness, or Thoughts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level 5</strong></td>
</tr>
<tr>
<td>Disaster/Horrendous</td>
</tr>
<tr>
<td><strong>Level 4</strong></td>
</tr>
<tr>
<td>A big deal</td>
</tr>
<tr>
<td><strong>LEVEL 3</strong></td>
</tr>
<tr>
<td>Inappropriate</td>
</tr>
<tr>
<td><strong>LEVEL 2</strong></td>
</tr>
<tr>
<td>Unpleasant or Disappointing</td>
</tr>
<tr>
<td><strong>LEVEL 1</strong></td>
</tr>
<tr>
<td>Not a big deal; just think about it</td>
</tr>
</tbody>
</table>
Message from Kristen Z. White, M.Ed., Director of Development
Kristen.White@aane.org

Over the past year, I have so enjoyed getting to know so many wonderful, caring people from AANE’s community. AANE had long wanted to bring our members and donors together through small networking receptions in different communities. This past fall we held four such intimate gatherings. Generous volunteer hosts in Newton, Swampscott, Cohasset and Lexington opened their homes to AANE members and donors in each area, and plied us with delicious food and drink. Then we enjoyed a delightful talk by AANE board member and speech and language pathologist Elsa Abele. Thank you so much, Elsa. Our whole community is glad to have you as our teacher! It was wonderful to see our community making so many connections throughout these special evenings, and we hope to hold more in 2008-09. Please contact me if you would like to host.

Thank you also to the many generous donors who supported our Annual Appeal! Our fiscal year runs through June 30th, so it’s not too late to contribute. You can now make a credit card gift online through our website at www.aane.org.

At the moment, I am deeply involved with the hardworking gala committee, and looking forward to a magical evening—one that will probably already have taken place by the time this issue of the Journal is in your hands. I hope to see many of you there, and look forward to reporting on its success in the fall issue.

If you would like to become active in one of our committees, share ways you would like to support AANE, or refer us to other prospective donors, please contact me. We would especially like to talk to anyone who has a personal connection with a decision-maker in a corporation or foundation, someone receptive to learning about AANE’s mission and exemplary work. Corporations can get good community visibility as sponsors for our gala or our fall conference.

Guests thoroughly enjoyed the hospitality of Michael Palmer and Noelle Palmer at AANE’s north shore networking reception last fall.

Pictured left:
David Nihill
Noelle Palmer
Dr. Alison Brookes
Peggy Nihill and
David Barach

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or contact us at autismconsortiumresearch@hms.harvard.edu
or by calling toll-free 1-866-518-0296
Parenting children with AS can be a joyous, rewarding and eye-opening experience. It can also be challenging, and at times exhausting. We all need breaks in our parenting hours to rest, refuel, and regenerate ourselves. For most families, that means hiring a babysitter—but where do you find one, and how can you help to ensure that the experience will go well?

Seek special sitter for special six year old girl

- 3 hours/week on Saturday mornings starting in April.
- Sitter can follow the easy schedule provided by parent.
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- All towns also belong to educational collaboratives, whose classrooms use para-professionals as well.
- Colleges may also be a source of more mature sitters, possibly including students who have a particular interest in special education, psychology or social work. BU, Lesley, and Simmons offer special needs programs that specifically address AS. Students often look for flexible hours to fit around their class schedules. They may be looking for a job that can also offer them experience in the field they are going into; a letter of recommendation from a parent might be a welcome addition to a student’s file. Sometimes a parent can even work with the student and a professor to enable the student to gain credit for an independent study designed around the specific care they give your child.
- AANE members can post that job description on the online parent support group. Some parents may be willing to share their prized sitters if they know that you are only looking for specific, limited hours.
- You can try: www.collegehelpers.com ($10 fee to advertise) or www.sittercity.com which can be more expensive to use.

Getting off on the right foot

Write out a few interview questions that you can use for each initial phone interview, once you start getting responses, e.g.:

- When are you available to sit?
- What experience do you have sitting other children?
- If they are classroom aides, “What children have you enjoyed working with?”
- For a student, “What interests are you pursuing, or what career are you heading toward?”
- Would you feel comfortable with following my child’s usual routine (simple playing, reading, bathing, etc.)?
- Be sure to ask for and contact references!
- Briefly describe your child and what s/he is comfortable with, and ask the sitter for thoughts about working with the child.
- Listen to the potential sitter’s answers to these open-ended questions, and ask follow-up questions as needed. Always listen to your gut feelings about a conversation. If it just doesn’t feel right, move to another person.

If you feel good about this person based on the phone interview, schedule a face-to-face interview, which might include the person spending some time getting to know your child while you stay in the house. Set clear expectations from the start, such as:

- Let the person know best strategies for a smooth interaction with your child, and how to handle any behavior problems. Explain the child’s Asperger Syndrome in concrete ways, letting the sitter know what s/he likes and dislikes (e.g. light touching, loud voice).
- Ask the sitter to avoid making or receiving personal calls while working.
- Show the person around the house, indicating where to find cooking implements, how to work the DVD player, etc.
- Post written house rules, and a written schedule (possibly with pictures). Include all necessary contact information and the time you will return. Ask the sitter to stick to it because it makes the child more calm and comfortable.
- Review when and how payment will be made.
- Remember to be very respectful of the person’s time, schedule, and needs. Consult the person to discuss any changes you might like to make, and express your appreciation. A little pampering may go a long way!

Hopefully these leads can help you find an excellent, reliable sitter, who will enrich your child’s life and also afford you some time to yourself or with a spouse or partner. If you know your sitter will be coming on a regular basis, you can plan ahead to do some of those things you used to do before you became a parent—remember those days?—and look forward to those adult activities. Then you will return to your parenting duties with new energy and a fresh perspective. Enjoy!
Getting Organized: A New Tool for Parents
by Carla K. Binswanger

Piles of paperwork are a fact of life for most of us, but for parents of children with special needs, there are few things as confusing, as chaotic—or as important—as the piles of paperwork that surround a child’s Individual Education Plan (IEP). When our child was diagnosed with an Autism Spectrum Disorder, he received months of cognitive, speech and physical therapy, and we received a huge pile of paperwork. As a professional organizer, I did the only thing I knew how to do: I got organized. The result is My IEP Toolkit: The Complete Organizer for Your Child’s Individualized Education Plan, a durable binder that helps parents sort through, organize and easily retrieve their paperwork, so that they can effectively advocate for their children.

My IEP Toolkit is modeled on a concept recommended by many education professionals: to gather together all your child’s relevant IEP paperwork, and to organize it into a 3-ring binder with tabbed dividers. However, My IEP Toolkit goes even further. Its 12 high-quality dividers each cover a distinct IEP-related topic, including Testing & Evaluations; Report Cards & Progress Notes; Communication with Teachers, and more. The front of each divider is pre-printed with clear instructions showing what belongs in that section and what doesn’t, as well as tips and strategies related to that topic. The back of each divider is designed to help parents easily record their own information on that topic.

“I used to spend so much time digging through piles of paper for misplaced information,” says one mother whose four elementary-school children each have IEPs. “It’s intimidating enough to go to team meetings, to try to understand all the information they’re giving you, and to advocate for what you think your child really needs—but it’s worse when you can’t even refer to the necessary information to justify those needs to the school. With My IEP Toolkit, I don’t spend hours sifting through papers anymore. Now I can easily review the information, and easily keep track of which child is getting which services. It’s helped me gain confidence in dealing with the school teams, and it’s helped me communicate with them much more effectively. I couldn’t survive the IEP process without it.”

My IEP Toolkit includes user-friendly charts for recording classroom observations, tracking student progress, and following up on issues discussed at IEP meetings. There are checklists on what to do before and after your next IEP meeting, tips on effective communication with school administrators, and resources for legal advocacy. There’s also a three-hole-punch, a catch-all pocket, and a tag for customizing the spine of the binder with the name and/or school year of your child.

“As an advocate for children with disabilities, I see a lot of parents/clients who are overwhelmed with paperwork,” says educational consultant Jennifer Swan, M.Ed. “In meetings where everyone is speaking a language you can barely understand, My IEP Toolkit gives parents the ability to locate documents, take notes and refer to previous meetings. It helps them be fully present at these meetings. And that’s key, because when parents are focused and organized, they’re a lot more effective about getting services for their children.”

A través del sitio web de AANE, Yolanda fue contactada por el señor Ruben Barmat, presidente de la Asociación Asperger Argentina. Recientemente Nancy Schwartz, miembro de la junta directiva, y su esposo Michael Levinger viajaron a Argentina y pudieron conocer a Ruben y a su hijo Matias, un adulto joven con síndrome de Asperger que asistió como traductor. Le dieron a Nancy una copia del libro de Isabel Rejtman, Síndrome de Asperger: Lo que sirvió... Lo que sirve. El artículo que aparece abajo es uno de los varios disponibles en su sitio web y es usado bajo el amable permiso de ellos.


Eduación Física y Síndrome de Asperger

Las clases de Educación Física para los alumnos con síndrome de Asperger son generadoras de ansiedad y de comportamientos inadecuados por varios factores:

- En primer lugar, porque cuando no hay normas explícitas y se proponen tiempos de juego libre, u organizado por los propios alumnos, las normas de juegos suelen ser implícitas y ellos no las comprenden a no ser que se le expliquen razonadamente.

- Por otra parte está el hecho de que las clases son grupales y en ellas se da una gran cantidad de interacciones sociales simultáneas, la enorme cantidad de energía que estos niños necesitan para procesar todos estos estímulos sociales puede hacer que el alumno se bloquee o comience a mostrar comportamientos no acordes a la situación, afloren estereotipias, adoptar posturas inadecuadas, etc., que por otra parte son vistos por los demás niños como algo extraño y “raro”. Esto va a incidir en una percepción negativa del alumno por parte de los demás miembros del grupo.

- El ruido y el bullicio general, los gritos o bien los ecos (si estamos en un gimnasio cubierto) suponen una cantidad excesiva de estímulos auditivos, ellos son incapaces de filtrar este tipo de estímulos y por tanto los reciben todos a la vez. Un fenómeno curioso que se da en ellos a veces es una especie de defensa del sistema nervioso central es lo que se conoce como “desconexión auditiva” en virtud de lo cual el alumno parece virtualmente “sordo” a las llamadas de los demás, del profesor, o de las explicaciones que pueda dar el mismo.

- En el respecto del punto anterior, sucede que las instrucciones dadas en grupo no suelen ser comprendidas, tanto por el fenómeno de desconexión auditiva, como por el estado de ansiedad en el que se encuentran. No se entran de estas instrucciones dadas por el profesor, es como si “la cosa no fuese con ellos”, así que, una vez todo se pone en marcha ellos suelen actuar por imitación de los demás, habilidad que por otra parte, suele en ellos ser deficitaria. Es posible que lo hagan todo mal o vayan al revés que el resto de la clase etc. En este punto hay que tener especial cuidado para que no sean objeto de burla por el resto de sus compañeros y sobre todo hay que tener presente que su actitud no es intencionada, ellos hacen “lo que pueden” intentando adaptarse a una situación que no suelen comprender, por lo que cualquier recriminación personal sobre “su actitud” no será comprendida y generará aún más confusión, hay que armarse de paciencia y explicar al alumno lo que se espera de él con frases cortas y concretas, las explicaciones verbales largas e insespecíficas harán que se pierda. Para esto vendría muy bien cualquier ayuda visual, una pizarra por ejemplo, el ejemplo de la conducta de un compañero que lo haga primero, etc.

- Nunca será suficiente insistir en el hecho de que al ser normalmente torpes de movimientos y con pobre coordinación motriz suelen ser objeto de burla y ello es muy perjudicial para su autoestima, que ya suelen tener por los suelos normalmente.

- Es a tener de esto importante que no se les incluya en juegos competitivos, (no tienen noción de la idea de equipo, ni apenas capacidad de colaboración). Cuando haya que emparejarse o formar grupos debe ser el profesor el que los forme y pre- asigne a cada alumno a un grupo, sin dejar a los alumnos que se orgulleen espontáneamente porque nadie lo querrá en su equipo y esto vuelve a hacer mella en el concepto de sí mismo. Ellos son conscientes de este rechazo, lo sufrén y lo peor de todo es que no lo comprenden.

- Es interesante que puedan trabajar con otro alumno que sea tranquilo tolerante y colaborador, trabajar con él, temas de psicomotricidad y de coordinación motora (botar una pelota, pasársele de uno a otro, encestar, etc). Siempre sin ánimo de competencia sino de colaboración.

- Y sobre todo hay que tener en cuenta que estos niños se fatigan enseguida tanto física como mentalmente, y además son insensibles a niveles bajos de dolor por lo que hay que estar atentos a su integridad física. También tienen alterada la propriocepción, pueden ser incapaces de darse cuenta de los estímulos de su propio cuerpo y responder a el sentimiento de malestar con conductas inapropiadas, por lo que hay que estar atentos a que puedan sentir sed, calor, frío o agotamiento y decirles que beban, que se abriguen o que paren un poco si están exhaustos, cosas de las que ellos muchas veces no son conscientes y ni se les ocurre pedir o plantearse. Es típico el caso del niño que esta en clase en Junio sudando a chorros y con el abrigo puesto (ni siquiera ha sido consciente de que se siente mal por el calor y no se lo quita hasta que el profesor le hace caer en la cuenta de ello y le dice “quítate el abrigo”) Si el ambiente de clase es estructurado y bien organizado y ellos saben lo que se espera de ellos, pueden al menos no sufrir males mayores y en algún caso ejercitar movimientos que les ayuden en su coordinación motora.

- Hay autores que recomiendan incluso que a los niños con síndrome de Asperger se les dispense de hacer gimnasia mediante un certificado médico, esto es algo que queda a la elección de los padres y de los profesionales. En muchos casos se recomienda que no den una de las clases de EF para dedicarse a ir al aula de apoyo a trabajar aspectos en los que tengan dificultades o simplemente para que trabajen solos en su clase sobre deberes escritos (ya que son muy lentos escribiendo), haciendo tareas atrasadas o en el mejor de los casos a llevar a cabo en ese tiempo algún programa de habilidades sociales dirigido por el gabinete de orientación del centro. Otra oportunidad de practicar programas de aprendizaje explícito de habilidades sociales es precisamente (además del tiempo de recreo) la clase de Educación Física y es por ello, que lo deseable es tener algún monitor de apoyo que incida en la misma integrándose él mismo en juegos cooperativos, con grupos de dos o tres alumnos en los que se trabaje de forma explícita el aprendizaje de la espera, el turno, la colaboración, la flexibilidad de las reglas, etc.

“Yo corría como una liebre, con todas mis fuerzas, y los demás creían que corría como una tortuga, y me decían: ¡corre, corre más!” (Andrea, 8 años)
Greetings from Max Sederer, M.A.T.
AANE’s Coordinator of Adult Services
617 393-3824 x302    max.sederer@aane.org

With the end of winter comes new life and new events for Adult Services social programming at AANE. This past winter AANE groups participated in a variety of activities, from investigating crime scenes at The Museum of Science, to touring the old executive state office of John Hancock. We created unique pieces of art, learned about personality types, and went indoor rock climbing. There is always something different going on, and AANE wants to offer its members an opportunity to participate!

We will continue to present an ongoing Art Series, Book Club, Film Series, Speaker Series and Anime Club. Additionally we have expanded our Pizza and Game nights to four locations, with one almost ever week. Make sure to take a look online for the most recent update of our Calendar:

http://aane.org/upcoming_events/events_adult_social.html

You, our members are vital to the social programming at AANE. We rely on your suggestions and feedback to plan the most fun events and enjoyable activities. We also encourage you to co-host or facilitate a group of interest to you. If you have an idea for an event or an ongoing group, contact me to start the process of seeing your idea come to life. Chances are if you are interested in something, somebody else in our community would like it, too! Spring into action!

If you have never attended an AANE social event, please feel free to make an appointment to meet with me to learn about events you might enjoy.

Look forward to seeing you soon!

Thanks to Emma’s for donating pizza for our Halloween Party!

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The AANE Teen Game Afternoon
by Aaron Levinger
(pictured above)

I’m a teen with AS, and I love games. I had read about charity game tournaments, and when I thought I could organize one, I never considered any charity but AANE. It took me five months to solicit sponsors and donors of space, food, and prizes; as well as plan a day that would be fun for teens. I actually really enjoyed planning the day. My mom, who has worked on the AANE auction, says I’m so good at getting donations that I should talk to the auction committee.

The actual event was held at the Wellesley Recreation Center on October 21, 2007. It went great! The game play (mostly “Apples To Apples”) was spirited, and the food and prizes were a big hit. I eventually estimated the final total raised at over $1,000 for AANE’s teen programs. I’d like to thank everyone who came, as well as all these sponsors and donors:

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These days, when Jamie Freed comes into her office at AANE, she finds her in-box filled with voicemail and email from men and women from across New England (or beyond). They all want to know more about living with Asperger Syndrome (AS).

In 2002, however, Jamie was the one on the other end of the telephone. Her daughter, then five, had recently been diagnosed with AS, and Jamie was urgently seeking answers. By most counts, six years ago is the very recent past, but for the AS community it was the Dark Ages, a time of limited knowledge and clumsy interventions. Even Jamie, who had worked with children with special needs, knew of only one or two other children with an AS diagnosis, and still labored under the prevailing misconception that people with AS were unable to connect or empathize with others. AANE Executive Director Dania Jekel returned Jamie’s call promptly, and provided much-needed support and resources. When she learned that Jamie was a social worker and interested in volunteering, Dania asked if Jamie would consider co-leading a support group for four women with AS. Dania already offered adult social activities about once a month, but this group would be AANE’s very first support and discussion group for adults.

“I didn’t know if I could do it,” Jamie recalls. “I felt like I’d be seeing my daughter in thirty or forty years. At the time, I just really wanted to stuff envelopes!” Nevertheless, she accepted, and the group starting meeting on Fridays. Says Jamie, “I was completely blown away by the group. They were incredible women. They had empathy. They wanted very much to connect to the world and each other, but just didn’t know how. I learned so much from them and continue to, to this day.”

The Friday support group still meets, albeit with new members, both women and men—and AANE now offers more groups, in several locations. Group members all have a safe place to tell their stories and not feel so isolated. Jamie says that although the groups are not designed to teach social skills per se, they “become a place where people can practice skills to try out in the larger world, and then come back and report how it went.”

In September of 2002, Jamie joined the AANE staff, and in 2004, she was given her current title. She and Dania continued to work closely together to develop innovative adult programs at AANE. In 2003, AANE relocated from its cramped attic office in Newton Centre to more spacious quarters at 182 Main Street in Watertown—and in 2007 moved again to 85 Main Street. AANE also expanded the Adult Services team, hiring Gail Kastorf in 2006 and Max Sederer in 2007. Gail Kastorf was hired to focus specifically on individuals’ employment difficulties and to cultivate more employment opportunities, both of which often present serious stumbling blocks for adults with AS. Active parent volunteers and consultants, plus social work interns Kathryn Jantz, Steve Nadel, and Lindsey Young, have also helped AANE to expand its services to meet a diverse range of adult needs, both in Greater Boston and in other parts of New England.

AANE also started to offer support groups for neurotypical spouses/partners of people with AS, currently facilitated by social worker Grace Myhill. (See page 27 for information on newly forming spouse support groups.)

AANE now offers a full calendar of social activities. Movie buffs, book lovers, and animé fans now have a place to connect with others who share their interests. AANE serves young adults with AS up through adults in their seventies, recently diagnosed adults and those who have known their diagnosis for years. Regardless of age, “people learn from each other,” Jamie says. “The support people get is beneficial at all ages.”

In 2007 AANE held its first annual conference exclusively for adults with AS, Know Yourself: The Key to a Better Life. Speakers—some with AS, some neurotypical—made presentations on self-advocacy, dating and relationships, and managing one’s physical and mental health. 140 attendees came from New England, New York, Maryland, Florida, and Oklahoma. They also socialized over ice cream. This year’s adult conference will be held on July 26 at Bentley College in Waltham.

In its new, larger quarters, AANE is starting to resemble Jamie’s vision of AANE as a community center for people with AS, “a place where people can develop work skills, find support and company, even work out at fitness center.” AANE does not yet have a fitness center (although on Friday afternoons in element weather some staff and adults with AS go out for a walk together), but it does offer “a comfortable home base to build relationships and go out into the world stronger.”

In the face of all the growth in adult programming over the last six years, simply talking to people—by phone and in person—remains one of the most rewarding aspects of Jamie’s job. “When the phone rings, I never know who it’s going to be. A lot of times, someone has read an article about Asperger Syndrome at the doctor’s office, or heard a program on the radio and thought, ‘That’s me.’ It is a real privilege to be present for people’s self-discovery. I have my daughter to thank for my incredible career.”

Jamie helps people understand the ins and outs of getting an official diagnosis, or working through the pros and cons of disclosing to employers or others. Most of all, she sees her role as fostering self-acceptance. “So many times, people have felt bad about themselves for years. I help them put their struggles into context, and help smooth over family relations sometimes, too. Many times, parents of adults also feel bad and guilty about parenting choices that were just a result of limited understanding [of AS].”

Some of the once-struggling adults with whom Jamie spoke have become eloquent spokespersons, teaching the community at large about educating, loving, and living with people with AS. Jamie’s initial fear—that seeing adults struggle with AS would offer a bleak view of her daughter’s future—has hardly come to pass. On the contrary, she feels her experience has left her both more hopeful and more realistic. “People might not be strong in every area, but they can build the skills to be strong enough. Success might come at a different, slower pace, but often it does come. I see such integrity and effort in the lives of people with AS.”

Laura Miller is a freelance writer based on the North Shore. A few years ago, she helped AANE pull together our Introduction to Asperger Syndrome book.
Good Morning Jamie, I want to thank you again for coming to the professional [psychology] practice group to which I belong. The TURNOUT for the meeting was larger than usual, and I believe that it has to do with the interest in the topic—a good thing! When I mentioned that we "need to have a Part II" in the Fall, the interest and response was clear. Thank you for the EXCELLENT presentation: good content, good pacing, a flow of interchange—from the personal to the professional—and then, not enough time!

Nick Dubin speaking to 100 teens, parents, and educators on March 2, 2008 in Newton, Massachusetts
Nick also presented in Portland, Maine on March 1st

Destination: Adulthood
a special workshop for teens and parents with Ellen Korin
June 1, 2008 at AANE office in Watertown
For more information, contact Stephanie.Loo@aane.org

Yesterday my 15-year-old son and I participated in Ellen Korin’s workshop called Destination: Adulthood, Achieving Success Through Self Knowledge. She began by having the kids think of their vision for themselves 10 years from now, and then do a checklist themselves of their where their strengths and weaknesses are, what they do well at and where they get stuck. She presented lots of strategies for moving forward toward greater independence and success. And she specifically addressed the time management and "stuck on the computer" issues, which are common to our kids. Both the kids and the parents enjoyed the activities, and my son, who had said “I don’t need to go, I don’t want to go, I have better things to do with my afternoon,” admitted that it was very useful. We came home with a notebook of materials and charts to keep us going.
Support for Spouses/Partners of Men with AS

Marriages or partnerships between men with Asperger Syndrome and neurotypical women can be successful and rewarding, but also pose many challenges to both partners. For several years, AANE has offered short term face-to-face support groups for spouses/partners of men with AS, currently facilitated by Grace Myhill, MSW. Face-to-face groups will meeting in AANE’s Watertown office, and be led by social workers with knowledge and experience working with adults and couples affected by Asperger Syndrome. If you would like to participate in any of the following programs, or want more information, please contact Grace Myhill, LICSW at (617) 504-3116 or gmyhill@gmail.com.

A Spouse/Partners Group for people married to or in partnership with someone with AS. 8 weekly sessions provide mutual support, increased understanding of the effects of Asperger Syndrome on relationships, and an opportunity to explore coping strategies, including ways to improve communication.

Divorced from an AS Spouse: Issues of Co-Parenting

This group will focus on how Asperger Syndrome affects the relationships between divorced parents. Participants will have the opportunity to meet and support others in similar situations. As a group, members will explore techniques and strategies for successful co-parenting. The group will meet every other week, for a total of 4 sessions. Led by social workers with knowledge and experience working with adults and couples affected by Asperger Syndrome.

On-line Support Group

We are delighted to say that we recently launched our first ever online support group, asperger-partners-support, moderated by Grace Myhill. Participants will be able to post emails online which will be available only to other participants for reading and responding. Each posting first goes to the moderator for approval. To join this group, first contact AANE make sure your AANE membership is current. Then contact Grace Myhill.

New Group Forming for Grandparents of Children with a Diagnosis of AS or a Related Condition

This group will reinforce the understanding of the diagnosis, discuss issues around supporting your children and grandchildren, and offer the opportunity to connect with others facing the same challenges. Meetings will take place at the Aspergers Association of New England in Watertown, and will be co-lead by a clinical social worker and a mental health counselor. There will be a charge for the meetings payable to the AANE. If interested, please contact Mary Ann Monheimer at 617-926-7001 or maryan13@comcast.net.

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Your donations sustain AANE and allow us to grow, so we can meet more of the needs of the AS community across New England. Thank you so much!

Please let us know if we have inadvertently omitted or misspelled your name, so we can print a correction.

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Avoiding Misunderstandings in the Neurotypical Workplace
by Barbara A. Bissonnette, Principal, Forward Motion Coaching

When a person with Asperger Syndrome (AS) becomes an employee in a neurotypical (NT) workplace, things do not always go smoothly. The employee with AS may not be aware of the unwritten social rules or expected behaviors for the workplace, and may behave in ways that surprise or dismay his or her neurotypical supervisor or co-workers. Sensory and executive function issues may also complicate the ability of the person with AS to adapt successfully to the demands of the workplace.

Then, as if the social, communication and organizational challenges of the typical workplace aren't tough enough, the fact that AS is an “invisible disability” significantly increases the chances of miscommunication and misunderstandings at work. By “invisible” we mean that there are no overt physical signs that someone has AS. In the book *Coming Out Asperger*, Jane Meyerding writes, “People ask why we need accommodation, rather than what accommodation we need.”

In most NT workplaces, little or nothing is known about AS, so it’s easy for people to assume that things like lack of eye contact and social gaffes signify rudeness, unfriendliness, or insubordination. For example, one coaching client of mine got so overwhelmed by people interrupting him at work that he’d simply sit at his desk shaking his head when someone stopped by. Knowing nothing about AS, co-workers interpreted his behavior as dismissive, and a refusal to answer their questions.

Workplace misunderstandings can result in confrontations with colleagues, or even formal complaints, disciplinary action, and getting fired. For the person with AS, these events are often thoroughly unexpected and can come as a shock. People tell me things like, “I felt as if I’d been hit by a bus.” “I was so panicked that I couldn’t speak.” “The wind was knocked out of me.”

While it’s unlikely that this kind of miscommunication will ever be completely eliminated, there are some proactive steps that you can take to lessen the probability that neurotypical co-workers won’t take your unexpected behaviors personally.

1. First, learn as much as you can about how others perceive you. Get feedback from people you trust, such as a family member, a friend, a job coach, or a friendly co-worker, about things you do or say that could be misunderstood in a negative way. For example, do people tell you that you ask too many questions, or ask the same question too often? Or that you look angry, when really you are puzzled? Pay special attention to behaviors that more than one person mentions.

2. Next, prepare “pre-emptive” explanatory statements to “neutralize” unexpected behaviors, so that neurotypical co-workers won’t take them personally. Remember, when people don’t know how else to explain something, they tend to assume negative intentions. Here are some examples of pre-emptive explanations: “I have trouble reading body language—could you please tell me in words what you’re thinking right now?” “Sometimes when I’m concentrating, I forget to say hello. Please don’t take it personally.” “People tell me that I look angry when I’m lost in thought. Have you noticed that?” “I have a tendency to take things very literally; would you let me know when I do that?”

3. Finally, think about whether disclosing AS to your employer is the right option for you. Of course, this is a very personal decision that requires careful consideration of the risks and the benefits. If your AS challenges are very noticeable, or if you have a hard time managing them, disclosing might be your best chance of getting a job offer or keeping your job. Remember that you don’t need to disclose every difficulty you have; only the ones that interfere with your ability to meet job performance expectations.

If you do decide to disclose, keep your explanation simple, direct, and solution-focused. Explain how an accommodation will mitigate or eliminate a problem, and offset any weaknesses with positives. For example, “I have a condition that makes it hard for me to remember verbal instructions. Writing them down enables me to commit them to memory so I won’t make mistakes.”

The more proactive you can be in giving reasonable explanations for things that may seem odd to the neurotypical majority, the greater the chance that you can avoid serious misunderstandings that could lead to negative employment outcomes.

*Barbara Bissonnette is the Principal of Forward Motion Coaching (www.ForwardMotion.info). She provides career development coaching for adults with Asperger’s Syndrome and NLD, and consults to organizations about how best to utilize the talents of this overlooked and very capable workforce.*

Interview with Jayson (age 11), CEO of Jayonisms, LLC

What was the inspiration behind starting the Jayonisms company? “Well it all started by me using sassy come backs to my family and friends at home and school and to my surprise it made them all laugh. Then, one night at dinner I had fired off three of my sayings at the dinner table with my family and my Mom stopped and said, “Hey, that sounds like a really good t-shirt.” And that was basically the moment the light bulb was turned on. I agreed that the world should enjoy my quick wit and sense of humor. I also think having my sayings on t-shirts are the best way for people to see the expressions because a hat would simply be too small!

What were peoples reactions around you when they read your t-shirts? My family and friends were all supportive. Every event and school activity we went to they would all be wearing one of my shirts. Hey you can’t beat free advertising. But the overall reaction from everyone has been great. They either laughed or laughed hysterically. It was really exciting when I found out that Diane Maxson from The Center for Therapeutic Learning decided to feature my shirts as product of the month in her clinic. That was awesome!

Mike Regner (far right, front row, with red bow tie), son of long-time AANE member Marcia Regner, sang in December of 2007 with the Indian Hill A Cappella Group with the Indian Hill Orchestra at the Indian Hill Christmas Pops Concert in Littleton, MA. The Director of the group, Paul Pampinella, is pictured on the right in the back row.

Hilary is a junior at the Lighthouse School in Chelmsford. She is taking a portfolio class at the Mass College of Art, and studies watercolor at Rhode Island School of Design. You may order cards with this painting by emailing her at haszard@gmail.com.

Caitlin Medlar on graduation day at the conclusion of her six month Disney World internship, through Westfield State College.
Who are these famous people with possible undiagnosed Asperger Syndrome? For the answer, see the front cover!

Drawings courtesy of Jamie Maxfield.