CONGRATULATIONS
COLBY!

Colby Shea-Perkins, a 14 year old with Asperger’s Syndrome (AS) who attends Cape Elizabeth Middle School in Maine, has been recognized in a national competition for his painting Lazy Dog (to the left). He is one of 51 artists whose artwork was selected from over 5,500 submissions to represent his or her state in the All Kids Can...CREATE! exhibit. The exhibit will debut in Washington, DC before embarking on a two-year tour of children’s museums across the country. Colby has won an all-expenses-paid trip to DC for a reception in celebration of the opening.

The exhibit is part of a national campaign sponsored by VSA arts and the CVS Caremark All Kids Can program to encourage inclusive arts education and increase public awareness of the arts in the lives and learning of young people with disabilities. It will also be featured in the 2010 International Very Special Artists (VSA) Festival, the largest celebration of arts and disability in the world.

Feel free to take a look at the festival website for more information: http://www.kennedy-center.org/programs/festivals/09-10/vsa/
Dear Friends of AANE,

Doesn’t it seem to you that almost every day there seems to be a new character with Asperger Syndrome (AS) on TV or in a book? Some of these portrayals seem fairly accurate, while others are stereotypical and fail to resemble anyone we know. Accurate or not, they increase public awareness of AS—and result in phone calls to AANE from across the nation. Just today for example, we got a request from Missouri to come consult with an organization who wants to replicate LifeMAP (our Life Management Assistance Program for adults). We hope that people continue to find their way to our web site, to our phone lines, to our conferences and workshops, and to our door.

AANE has now been in existence for 15 years. It’s been a pleasure to see children and adults in our community mature and achieve new milestones. Many have been successful in creating lives which use their strengths, and serve as role models for others. Many are lucky to have parents and educators and employers who provide the accommodations and support they need. We know that not all individuals with AS are geniuses or successful. Many children and adults continue to struggle with various issues, and both individuals and families continue to need support. We hope we can be available for the full spectrum of individuals with AS—those that have done very well, and also those who continue to grapple with the difficulties of living in an neurotypical world—as well as the families, professionals, teachers, and partners who live and work with them.

In the upcoming year we will be conducting a strategic planning process, with the goal of planning pro-actively for a healthy, sustainable future for AANE. We face a number of challenges and a rapidly changing environment, for example: dramatic changes in how people connect to one another and get information, the availability of new technology, the increased numbers of people diagnosed with AS, the uneven economic recovery, and the possible elimination of the AS diagnosis from the DSM-5. We have to position AANE in a way that will ensure that we can continue to support one another and create community for families and professionals in many different locations and a variety of needs. During the strategic planning process, we may solicit feedback and input from you through online surveys or telephone calls. We thank you in advance for your response; no one knows better than you, our community members, what is needed and what is possible.

Our immediate concern is to maintain the high quality of our programs and services, including responding thoughtfully to phone calls and email, producing helpful written material, and developing new workshops and trainings, while we continue to raise awareness about AS. As always we thank those of you who in the past half year have donated money and time to sustain AANE’s mission. For those of you who have not donated recently, please consider making AANE one of your top priorities for charitable giving in the year ahead—since you have a unique understanding of the value and importance of our work.

Speaking about fundraising, the AANE spring Gala was a fun and successful event despite the fact that some of the partying was done in the Marriott parking lot following the water main break in Weston, which resulted in an electrical blackout, followed by an evacuation of the building! For the first time ever, the Boston Globe published pictures of the event, showing partygoers evacuating the hotel. Despite the obstacles, we again managed to meet our revenue goal for the event, thanks to the hard work of our co-chairs, Jill Purpura, Natasha Chomas, and Lynn Flaherty, their wonderful committee, and AANE Director of Fundraising Kelly Genois. For all who donated items, or attended and bid, thank you so much for your incredible generosity. Save the date of the next Gala, April 30, 2011 for the next Gala—an event that we hope will have more water, food, and electricity—and even more laughing out loud!

We hope you will stay connected to the AANE community over the coming months, join us for learning and for fun, and use our programs and services to strengthen and enrich your life.

Sincerely,
Nancy Schwartz & Dania Jekel
Recent statistics suggest that as many as 1 in 99 people may have an Autism Spectrum Disorder (ASD). The criminal justice system (CJS) may have contact with individuals with ASDs as victims, witnesses, and/or offenders. All criminal justice professionals who have contact with individuals with ASDs will need to establish clear and consistent communication methods, verify facts, make appropriate accommodations, and ensure fair justice and consequences for all concerned. Communications, behaviors, intent, and ability levels of people with ASDs vary greatly and present challenges for even the most experienced criminal justice professionals. Attorneys and judges must avoid misinterpretation of behaviors and characteristics typical of those with ASDs since these behaviors and characteristics could be misinterpreted as evidence of guilt, indifference, or lack of remorse (1). This article focuses on a specific subset of the ASD population: people with Asperger Syndrome.

What Is Asperger Syndrome?

Asperger Syndrome (AS) is a neuro-developmental disability, meaning that it involves the brain and starts very early in life when the brain is still forming, still plastic, and still changeable. AS describes those people with ASDs who are high-functioning, verbal, may pursue higher education/careers/marriage, and live semi- or fully independent lives. AS involves differences and difficulties in several areas: social interaction; communication; the presence of narrow, repetitive behaviors; and difficulty adjusting to change. General intelligence is not affected; indeed, the IQs of individuals with AS can range from normal (100 or so) to very superior (above 150). AS may occur more frequently in males than in females—diagnosis is at about a four-to-one ratio.

Asperger Syndrome Victims

As crime victims rather than criminal offenders, individuals with AS present the perfect victim. People with AS reveal great difficulty in communicating details and experiences of their victimization, thus resulting in a lack of credibility in interview and court room situations. This reality creates major issues regarding time and resource considerations for investigators and attorneys. Investigators and attorneys should consider the following accommodations and guidelines in preparation for the victim-witness interview of a person with AS:

- Interview a parent, other family member, friend, or the person who first heard the disclosure of victimization.
- With the help of those who know the person, determine the person’s communication strengths and deficits.
- Investigate the possibility of multiple victims by interviewing all people with whom the perpetrator had contact.
- Review all records of assessment.
- Interview parents or people who know the individual with AS to determine how he or she best receives and provides information.
- Consider videotaping all interviews.
- Plan questioning based on the person’s communication ability.
- Use person’s first name.
- Speak to adults as adults, children as children.
- Use simple, direct language.
- Deal with one issue at a time.
- Have the individual re-create events in his or her own words—a narrative interview.

- Make sure both your word choice and the individual’s word choice have the same meaning to each person.
- Make sure all individuals understand to whom a pronoun refers when using pronouns.
- Ensure question is short, direct, and concise.
- Utilize maximum patience, as formulating answers takes longer for individuals with AS.
- Determine the person’s ability to tell the truth.
- Take frequent breaks; person may have short attention span.
- Be alert to non-verbal cues indicating the person is confused or does not agree to your statements or questions. Get confirmation through direct questions. (2)

Currently, no statistics have been developed about the rate of contacts people with AS have with the criminal justice system, although research indicates that people with AS and other developmental disabilities will have up to seven times more contacts with law enforcement during their lifetimes than members of the general population (3). However, there is no evidence to suggest that people with AS commit crimes at a higher rate than the general population.

Asperger Syndrome Offenders

People with AS often get into trouble without even realizing they have committed an offense. Offenses such as making threatening statements; personal, telephone, or internet stalking; inappropriate sexual advances; downloading child pornography; accomplice crime with false friends; and making physical outbursts at school or in the community would certainly strike most of society as offenses which demand some sort of punishment. This assumption, though valid at face value, may not take into account the particular issues that challenge the AS individual. Problems with sensory overload, poor social awareness, semantic misunderstandings, inability to deal with changes in routine or structure, and limited to absent understanding of non-verbal communications are the very kinds of things that make more appropriate responses to society very difficult for someone with AS.

For example, what appears as anti-social behavior to the “regular” world is often simply the manifestation of the AS person’s social misunderstandings. While most would see too many phone calls in the middle of the night as aberrant phone stalking, the AS person might well view the situation as one friend wanting to talk to another, without regard for the time or frequency of calls. And a physical outburst at school might well be related to the AS person’s sensory dysfunction, inability to deal with interruptions in the daily routine, or emotional liability. Emotional lability means to be susceptible to change, error, or instability and stems from its Latin roots meaning “prone to slip.” This often presents itself in individuals with AS: their emotions can change very quickly. They can become upset, scared, or anxious very quickly. They may also be very anxious one minute and then calm the next, or vice versa. So, while the individual with AS may have committed the offense in question, the criminal behavior might have been an act of emotional impulsivity, with no intent to do harm.
AS offenders often appear “normal” and be more able academically and vocationally and more independent than people with classical or low-functioning autism. Yet, these strengths can mask social and communication deficits that go unseen or are misunderstood by those with whom they have contact. Their communication difficulties include hardships in making sense of the verbal and body language of others. Their difficulty in maintaining eye contact or insistence on changing the subject of conversation to a topic of their choice—all typical diagnostic behaviors of a person with AS—can mislead an investigator, attorney, or judge. Criminal justice professionals may see someone who seems to lack respect and observe a “rude,” “fidgety” and “belligerent” person who, by nature of his or her lack of eye contact and evasive conversational style, appears to have something to hide. Standard interrogation techniques that utilize trickery and deceit can confuse the concrete-thinking person with AS into producing a misleading statement or false confession. He/she can be overly influenced by the “friendly” interrogator. Isolated and in a never-ending search for friends, the person with AS can easily be led into saying whatever his/her “new friend” wants to hear (6).

What are AS dilemmas for prosecutors, defense attorneys, probation officers and judges? Left unexplained, the person’s courtroom displays of laughing or giggling, loud vocal tone, and aloof body language—also inherent to the condition of AS—could lead many judges to conclude that this is, indeed, a guilty and remorseless person. Everything in the suspect’s demeanor says so. The person may very well have no idea of the effect his/her behavior is having on a judge, jury, or even his/her own defense attorney. Even the best defense attorney might see guilt in his/her client’s display of behaviors.

Upon initial contact, during questioning, or in a courtroom setting, a person with AS might also display these additional behaviors and characteristics:

- An inability to quickly process and respond to requests, commands and questions.
- Be a poor listener; not seem to care about what you have to say.
- Be unable to deduce what others are thinking and why they are thinking it.
- Make statements that seem tactless or brutally honest. If you are overweight, bald or smell of smoke or perfume, they may bluntly remind you.
- Have difficulty understanding slang terms, innuendo, colloquialisms, figures of speech or jokes. Ask “What’s up your sleeve?” and the concrete answer may be, “My arm.”
- Not notice or have difficulty interpreting communications such as rolling of eyes, raised eyebrows and other non-verbal signals of frustration or disbelief (7).

Interview/Interrogation Techniques

So, what can the criminal justice professional do to prepare for interactions with people with AS? Try to avoid jumping to conclusions or making attributions based on unusual
or “inappropriate” behaviors. Remember that AS is a social impairment. A component of the social impairment is that many of the things individuals with AS do appear impolite or disrespectful. Criminal justice professionals who interact with and question people with AS will enjoy the best opportunity for success by incorporating the following strategies:

♦ Approach in a quiet, non-threatening manner.
♦ Talk calmly in a moderate voice.
♦ Do not interpret limited eye contact as deceit or disrespect.
♦ Avoid metaphorical questions that cause confusion when taken literally, e.g., “Are you pulling my leg?” “Cat got your tongue?” “What’s up your sleeve?” “Spread eagle” or “You think that’s cool!”
♦ Stand or sit calmly and avoid using body language. People with AS may misinterpret body language as threatening.
♦ Understand that you may need to repeat and rephrase questions.
♦ Understand that communications will take longer to establish.
♦ Use simple and direct instructions and allow for delayed responses to questions, directions, and commands.
♦ Seek assistance from objective professionals familiar with AS (8).

The interviewer should develop a plan of action that incorporates patience and persistence on his or her part. The interviewer is interacting with somebody who might not always get the message, question, or concept straight. Much patience is necessary because impatience will make them very anxious. Usually they really do want to please; they just don’t know how to do that all the time. But they can sometimes tell if they’re doing it successfully or not. Therefore, practice patience in all situations when dealing with individuals with AS. Interviewers must understand that they will not necessarily get the answer the first time or during one modality of questioning because of the individual’s altered understanding of the context, and their questioning speed and pacing will probably affect that understanding. People with AS are inconsistent processors. So, they might understand one question perfectly well and then not understand the next question at all. Sometimes interviewers may have to write something down or draw it out and let the person with AS look at it. The key is to be patient so you don’t get them emotionally aroused and upset. Being supportive and continuing to try different methods of communication will help the person with AS to answer in a way that can be understood and makes sense to all involved parties.

Environmental Accommodations

People with AS may have more difficulty in that they are over-stimulated by the sensory environment—sights and sounds and smells and touch. Noises are louder for them. Normal background noise that may seem negligible to the average person can be completely overwhelming or overpowering to this population. When this occurs, not only can they not hear what people are asking them, but they can sometimes become very anxious and even terrorized by the situation or by the noise.

Additionally, lights are often brighter for those with AS. For example, when a person with AS is outside on a sunny day, the light may be very over-stimulating, causing the person to become upset. For the person with AS, it would be like somebody shining a very, very bright flashlight right in the eye. Therefore, in many environments, the lighting itself causes distress. Intense sensitivity can extend to any of the senses and really interrupt functioning on many levels. Many very, very capable people with AS will score high on an IQ test but can have horrible school records. The common noise, disruption, and movement in a typical classroom in a typical school can be so disruptive, annoying, upsetting, and distracting that they cannot focus on that one thing in the classroom on which they are supposed to focusing—which is the teacher, or maybe an assignment. The same situation may exist in a courtroom or interview room. As a result, adjustments in the environment can be crucial to a successful interview.

Consider making accommodations to the sensory environment when interacting with a victim, witness, or offender who has AS. Keep lighting low; use subdued colors; limit distracting images or pictures; eliminate the presence of non-essential personnel; avoid using perfume, aftershave, or scented soaps; and avoid touching the person with AS.

Sentencing Considerations

In those cases where it has become clear that the person has committed the crime and qualifies for a diversion or probation program, the offender may be further stymied by his or her AS. Traditional options might include group therapy with other offenders. Meeting with strangers, holding group discussions about personal feelings, sharing personal information, and contributing comments about others will be difficult conditions for the person AS to meet (9). Corrections professionals can find success with the AS population when they create diversion or probation programs that:

♦ Use language and terms the person will understand.
♦ Avoid the use of technical terms.
♦ Involve people the individual knows and trusts.
♦ Describe (use photographs) beforehand the people the individual will work with and venues in which they will meet.
♦ Assure the individual that the new people are safe.
♦ Utilize the individual’s strong rote memory skills.
♦ Teach the rules of the program with visual aids, such as pictures.
♦ Create a chronological list of the program; develop a poster with bullet points.
♦ Discover what is important to the person with AS. Avoid trying to make him or her fit in with what is important to you (10).

If an individual with AS is taken into custody, alert jail authorities. This person may be at risk in the general jail population. For short-term custody, consider segregation, monitoring, and a professional medical and development evaluation. Incarceration will be fraught with risk for the person and anyone in contact with him or her. The direct manner, offbeat behaviors, and other characteristics of the person with AS may be read by other inmates as an invitation to exploit and control. Corrections professionals may see a rude, incorrigible person. Good behavior privileges will be hard to earn. Corrections professionals who work with the incarcerated AS population will benefit greatly from a comprehensive training—or at the least a good briefing—and access to ongoing assistance from a professional who is familiar with AS (11).

Conclusion

Some people have described AS as a culture. Consider the need for a translator when dealing with a person who speaks little or no English. Working with someone with AS is analogous to that situation in that successful communication may be blocked, but is not as easily overcome. AS as a culture is an analogy that emphasizes the very different ways in which the affected person processes information and understands things—very much as people from different cultures view things differently. We are obligated by profession to understand that those cultural differences
may loom larger in a person with AS than most cultural differences stemming from language, tradition, or history. The cultural differences of AS come from the way the brain works. They are differences in understanding and perception. Our role becomes the role of translator. The quality of our translation is dependent upon our resourcefulness, knowledge of AS, patience, and understanding. We can and must meet the challenges of this increasingly visible population by embracing our roles in the process.

Consider utilizing as a resource an objective AS professional who can act as a “friend of the court.” This person could help interpret the behaviors and communications of people with AS. This expert could help people understand what the person with AS understands. He or she could also advise about the impact of some of the language or approaches the questioner is using. Each case will be different, each fact pattern is different, and the ability of people with AS to form intent and to control actions certainly differs from one individual to the next. All concerned parties should consider choosing an expert who can both interpret and testify in court if needed. There are so many things in life that people with AS can misunderstand, even when they are trying hard and doing their best. The world is just complicated for them.

References:

Parents of Adults Find Support: New Online Support Group Growing & Active
by Steve Snitzer

The Parent of Adult Google group went online September 3, 2009. Since then, our group has grown to 185 members. I say “our” group because I, too, am a parent of an adult; I have a 20 year old son with AS, Alex. Some members have a great deal to say – advice, support, and the full range of emotional outpouring. It is fascinating to read the narratives about our children, their struggles and their successes.

It is my privilege to be the group moderator. I do this every day – well, almost every day. Mostly I pass along messages that I receive from members. I help new members to get enrolled and use the system. I also relay information from the AANE staff and the community about events and programs of interest to our group. My goal is to facilitate and encourage a broad discussion of all the issues that relate to AS.

Mutual support is a key function of the group for many members. Others are seeking – and finding – specific information, like a therapist in a certain location. New friendships have started through the group. A few families have gotten together. New projects have even been suggested. Who knows? This group of parents has tremendous combined experience with AS! We may come up with something brilliant to help our sons and daughters improve their quality of life.

Here is what the members are saying:

“I’m glad to be connected to the group. I wanted to let you know that you have given me some pearls of wisdom at critical junctures in my son’s life over the past several months.”

“I can’t tell you how thrilled I am that this online support group for the parents of adults started. I was talking a year ago to AANE staff about forming it. Ideally, down the road a group where we meet in person on the South Shore would be fantastic as I cannot attend the parent support groups in Watertown, but this is fantastic!”

“Thanks again AANE for providing this forum for the parents of our adult children; we had so much support when they were in school, and when they graduated - its a WHOLE NEW WORLD - different laws, rules, and so isolating! I am now no longer feeling so alone! I just knew I couldn’t be the only one going through this; Thank God we found each other thru this forum!”

Steve Snitzer is a pianist, piano teacher, and member of the AANE Program Committee. He and his family live in Needham, Mass.

Anxiety & Asperger Syndrome Conference: Videos Available Soon

On April 26-27, 2010, AANE and MGH YouthCare held a conference on Anxiety and Asperger Syndrome at MIT’s Kresge Auditorium. Those of you who were unable to attend will soon have the option of downloading individual speakers’ presentations from the AANE web site. Check our home page and enewsletters! Many thanks to Scott McLeod, Ph.D. of MGH YouthCare, and to Steve Snitzer, for working with Dania to organize the conference.
It's summer at Camp Lone Tree. I am sitting on a picnic bench next to Gordon, the Aquatics Director, trying not to look at the nine and ten year old boys lining up to take their swimming test on Country Pond. My fear is that my son William will panic. Then, just as I had envisioned, he is running down the dock screaming with his arms flailing like he is being chased by an angry swarm of bees. You see, William has Asperger Syndrome (AS), and the most important thing in the world to William is Scouting. Scouting is a program that encourages every boy to do his best, to fulfill his potential, and to become a good person. There are adventures to go on, skills to learn, and games to play, all in a structured and caring environment. Even though it has not always been easy, the four and a half years he has been a Cub Scout at Pack 61 in Saugus has opened up an entire world to William.

I am a Scout Leader. Together, William and I are attending Webelos residential camp at Lone Tree Camp in Kingston, New Hampshire. Webelos camp is for fourth and fifth grade boys who need more of a challenge than Cub Scouts, and are not quite old enough to join the big boys in Boy Scouts. We are spending four days and three nights sleeping in tents, fishing, doing nature crafts, having campfires, and doing all those other fun things that boys this age want to do at summer camp.

William will do anything, try anything, and work on any goal that is involved in Cub Scouts. Unfortunately, the first thing to do at resident camp is to take the Boy Scout swim test. Everyone who wants to go in water above his or her waist needs to take the test. This includes jumping feet first into water over your head, swimming a hundred yards, and then floating. After completing the test, you receive a “Buddy Tag”, a small round tag with your name on it. Buddy tags are placed on a board at the waterfront to keep track of who is in the waterfront at any given time and how proficient they are at swimming. Non-swimmers, referred to as “Learners”, have white tags. They are only allowed to swim in the shallow area. “Beginners” have the top half of their buddy tag colored in red, and are allowed in a four-foot deep swim area. The red and blue buddy tag of the “Swimmer” grants the privilege to swim in water over their heads and to dive off the dock in the lake.

Not only can’t he swim, William does not like to get his face wet! I am not talking about being afraid of diving under water. I am talking about him needing a dry face cloth on the edge of the tub in case his face gets wet in the shower. There is no way on earth that he can pass this test, and only a small chance that he will even go into the water. Having a bad experience with the swim test might not only set the tone for the entire camp stay, it could mean packing up the tent and going back home. William has stopped screaming in front of us crying and threatening to go home. Gordon points to a beach chair and a spot in the sand about a foot in front of him “Get that chair over there and sit down right here so that I can talk to you”. Gordon’s “day job” is being a special needs teacher and always knows just the right thing to say to the boys. While he speaks words of encouragement to William, I somehow manage to keep the tears in my eyes from overflowing down my cheeks. I can’t look. I can’t even listen. The next thing I know, William was heading back down the dock and to my great surprise is in the water. He returned grinning and holding up his white “Learner” buddy tag. While he hadn’t come anywhere near passing the swimmer test, he was very proud of himself and content to stay at camp. William and I survived Webelos camp and the rainstorms that accompany every Cub Scout event. Some activities, like BB shooting, were great success for William. Other activities, a little more hectic and athletic, proved to be more of a challenge, and there were times when he needed to back away and “take five.”

On the last day of camp, sixty damp, overtired boys sat in the camp mess hall while it poured outside. Many camp awards awaited their recipients. They were going to be presented to the Webelos with the highest BB shooting and archery scores, the winners of games, and various other achievements. After many other boys, William was called to the front of the room and Gordon stepped up and announced that William had won the “Special Waterfront Achievement Award” for doing his best. This was a black and white, eight and a half by eleven sheet of paper, and on it was William’s name handwritten in magic marker. William said nothing and stuffed the piece of paper in his backpack.

Later on in the summer, William attended Cub Scout day camp; and again, Gordon was at the waterfront cheering him on. I can’t remember exactly when, but weeks later, riding in the car, William made the proclamation that he was going to pass the Boy Scout swimmer’s test at Webelos Camp next summer. I was shocked. Holly cow, how were we going to pull this one off? I always encourage him with the “You can do anything you really want to” attitude, but this was a big one.

I called the YMCA and signed him up for private lessons hoping that this would give him a good start. I explained to the instructor that William wanted to pass his swim test in the summer. She admitted that this was going to be a tough one for a kid who was afraid to get his face wet. Well, William did go to swimming lessons; mostly group lessons, some private, once, sometimes twice a week, in the fall, and in the dead of winter. He took the Beginner Polliwog swim session four times, keeping up with the class but having occasional meltdowns, and many tears, both his and mine. The “I don’t want to go to swimming anymore” was countered with my, “You want to pass the Boy Scout Swimming test this summer, don’t you? Gordon will be there for you.” William did learn to put his face in the water and went on to Advanced Polliwog swim class, but this was still very different from swimming a hundred yards. I told him, “Maybe this summer you can get the ‘Beginner’ buddy Tag. That would be OK, and you could pass the test next year when you go to Boy Scout Camp”.

Luckily, we were going to Webelos Camp at the end of the summer and there was more time for more swimming lessons. William was getting closer to being a proficient swimmer. Even though I told William everything would be fine, and that Gordon would be there for him, I worried for weeks that the swim test was going to ruin camp.

At least this time I didn’t have to just watch William take his swim test because; although I had no interest in swimming out to the dock, I had decided to take the swimming test as a show of support. As I prepared to enter the water, I could hear William tell the aquatics instructor administering the test that he didn’t want to jump into the lake. Even as I thought, “Well this isn’t the end of the world,” I knew that to William it was. Crawling back onto the dock with my out-of-shape middle-aged legs all rubbery from the swim test, I see William standing there waiting for me. I was almost afraid to ask “How did it go?” “Good.” (William is not much of a conversationist.) “How good?” “I passed” “Did you get Beginner?” “I got Swimmer.”

It’s hard to explain that my son holding up a one-inch blue and red disc could be one of the happiest moments of my life, but it was. It’s right up there with my marriage to Greg and William’s birth. William has a hard time with so many things. He had struggled with swimming for a year, and here he was—not only keeping up with his peers, but even surpassing several of them. When William held up his Buddy Tag, I knew it, and he knew it: he was going to make it. He could do anything that he really wanted to do.

William spent his free swim time in the knee-deep murky water of the “learner” area, looking for “special” rocks. He never did swim out to the dock, but he could have, ’cause he had a Swimmer Buddy Tag. On the last day of camp, I took a photo of William with Gordon, and one of William with his Buddy Tag. When I got home, I took down the frame holding William’s school photo, and replaced it with one of William and his Buddy Tag. This was the birth of our “accomplishment” wall. We now have all William’s award certificates from school and Scouts in frames, hanging on our stairway wall. They’re all proof of William’s accomplishments, but none of them is as significant as the photo of William and his Buddy Tag.

Donna-Marie Mironchuk is a graphic artist, a graduate of the Massachusetts College of Art. She is the mother of 11 year old William, a fifth grader with Asperger’s Syndrome. She has been a Cub Scout Leader for the past four years, and is currently an Assistant Cubmaster at Pack 61 in Saugus, MA.
AANE member and college freshman Scott Leung (pictured above & below) performed remarkably at his first concert with the Clark University Concert Choir on November 20, 2009. Scott’s rich bass vocals resounded through St. Peter’s Church in Worcester, MA as the choir sang classical European pieces, works by American greats, and finishing with a thoroughly enjoyable uptempo gospel piece.

Elizabeth Avery, an adult with AS and active member of AANE, chooses to give back to her community through volunteering and speaking about Asperger’s.

As a volunteer for the award-winning Understanding Our Differences program, she has visited several local schools and talked with students - third, fourth, and fifth graders - about what it’s like to live with AS. She explains to them what Asperger’s is and how it affects her life, and tells them what she was like at their age. This successful program has increased understanding and respect for all kinds of people with differences, and Elizabeth’s contributions have been invaluable.

Elizabeth has also been a long time advocate for AS & Autism legislation in Massachusetts. She represenst her community and speaks at the State House for events like Autism Awareness Day, promoting better understanding and resources for people on the spectrum. She will be speaking at the next Autism Awareness Day in April 2011.

Local Cub Scout & Girl Scout Resources:

♦ For more information on Cub Scout Pack 61 in Saugus, MA, contact Cubmaster Kathy Landrigan at: kathleen.landrigan@washdepot.com.
♦ Cub Scout Pack 222 is exclusively for boys with developmental problems & other special needs. They may know of other troops that now welcome scouts with AS. Cub Scout Pack 222 has 30 boys, ages 6-11, and meets at the Weston, MA Scout House. Contact the Knox Trail Council of Boy Scouts of America at: (508) 872-6552.
♦ Daniel Webster Scout Council Service Center offers programs in New Hampshire: www.dwbsa.org.
♦ Girl Scouts Swift Water Council offers summer programs at 6 day camp sites and 2 overnight camps in New Hampshire and Vermont: www.swgirlscouts.org.
ESJW lives in Brattleboro, Massachusetts and was diagnosed with Asperger’s in 2004.

All pieces are untitled, but can be identified by the date and media used in parenthesis below each one.

These images and many more can be found at: http://esjwmazesandmandalas.blogspot.com/.

Check out hundreds of creative and intricate mazes by ESJW at:

**Another Stage**

If you touch the heart of what cannot be seen you can touch the heart of everything. Sorrow turns to laughter. Big issues become small. To breath is to live. To see a baby smile is to see the face of God so innocent yet demanding. To create a tune out of thin air. To hear the voice in the wind. To release yourself to that call. To sail with the tide on any given day is to be prepared for what comes or does not. I danced on my grave along time ago and discovered I can touch the stars. Now thought tone colours awaken my ears to lighten my steps beyond restlessness. I move to gain what has not come forward. Darkness is an adventure into wisdom. Wisdom is folly at play in darkness but I have what I have so forward onward we go my friend to view another stage.

by Johnny Meehan

“I am sixty one years of age. A man with AS who has parented five children, one NT, three AS, and one full blown autism. Three grandchildren, one ten years of age with Dyslexia, a four year old on the AS spectrum and an eight month old baby. I am a singer songwriter who also writes prose poems and does drawings. I have written and recorded over 200 songs and 10 instrumental tunes. I play guitar and harmonica simultaneously. I am self taught in all my artistic abilities. I had very basic schooling from 4 to 13 and a half years of age. I am Irish and I live in Dublin Ireland.”
There we were. We in Kearney Hall, a dormitory—of Nazareth College of Rochester. And there we were. He stood down the corridor from me, next to the lounge and vending machines. I stood opposite him, next to the computer lab and RA desk. We were discussing linguistics. Well, we weren’t discussing linguistics, I was engaged in what my family and other熟悉者 called a “monologue,” and this time the topic at hand happened to be linguistics. This was common enough, however. Participants in my conversations rarely participated at all. Instead, they were merely subjected to long and breathless monologues concerning a topic in which they probably didn’t have any interest. Usually, they didn’t. Really, who cared that much about cetaceans, Testudines, and the affinity between the evolution of languages and animal species? Obviously, I did, but so did he, which was unusual. This—and nothing else amidst an endlessly multiplying menagerie of oddities—was the uncommon element. Generally these monologues were met with proclamations of boredom, annoyance, or even anger. Occasionally there was tolerance, but interest? Rarely. But here in a drab, dormitory corridor he was actually showing interest in my “rant,” as I would later style it. Recalling the usual responses to these unwelcome monologues, I thought to myself, “Is this guy really going to let me keep talking? Apparently, yes. Okay, I’ll keep talking then.”

Throughout this seemingly pathological eruption of information, this newly discovered, one-man captive audience stood firmly to the left of the vending machines, unbudging, never once attempting to escape the wholly impotent bondage of his nigh incompetent captor. Quite the contrary. He stood there, seemingly poised, confident, and perhaps even relaxed. He could have been bored, tired, hungry, or even completely and utterly immobilized by my monotonous droning, and I probably wouldn’t have noticed, but he heroically, or perhaps stoically, withstood the relentless onslaught of data, sustaining the barrage without evident psychic injury. A true warrior, I thought. As the victim of my monologue, he was very much the opposite of its author, whose eyes were squirming inside their sockets, trying to look in any direction other than his; whose arms were held rigidly against his sides, incapable of lifte motion; and whose tongue was nothing more than the unwitting instrument of his incontinent mind. He assuredly learned more about Chinese kanji than he ever needed to know. Why did he tolerate this? I had long ago become inoculated against the horror I elicited. He didn’t need to worry about hurting my feelings. That, however, mustn’t have been it, because he permitted himself to be the target of these monologues not once more, twice, or even three times, but seemingly indefinitely—a willing and welcome victim of Stockholm syndrome. Where others had failed, he would endure, enduring contemporary German philosophy from Kant to Gadamer, classical Chinese philosophy, the history of Confucian thought, and the wholesale importation of neo-Darwinism into my hitherto predominantly philosophical thought process.

“Zhuangzi was last week, Tony, this week I’m onto Richard Dawkins. Let’s talk about the gene-centric view of evolution.”

His tenacity in the face of this and other of my ill-concealed idiosyncrasies was perhaps the basis of our friendship, although time would prove that sheer stubbornness wasn’t an adequate substitute for an authentic foundation. An authentic foundation might have been achievable if one of us had managed to so much as mumble “Asperger’s syndrome.” This five syllable utterance, however, would never make its appearance onto our (my) long list of conversation topics, as it was known to neither of us, at least not until after our friendship had suffered from a gruesomely violent death at the hands of one of its chief participants—me. Although this death was by no means foreordained, it was perhaps virtually guaranteed by each party’s want of understanding concerning the other.

Did you know that it’s possible to be so engrossed in what you’re saying that you blithely walk into oncoming New York City traffic? I didn’t, at least not until I found one of my monologues rudely interrupted by the panicked embrace of my best friend pulling me away from the curb and back onto the sidewalk. This irksome disruption of my thought-process also proved to be not a one-time inconvenience, but a chronic one. Various attempts on my part to evacuate the contents of my mind into the earth’s atmosphere were frustrated by two caring hands pulling me away from a precipice, past which were the speeding taxicabs that occupied the bit of street I sought to traverse. His tolerance for “rants,” evident knack for preventing one of my garrulous fits of itinerancy from ending in tragedy, and recognition that I couldn’t be expected to navigate the New York City subway system, all bespoke a certain understanding, but in hindsight it was simple know-how, and not enough to cope with the problems to which they were merely a forward.

“You know, Alex,” he once said, “it seems like you get obsessed with one thing and run with it for as long as you can and then get fixated on something else.” Anxious rage? Was that what I felt in response to this totally accurate description of my obsessive compulsive relationship to my most beloved facts? “Don’t completely flip out,” I thought to myself, “just use a little razzle-dazzle to dismiss the charges, a bit of sophistry to set him off the trail. You’ve gotten good at this over the years, Alex, don’t freak out.” I had long ago become highly sensitized to accusations of “obsession” with respect to my serialized engrossments with esoteric bodies of knowledge. I loathed this accusation to the point of even denying its truth; it felt like an indictment of everything I was. Such critiques always seemed to suggest that I had no authentic relationship to learning. My erudition, it seemed to imply, was nothing more than an addict’s frantic imburement of his regular fix. There always seemed to be a suggestion of the pathological. My family members had come to refer to these as “Alex’s obsessions.” The technical name for this is “circumscribed interests,” which means that a person will pursue a favored topic with an unusual intensity of focus, to the exclusion of all others.

In response to these despised suggestions of obsession, I developed several strategies. Trying not to do this was an option, but when the compulsion, both to pursue the topic and to talk about it, is that strong, this strategy, I soon realized, was always condemned to failure. Thus, unlearning two behaviors, pursuing a topic and reporting on it, was not a possible solution. Feigning normalcy, however, almost certainly was. Just conceal the pursuit of your obsession from friends and family, like an alcoholic might hide vodka bottles in small, dark places, and you’re already halfway there. Next, without one more second of procrastination, develop some basic turn-taking skills for when you’re expected to have a conversation and just work on becoming cleverer and cleverer at subtly working your interest into that conversation, completely irrespective of its belonging there. Does the emperor of China have anything to do with basketball? Perhaps just ever...
quirk’s capacity to hinder communication and contribute to an ever-endearing, as my friend did, if he does not grasp these very same 

Although a neurotypical person may find an AS individual’s quirks normalcy, this strategy is anathema to the AS person’s mental 

be tempting to satisfy a friend’s expectations by pretending to 

are familiar with the phenomenon of “pretending to be normal,” 

mutual understanding. Within the AS community, many people 

urgently needful between friends than to cultivate a genuine 

in the emperor’s direction, and your perplexed interlocutor 

so slightly, and with the right skills, you can turn the conversation 

in the entire world was now unrelenting who I really was, and I couldn’t have thought of anything worse than 

that I hated who I really was, even though I didn’t even quite know what that was. “Think fast,” I thought, “he can’t find out. 

Stay calm.” But the charges echoed in my head and my ire had already been set free. Not only had he seen through my act, but 

in so doing showed the inadequacy of the act itself. Double ire. Slam the book shut. Bang your right fist against the table. Stand 

up and scream. “No, no, no! You’re wrong! It’s not like that, it fits into my broader research topic, see?” Silence the bum, stitch 

up his mouth, make him shut up! “Shut up! Shut up! Shut up!” Cowed into submission, it never came up again. 

“Don’t you ever just play?” he once asked me, casually 

suggesting an answer in the negative as he lazily reclined in front of 

some video game. As the question slid off his tongue and lingered in the air, the juxtaposition couldn’t have been more complete: 

there he was, enjoying some mindless video game, muscles relaxed, gut slackened, and posture lax; and here I was, standing 

tightly by the table, deeply unsettled by the question, hands 

flickering disobediently by my sides, and every cell in my brain 

frantically conspiring to counter this irksome specter of judgment. 

Not wanting to corroborate the question’s presumption, I managed 

to commence an unconvincing denial: “Yes, I play sometimes...” Damn it, I thought, I didn’t even believe me. What’s wrong with 

me? No, that’s the wrong question—rather, what’s wrong with 

him, asking an offensive question like that? An admixture of 

contempt and annoyance, fear and diffidence bubbled up, and foul 

concoctions such as these worked night and day to dissolve the few 

remaining fibers of affection binding me to this nagging glimpse of 

Kansas. I didn’t terminate the friendship right then and there, but 

within months, there was no “friendship” left to speak of. 

It was in instances like these that the erstwhile harmonious 

balance between my friend’s affection for the quirks that made 

Alex “special” and the reality of those quirks’ power to impede 

a deeply cherished human relationship broke down, and the 

power to impede won the battle. There is perhaps nothing more 

urgently needful between friends than to cultivate a genuine 

mutual understanding. Within the AS community, many people 

are familiar with the phenomenon of “pretending to be normal,” 

but people cannot be friends with feigning, and although it may 

be tempting to satisfy a friend’s expectations by pretending to 

normalcy, this strategy is anathema to the AS person’s mental 

health and an insincere way to conduct a human relationship. 

Although a neurotypical person may find an AS individual’s quirks 

dearing, as my friend did, if he does not grasp these very same 

quirk’s capacity to hinder communication and contribute to an ever-

lengthening list of misunderstandings, then the friendship is very 

likely to decompose. If I had been diagnosed earlier, certain injuries 

could probably have been prevented and I wouldn’t be presently writing 

in such a cautionary tone. 

Alexander Christopher 

Eustice is a graduate student at 

Boston College studying Philosophy. He is also an active member and volunteer of AANE. 

Choosing a Summer Camp

by Eugene Bell

Selecting a camp for a child is often a difficult task, but it becomes even more arduous when your child has Asperger Syndrome. There are so many items to explore, so many questions to ask—

with no clear path through the wilderness! However, you may find this task easier if you consider the following during your search:

♦ Clearly explore the mission and philosophy of each program you are considering to make sure it meets the needs of you and your child.

♦ Investigate how the program is structured and how the staff deliver their services to campers. How do they respond to children with extended responses who might require special handling? Are they pro-active or reactive? Are they flexible?

♦ Review the nature of the population served. Will other campers be similar to your child? Does the camp cater to children with a large range of issues, or do they specialize?

♦ Ask the camp about the opportunities for camper growth. What outcomes might you expect for your child?

♦ A camp should be a partner with their campers’ families. Systems for communication should be reasonable and meet your needs. They should be able to explain easily how they plan to facilitate communication and respond to questions. Many camps use the web to publish photos or send a newsletter.

♦ What are the management and support schemes that the camp uses, and are these in concert with your youngster’s needs and experiences? Are the interventions or systems easy to embrace and continue at home after camp?

♦ Be sure the intake or evaluation process is longer rather than shorter. Your child has some special needs and a good program wants to learn about them. Input may be gathered from your child’s school or counselors/therapists. If a camp only requires a few short forms, be careful.

♦ What are the credentials and experience of the staff—administrators as well as line staff? Ask about their staff training program and how many of their staff have worked with them previously.

♦ Camp is meant to be a great place for your child. You should ask them about the fun that goes on: special events, program content, and the energy level of the camp/program.

♦ Ask about their health support: who distributes medication, what is the overall staffing scheme, and how do they access a physician or emergency medical support?

♦ Ask about their licensure: what agencies authorize the program? Many camps choose to belong to the American Camp Association, an important credential that tells you they have gone through a complete review of program, philosophy, and management areas.

♦ If you are considering the program for the following year, ask if you may visit them while in operation this year.

♦ Be sure to speak with other families who have had children in their program. The camp should be prepared to give you the names of parents who would be willing to speak with you.

A camp experience should be magical and special—certainly for your child, but also for the family. The program you ultimately chose needs to live up to it’s publicity and catalogs. The “product”—your child—is too important for you to settle for an inappropriate or poorly run camp. Happy hunting!

Eugene Bell is the Senior Director of Summit Camp and Travel, programs that support campers with attention issues, Asperger Syndrome, and related issues. He has been involved in special camping for 29 years, after several years as a special educator. He particularly enjoys being part of a solution instead of the problem! You can reach him at geneb@summitcamp.com.
A Neurotypical Family’s Journey into Aspieland

by Karen Lewis

Karen Lewis delivered this speech on May 15, 2005 at the annual AANE Gala.

My goal this evening is to recognize and honor the parents of children with Asperger’s Syndrome and to express thanks to AANE for being there to assist us all as we meet those special challenges of Asperger’s parenthood. As parents, the unique struggles of our children to cope with the neurotypical world have become our struggles. Because of this common bond, we have much to learn from the similarities and differences in our family histories, present circumstances, and in helping our children plan for the future. Tonight, I feel privileged to share my family’s experiences with Asperger’s Syndrome. I normally reserve such intimate personal details for living room conversations with family and close friends. But because we all share a direct or very close exposure to Asperger’s, I feel comfortable with considering all of you as comrades in intimacy. So welcome to my living room and let me share with you a short story entitled, “A Neurotypical Family’s Journey into Aspieland”.

Chapter 1: The Discovery

About 5 months ago, on December 30th of last year, my husband and I were enjoying a cozy evening in the Berkshires around the fireplace of new friends. The conversation turned to family and we proudly mentioned our dear, loving son, Ryan, a Boston University graduate, who recently served his country in computer security with the US Army in Baghdad and was now 25 years old and stationed in Heidelberg, Germany. Our friends are both clinical psychologists and when we described the details of our son’s life-long struggles with organization, social behavior, time management, etc. They both said almost simultaneously, “I bet he has Asperger’s Syndrome”. My husband is a college professor and I have a master’s degree and we had consulted many mental health professionals about our son through the years, but, until that remarkable moment, we had never heard about Asperger’s Syndrome. Asperger’s dominated the remainder of that evening and the next few days were spent on Asperger’s web searches. Within a few weeks we met with Dania Jekel at AANE to develop a strategy for talking to Ryan about Asperger’s and for dealing with his very high functioning neurotypical sister, Mindy—and to hopefully repair the intra-family strains from her growing up with a brother who was “pretending to be normal” but really wasn’t.

Chapter 2: The History

After 9 years of unsuccessfully trying to become pregnant, we adopted Ryan, a handsome, adorable 4-month old with very high APGAR scores. He also was sweet and good-natured, so we seemed gifted with the perfect child. Like the age-old story, Ryan had a “hard-wiring” problem that caused him to process information very slowly and that he would progress adequately but about 5 years behind his peers.

My husband and I were coping day to day with a very puzzling child with no one else to talk to and support us through some very challenging parenting. There was nothing else the psychologists could do and we just had to get through this parenting challenge the best we could. This was not easy!

Ryan was bullied often, called a “nerd,” and suffered periodic meltdowns with weeks of complete detachment from the world and from appropriate organization and responsibility behaviors. Many of Ryan’s homework assignments were surreptitiously avoided by tucking comic books inside of his textbooks. Instead of many of the usual peer group activities of adolescent boys, Ryan would often retreat to the fantasy world of science fiction, mysteries and Magic Cards in his room. Some other notable eccentricities included difficulties with understanding time and scheduling, prioritizing, difficulty in crossing the street, wearing clothing inappropriate for the weather, and inappropriate social responses with his peers.

On the positive side, Ryan possessed several highly unique and wonderful qualities. He was exceptionally gentle, kind and capable of relating especially well to adults and younger children. He had a great sense of humor and also was able to recall minute details of books and videos. My husband and I are both highly functioning neurotypicals, always pushing ahead in our worlds and very rarely taking time to smell the roses, and were always enamored of Ryan’s ability to savor the moment. One particularly vivid example is unforgettable. On an unusually balmy and tropical April Brookline afternoon, Ryan, who was 15 at the time, arrived home almost 2 hours late from school. I was frantic because Ryan had to cross Beacon Street to get home and I was always concerned about his safety. When he finally got home, he took my hand and walked me outside. He said, “Mom, close your eyes and feel that breeze. I took the long way home from school. I was just enjoying the breeze!!!”

Both my husband and I were baffled by Ryan’s widely varying behaviors and always uncertain whether to push him harder, make excuses for him or just “kill” him. Ryan’s behavioral strengths and weaknesses had us vacillating between “he’ll eventually be fine” denial and the feeling that he would never be able to function adequately in this world. He is such a good person and tried so hard that many of his teachers just kept giving him extra consideration to help him get by. (He recently admitted to us that in the army they help him out as well.)

In contrast to Ryan, sister Mindy in pre-adolescence began her life-long role as the classic over-achiever, driven to succeed academically, athletically and socially. As Ryan, and then Mindy, entered their peer-pressured early teenage years, their especially
close relationship began to deteriorate. The sparkling sister, honor award winner in just about everything, became highly resentful of her brother, who barely was getting through school, lying to his parents about meeting his responsibilities, and generally seemed spaced-out, but yet getting the lions-share of her parents attention. Mindy also was embarrassed when friends met her brother and told her he was strange and weird. At worst, Mindy began to feel unloved by us and at best, felt her strange brother was loved much more. As the years passed, Mindy’s resentment hardened into anger and, after she left for college, largely avoided speaking to, or even about, her brother. Ryan would reach out to her many times through the years but she would not let him in. Mindy also was very, very angry with my husband and me, and our relationship with her was extremely difficult for about 10 years. Reality was that many years of stresses and strains of three high achieving neurotypicals living with one Aspie shattered our vision of the perfect family.

Chapter 3: What AANE Has Done for Our Family

Meeting with Dania Jekel and learning the specifics of Asperger’s Syndrome gave explanation to years of mystery, confusion, and doubt about Ryan’s struggles to cope with the neurotypical world. These revelations, only a few months old now, have already profoundly affected our family dynamic.

Ryan, for many years, has felt different from most people. AANE has helped Ryan understand these feelings, and has given him confidence in his continued struggle as a member of the Aspie minority attempting to cope with the overwhelming neurotypical majority on our planet. This confidence has helped erase his self-doubt that he might just simply be lazy or stupid. Dania’s reassurance to Ryan that Aspies can live happy productive lives with the right guidance has made Ryan feel so much more comfortable in his own skin. The difference in his personality since he internalized his Asperger’s diagnosis has been significant. Ryan now knows that after completing his Army duty, the support services offered by AANE will help smooth his transition to the civilian world and his progression toward a satisfying and rewarding personal life and career.

Mindy, for many years, felt unloved because her parents heaped attention on her much more needy brother. For the first time, with our understanding of Asperger’s derived from AANE, my husband and I have been able to clearly understand our family dynamic and to explain it to Mindy. We have now fully acknowledged her perception of being “under-loved” and our limitations as confused parents coping with gnawing frustration and uncertainty. These frank discussions already have led to great improvement in Mindy’s relationships both with Ryan and with my husband and me.

I, for many years, felt failure in my relationship with my daughter. Because of my special relationship with my mother, and my mother’s special relationship with my grandmother, a similar special relationship with my daughter was one of my lifelong aspirations. I was certain I loved Mindy every bit as much as I loved Ryan, and felt terrible guilt about giving her less attention than him. The recent revelation of Ryan’s Asperger’s Syndrome and the knowledge that AANE is a key resource to our family has provided support and confidence in my own family-related emotional struggles. Recently, for the first time in 10 years, my daughter and I have begun to develop the close emotional bond I have dreamt about for so long.

And that is the end of my story…..... for now.

Dania’s invitation for me to speak tonight enabled me to compose thoughts and verbalize feelings that for so many years were shared only with my husband and parents in a much less organized and often emotionally-charged manner. As parents of children with Asperger’s Syndrome, you can surely understand my embarrassment in discussing my child’s problems in casual conversation. In providing knowledge that there are many others like my son and that there are strategies to help us all, AANE has given me hope and a new direction. I recently met with 5 other Aspie mothers at AANE. We shared stories and cried and hugged.

When I left and got into my car, I sat there a moment before driving off and cried just knowing that my child was not the only one who didn’t know to take his heavy jacket off when he was sweating.

Aspies have struggles all through their lives but the struggles of young adults with Asperger’s is very “real world”. This goes beyond the bullies on the playground and reading comic books instead of textbooks. We are dealing now with getting a job and supporting themselves, driving a car, getting married, having children. We, as Aspie parents, need the support of AANE so we can feel sure we are doing all we can to guide our adult children in the right direction. And our adult Aspie children need the comfort of knowing they are not alone in their struggles as they grow and go out into a very neurotypical world.

Physically, Ryan looks great. He is handsome, well-built, and, from the outside, there is no evidence of his difficulties and so people expect him to act as a neurotypical. Mentally, however, dealing with each day is so draining for him as he continues “pretending to be normal.” Now that he is aware of Asperger’s, he pays very close attention to the Aspie things he does. Ryan tells me he tries to think like a neurotypical but it is too much work. He wants to learn to drive, he wants to retire from the army next year and get a job in the civilian world, he wants his own apartment, to be independent and have a girlfriend. Naturally, I want all that for him. However, his transition to civilian life will require special support, what I will call “Phase 2 Parenting,” and guidance from AANE.

It’s like Ryan is on a sailboat without a compass OR a rudder; he will have difficulty staying on course, but somehow he will manage to stay afloat. I feel AANE is his compass and his parents are his rudder, and with the three of us working together, Ryan will sail away into life. And if his sister continues to open up her heart, and support Ryan as well, Ryan will win the Regatta!

This is my dream for him. And my dream for the rest of us here tonight is that we all spend more time “enjoying the breeze.”

Post-Script

We e-mailed a copy of my speech to our children...here are their reactions:

Mindy: Growing up, I envied my friend’s relationships with their parents. The support and love these parents showed for all their children was second to none. At times, I would even look to them for praise when I accomplished something. I never felt that my own parents didn’t love me, but at times I felt that I was living in my brother’s shadow. I felt as if our family were more concerned about Ryan’s season-inappropriate wardrobe than the great heights I was achieving in my life. As a defense mechanism, I built a wall—a wall so strong and intense that I didn’t let anything out or in. If my parents tried to talk to me, I stared back with a blank face—unwilling to listen—as I built this mental wall higher and higher. It took 23 years to build this wall—and only 15 minutes to
After reading my mother’s speech, I was finally able to realize and accept my family for what it is. We are four amazing people with our own strengths and weaknesses who deeply care about one another and want nothing but the best for each other. We look to each other for strength when we feel weak, and lend support when we are the strong one. After 23 years, I am finally able to comfortably and willingly look toward my parents for praise, love and strength.

Ryan: Now that I know I’m an Aspie, I focus on the “how” instead of the “why”. For example, if I was in a class with a lot of other people and everyone was “getting it” I used to think, “Why am I not getting it”. Now I think, “How is the best way for me to get it”. In other words, what strategy can I use to catch on? For me, the focus on the “how” instead of the “why” is much less emotional and much more rational. Instead of blaming myself for something I didn’t understand, I am now strategically coping with the neurotypical world.

Karen Lewis is a business woman living in Newton, MA. AANE extends our best wishes to her husband, Steve Lewis, for a healthy recovery.

Ellen Korin’s New Book Wins Award!

The National Parenting Publications Awards (NAPPA) has honored Ellen Korin’s new book, Asperger Syndrome - An Owner’s Manual 2, a NAPPA Honors Award. NAPPA recognizes the best in children’s and parenting resources, and has chosen to recognize Ellen’s sequel to her earlier Asperger Syndrome - An Owner’s Manual with this prestigious award. While the first book was written for grades five through eight, her latest publication is an interactive workbook for adolescents and adults. It is designed to guide people on the spectrum to attain the quality of life they desire and deserve.

Visit her website for more information: www.ellenkorin.com.

Ruth Ryan Receives Unsung Hero Award!

Ruth Ryan, a single mother from Rye, New Hampshire, has been praised as a role model to other parents and caregivers for her dedication and hard work in raising her two children, one with Asperger’s. Her willingness to always put them first while remaining optimistic has drawn the attention of the NH Children’s Trust Fund, who honored her this past February with an Unsung Hero award, presented at the NH Statehouse by Governor John Lynch.

Ruth finds raising a son with AS challenging but rewarding, and encourages parents to reach out to their community for support. She is involved in several support groups at Families First, as well as being a member of AANE. Her advice to other parents is: “You have to become your child’s best advocate.”

Read more about the awards at: http://www.nhctf.org/primary/unsunghero.html.

Welcome Diane!

AANE welcomes Diane Burke, our new Controller beginning January 2010.

Welcome Lucy & Jody!

AANE would like to welcome two new members to the AANE Board of Directors, Jody Acford and Lucy Berrington.
An Aspie Path to College
by Jo-Louise Allen

During the fall of 2007, Daniel’s senior year in high school, we visited several college campuses: Wheaton, Adelphi, Clark, UMass Amherst, and Brandeis. We had cast a bigger net than what Daniel had expected when he was a child, when he stated, “Mom, I will only apply to Boston College, because it is in Newton, and I never want to leave home.” I told him to wait until he was 18 years old, and see how he felt then. He changed his mind, and was more than ready to get away from us and his younger siblings by the time he was a senior!

Daniel met weekly with his guidance counselor to write his college essay, fill out applications, and make appointments. I was not allowed to read any of his material until months later, after he had been accepted at every school he applied to, and he made his decision to attend Emerson College.

So, all I could do was surf the internet, researching colleges with disability services departments, and make inquiries as to whether any of them had ever heard of Asperger’s, and if they had staff who were experienced working with college students who had this “invisible” disability.

Most of the research was discouraging. Actually, every school I read about had a disability services office. However, they were not familiar with Asperger’s or non-verbal learning disabilities. They were traditional offices, working with students with ADHD, mobility issues, vision issues, hearing issues. Even disabilities. They were traditional offices, working with students with disability services departments, and make inquiries as to...

Between AANE’s office and the Director of Disability Services, we did find one school, Adelphi University, on Long Island, in a beautiful community called Garden City, that met the needs to a “T.” Adelphi was the pioneering school in the United States to develop a forward-thinking disability services program in the 1970’s. Due to their excellent reputation for over 30 years, the UJA Federation of New York and the J.E. and Z.B. Butler Foundation asked Adelphi to pilot a new program called Bridges to Adelphi. The description stated, “Students embarking on college life often feel lost and anxious. But for students with Asperger’s Syndrome, Autism, Social and Anxiety Disorders, and other non-verbal learning disabilities, the college experience can be especially confusing and isolating.”

The Bridges to Adelphi program was set up to help students struggling with:
1. Social isolation and loneliness.
2. Establishing and maintaining friendships.
3. Transitions or changes.
4. Feeling overwhelmed by the demands of university life.
5. Academic issues.
6. Roommate problems.

The best line came from the Director of Disability Services at Adelphi. We were having a pleasant conversation and she mentioned that they pair students up with professors for mentoring and companionship. When I asked how the professors interacted with students who have social skills deficits and executive function weaknesses, she laughed, and said, “Most of our
professors are on the spectrum themselves! Listen to the profile of a college professor: brilliant, highly knowledgeable in one field (a.k.a. their perseverative interest) and loves talking on and on about their subject, rumpled suits, disorganized papers, etcetera!"

You may be wondering, if all this great support was offered at Adelphi, how did Daniel choose Emerson? Well, as his mom, I wanted Daniel to choose Adelphi more than Daniel wanted it for himself. I loved the campus, the proximity to Manhattan, and the warm, nurturing culture. Daniel explained that he was too anxious to be so far away from home. If I had to get to Adelphi in an emergency, it would take a minimum of 4 1/2 hours. (A topic for another day is my hope that Adelphi will be a model for all colleges and universities to emulate.)

Daniel was accepted at every other school that he applied to, but wait-listed at Emerson, and was severely disappointed. He wanted to be in Boston, and he wanted to be at one of the top schools in the country for graduating talent in the entertainment industry. He reluctantly agreed to attend Clark University in Worcester, as his second choice. One day after mailing the non-refundable $400 deposit to Clark, the phone rang, and it was Emerson: Was Daniel still interested in going there? Because they were taking him off the waiting list. And the rest is history.

The disability services office at Emerson did not specifically mention that they had experience with students on the spectrum, but we set up an appointment with the Director of Disability Services, and were pleasantly surprised. Dr. Anthony Bashir, the Director at Emerson, knew all of the players in Newton that had worked with Daniel during his elementary, middle and high school years. Dr. Bashir was a consultant to the Newton Public Schools on EmPower, a writing model using approaches that involve strengthening executive function and the planning process. Dr. Bashir had worked at Children’s Hospital for twenty years as head of the speech and language pathology department. He “got” Daniel and knew how to balance pushing him to succeed and supporting him emotionally simultaneously.

The Emerson Learning Center offers writing support, time management, note takers, extended test time, and the option to take exams in a quiet space outside of the regular classroom. Daniel took advantage of all these services during his freshman year.

He lived at school in a suite with five guys. Dr. Bashir offered him a single, but he chose to live in a suite, not wanting to isolate himself and fall into a pattern of withdrawal. The suite posed the biggest challenges for Daniel during his freshman year, much more difficult than any academic adjustment. I got too many calls at midnight from a depressed, anxious son who was having roommate problems and didn’t know how to handle them. He did learn a lot about working on the suite relationships, but the biggest challenge was to work on non-avoidance, and not to let things build up and fester. Because he is a champion at procrastination, and fears any constructive criticism or rejection, Daniel waited until some issues were over the top before seeking help. He also needed some role-playing of scripts that he did with Dr. Bashir, because he didn’t know how to initiate difficult conversations about sloppiness, odors, drinking, space boundaries, and exclusion with his suitemates. I would say that he made significant progress, but that it was painful, and very challenging.

Daniel began his sophomore year 5 weeks ago, in a new suite that he handpicked and with four new roommates that he likes a lot, and with some new strategies in his toolbox to approach issues as they arise, and not let them get so big that he can become shut down. I don’t expect this year to be without bumps, but I think that he is in a much better place than one year ago.

Thank You.

Author’s Note: This talk was given in October, 2009 just a short time after the beginning of Daniel’s sophomore year. Sometime in early December, during an extremely stressful period of final exams, final projects, and PowerPoint presentations, Daniel started eating poorly, pulling all nighters, and skipping appointments with the Disability Services Office. We were not aware of this until he came home for Christmas vacation. We had to pick up the pieces and start over. Daniel has returned to school with a reduced course load. He is living with his suitemates four nights a week, and staying in our home three nights a week. He is watching his nutrition more carefully, and sleeping more hours. He has contributed to The Berkeley Beacon, the Emerson newspaper, with some great movie preview and review articles. He continues to work at the Campus Center, and is responsible for his laundry and incidental purchases with the money he earns. The rollercoaster came screeching at us again this past semester, but we remain optimistic that with proper self-care, and self-understanding of the importance of utilizing all his support systems, that Daniel will have a successful semester.

AANE Program Update: Plymouth County

Catherine Mayes
Coordinator of Plymouth County Teen Services
(617) 999-7639
Catherine.Mayes@aane.org

Second Saturday Socials

AANE’s Second Saturday Teen Socials have been ongoing in Plymouth County. The monthly gatherings have included bowling, pizza and games, going to the mall, and just hanging out. The group is flexible about trying new things and meeting in different parts of Plymouth County to make it more convenient for everyone. Usually food is an important part of the event. It seems that Plymouth, MA is a good location for many of the teens, because there are a variety of things to do. But we are open to traveling to different places in Plymouth County.

On February 13, the AANE sponsored social began at Boston Bowl in Hanover, MA. The group of eight teens, supervised by Amy Gordon, M.Ed. and Catherine Mayes, AANE Plymouth County Teen Program Coordinator, enjoyed a round of bowling in the large family friendly bowling alley. The group was hungry, and then went on to the Boston Beer Company for dinner. Pizza is one of the many entrees that can be ordered at BBC, but all but one member of the group opted to choose other items listed on the menu. Conversation was animated and a good time was had by all. Parents met the teens at the restaurant to get everyone back home. While at the restaurant, the group decided that next month, they want to eat first and then go bowling.

The February Second Saturday Social exceeded our expectations. The teens were wonderful- it was great to see their success with so many things, including: incorporating a new teen into the group, waiting their turn when a new teen joined them and it messed up the order of who was going to bowl, attentively watching each other as each person took their turn, and making suggestions for the next social event. But what was most impressive and important was to see how genuinely happy they are to be together. The subtle embedding of budgeting of time and money into the program worked very nicely as well.

All programs in Plymouth County are supported by the Phillips Foundation. For further information, including the date of the next upcoming social, please contact Catherine.
Guía Básica Para Escoger a un/a Defensor/a Para su Hijo/a

Por Stephanie LeBlanc y Christine Riley, defensoras de niños, parte de SPAN (Red de Apoyo de Necesidades Especiales)

This article is also available in English at: www.aane.org.

Trabajar con su distrito escolar para asegurar que su hijo/a reciba una educación adecuada puede ser difícil. Muchas veces los padres creen que no son miembros iguales del equipo educacional de sus hijos/as y que las decisiones que se toman no se consideran las necesidades únicas de sus hijos. Además las leyes de educación especial tienen muchas complejidades con cronologías y procedimientos que no son familiares para la mayoría de los padres. Puede convertirse en un gran obstáculo para muchas familias. Entonces muchas veces los padres buscan la ayuda de un/a defensor/a.

El rol de un/a defensor/a educacional

Como padre, se preocupa mucho por cómo su hijo/a aprende y madura y por ser un miembro igual del equipo que desarrolla y lleva a cabo el plan individual educacional (IEP) de su hijo/a. Un/a buen/a defensor/a quiere ayudarle a asumir el rol principal en la educación de su hijo/a. Él o ella no toma decisiones por usted, sino que le ayuda a informarse y considerar sus opciones y alternativas. Un/a buen/a defensor/a le apodera.

No todos/as defensores/as son lo mismo y el rol preciso que tienen en su caso puede variar según su capacitación, experiencia, área de habilidad, y personalidad y según la situación particular. Por lo general, un/a defensor/a educacional puede:

- Contestar sus preguntas y simplificar el laberinto educacional para obtener una mejor y adecuada educación para su hijo/a.
- Examinar los resultados de pruebas y archivos escolares para determinar si se necesita más evaluación.
- Sugerir posibles áreas educacionales y/o clínicas para investigar basadas en las necesidades únicas de su hijo/a.
- Darle referencias a profesionales como médicos, evaluadores, asesores educacionales, terapeutas de lenguaje, terapeutas ocupacionales y terapeutas físicas.
- Preparar documentación para apoyar el programa que necesite su hijo/a.
- Ayudar con el proceso desde la evaluación hasta la elegibilidad y el desarrollo de un plan individual educacional (IEP).
- Sugerir acuerdos a agregar al IEP de su hijo/a para apoyar el aprendizaje.
- Seguir el progreso y pedir acuerdos necesarios.
- Investigar y explorar alternativas colocaciones educacionales para su hijo/a.
- Ver soluciones que no son inmediatamente obvias.
- Colaborar con otros profesionales como médicos, psicólogos/as, terapeutas, y abogados/as.
- Monitorear la implementación y la eficaz del IEP.
- Asistir reuniones y/o ayudarle con la preparación para estas reuniones.
- Apoyar a los padres con la mediación y otras maneras de resolver conflictos.
- Enseñar a los padres a luchar con eficacia por su hijo/a.
- Aunque la mayoría de los/as defensores/as no son abogados/as, pueden darle referencias a abogados/as si es necesario. Además, muchos defensores/as consideran que su rol incluye fomentar una relación positiva y colaborativa con las escuelas hasta la mayor extensión posible mientras siguen haciéndolos responsables a las leyes federales y estatales que protegen a su hijo/a. Los/as defensores/as hacen mucho esfuerzo para mantener un ambiente profesional, respetuoso y colaborativo que promueva que el equipo entero mantenga el enfoque en las necesidades educacionales de su hijo. A veces éste es su rol más importante y difícil.

Escoger al/la defensor/a adecuado/a para su hijo/a

Cuando ya ha decidido que necesita la asistencia de un/a defensor/a, ¿cómo lo/la elige? Aunque las respuestas de las preguntas abajo le darán información importante, es esencial que se sienta un vínculo con su defensor/a. Tiene que tener confianza en él o ella. A menudo tendrás la impresión si es la persona ideal durante el primer encuentro. Aquí están algunas preguntas y respuestas posibles que le podrían ayudar:

1. ¿Cuál es su nivel de educación y capacitación?

   Actualmente no hay ninguna capacitación obligatoria para ser defensor/a. Massachusetts, entre otros estados, ha participado en un estudio experimental de un plan de estudios diseñado al nivel nacional. Algún día es probable que exista alguna regla formal para la gente que quiere ser defensores/as. Hasta entonces, somos muy afortunados aquí en Massachusetts porque tenemos el Instituto de la Capacitación de Defensores/as de Padres (PTI) a través de la Federación para Niños con Necesidades Especiales. Con esta capacitación bien equipada, muchos defensores/as pueden empezar a ver la carrera y desarrollar sus habilidades. Este programa es único a Massachusetts; no existe en muchos otros estados. Se puede aprender más en su página web (www.fcsn.org) o llamar a 1-800-331-0688 para saber más de sus talleres. La Federación puede contestar sus preguntas más básicas y ayudarle a localizar a un/a defensor/a que ha asistido la capacitación. Cuando se pide, le dan los datos de varias personas en su ciudad que le sirvan. (Gente que acaba de completar la capacitación - muchos que ya tienen otras habilidades profesionales antes como defensores/as - posiblemente pueden donar su tiempo gratuitamente.

2. ¿Qué hace para informarse de las novedades en su profesión?
Busque a un/a defensor/a que siga desarrollando sus capacidades por asistir seminarios y talleres. Hay muchos cambios de leyes de educación especial y su interpretación e implementación así que es importante que los/la defensores/as se mantengan actualizados/as. Para ayudar, hay una organización sin fines de lucro que se llama la Red de Apoyo de Necesidades Especiales (SPaN). Ofrece talleres, capacitación e información profesional de asuntos relacionados a la educación especial. Además sirve como un foro para que los padres, profesionales y defensores/as puedan compartir información entre ellos mismos. La página web de SPaN contiene listas de sucesos dentro de la educación especial y una guía de defensores/as profesionales. (Para más información, vea las notas al final del artículo).

3. ¿Cuánto tiempo puede dedicar a mi caso?

Muchos/as defensores/as creen que aunque la capacitación inicial y actual es importante, poner todo en práctica cada día hace un/a defensor/a eficaz y avezado/a. A través de la experiencia los/las defensores/as encuentran y luego perfeccionan un estilo que funcione bien para ellos/as. Además la experiencia práctica ayuda a formar redes de recursos para que puedan buscar los servicios que necesita su hijo.

Cualquier nivel de experiencia que tenga su defensor/a, debe creer que él/ella sea honesto/o y claro/a sobre si su experiencia puede servirle. Sin embargo, si se encuentra en una situación de urgencia, una posible expulsión, por ejemplo, es importante tener a un/a defensor/a que conozca bien este tipo de problema. Las líneas cronológicas son muy cortas y las consecuencias de un error son demasiadas.

4. ¿Ha defendido a niños con el Síndrome de Asperger (o HFA, o PDD-NOS, o NLD) antes?

No es esencial que un/a defensor/a se especialice en el S.A. - muchos defensores/as pueden ayudarle porque conocen bien el proceso de educación especial - pero puede ser útil. Un/a defensor/a que tenga mucha experiencia con los trastornos del espectro autista (o se especialice en ellos) puede ofrecerle conocimiento útil además de su experiencia más general. Muchas veces él o ella tiene un conocimiento fuerte de los tratamientos, terapias, y programas disponibles y le puede dar acceso a una red de profesionales probados/as: médicos, evaluadores/as, analistas de comportamiento, proveedores/as de terapia y asesores/as con un conocimiento especial del S.A.

Aunque las fortalezas y debilidades de cada niño/a son diferentes, muchas veces los niños con diagnósticos parecidos comparten las mismas características. Un/a defensor/a que comprenda bien estas características y tenga los recursos para remediarlas puede simplificar el proceso de formar un programa educacional que sirva las necesidades de su hijo/a.

5. ¿Ha defendido a otras familias en mi distrito escolar?

Muchas veces es útil, aunque no esencial, que un/a defensor/a tenga experiencia en su distrito escolar. Trabajar en un específico distrito escolar les permite tener una mirada a los programas ofrecidos, experiencia trabajando con el personal, y una idea de cómo funciona el distrito. Sin embargo, a pesar de la ventaja de tener experiencia allí, un/a defensor/a que tenga una situación difícil en su distrito puede referirle a otro/a defensor/a para evitar la posibilidad que su involucramiento cree prejuicios en contra de usted en el distrito.

6. ¿Cuánto tiempo puede dedicar a mi caso?

Tiene que informarle a su defensor/a de sus necesidades.

Muchos/as trabajan con varios casos a la vez y tratan de tener en cuenta la cantidad de trabajo que tienen. A través de la conversación inicial con su defensor/a, sus necesidades y el número aproximado de horas requeridas para lograr su objetivo serán más claros. Si sus necesidades van más allá de lo que puede ayudar su defensor/a, quizás debe pedirle a recomendarte a otro/a defensor/a.

7. ¿Cuántos son sus honorarios y qué incluyen?

Hay que obtener esta información mientras que habla con posibles defensores/as. Muchos/as hablan de sus precios cuando habla con ellos/ellas por la primera vez. Además muchos/as defensores/as le mandan un acuerdo con sus honorarios y otras políticas y limitaciones.

Algunos/as defensores/as piden un depósito al principio mientras que otros/as prefieren cobrar por las horas después. Los honorarios varían y los servicios que cobran también. Muchos/as defensores/as cobran por hora y la gran mayoría cobran por el tiempo de viajar. Pregúntele cuales son las actividades que cobran. Además es razonable pedir un cálculo aproximado de la cantidad de horas que requiere su caso (o al menos la primera parte).

Los estilos de los/las defensores/as varían tanto como los de los padres. Cuando ha identificado a los candidatos, escoja al/la defensor/a que sea más compatible con su personalidad. Debe sentirse cómodo/a al hablar y compartir información importante sobre su hijo/a con él o ella. Va a empezar un “viaje” y su relación con el/la defensor/a puede hacerlo productivo y exitoso si se entienden bien y comparten los mismos objetivos.

¿Qué recursos están disponibles para ayudarme a encontrar a un/a defensor/a?

Además de conseguir nombres de AANE, FCSN y SPaN, Los/Las Defensores/as de Niños en Massachusetts (MAC) es otra buena herramienta para conectar a los padres con defensores/as y abogados/as. Puede pedir referencias de familias que han trabajado con un/a defensor/a antes. Muchos/as pediatras, evaluadores/as, terapeutas, y abogados/as pueden darle sugerencias también.

Trabajando con un/a defensor/a

Muchos padres se enfrentan con un infinito número de decisiones relacionadas a la educación de su hijo/a. Si elige a navegar el sistema con la ayuda de un/a defensor/a, acúrdese que está creando una colaboración. Como es necesario en todas las colaboraciones, la comunicación frecuente es esencial para poder el “viaje” para asegurar el mejor resultado para su hijo/a. Atr. de tomar decisiones como pedir una reunión, firmar un individuo plan educacional, o incluso contratar a un/a evaluador/a, siempre es mejor consultar a su defensor/a. Comparta cualquier tipo de información tiene de la escuela con el defensor/a para que pueda mantenerse informado con el caso de su hijo. Su defensor/a tiene la capacidad para ayudarle a entender las leyes de educación especial y a contestar sus preguntas. Mientras tomar decisiones como padre, colaborar con su defensor/a aprovecha su conocimiento del proceso y eso le puede ayudar a lograr su objetivo.

La conclusión

Los/as defensores/as pueden ser puentes importantes entre las familias y los/as educadores/as. Durante todos los años de la educación de su hijo, es probable que vaya a conocer a muchos educadores/as y especialistas diversos. Necesita poder trabajar con ellos/ellas con eficacia, compartiendo ideas y preocupaciones, y comunicando lo que funciona y no funciona.

Continuado en pagina 20...
Time Management Tips
by Robin Lurie-Meyerkopf, M.Ed., AANE Associate Director

Having good time management skills sets a person up for a life of success. People who can get up, arrive on time, and prioritize tasks will be offered more opportunities and use them more effectively. Yet time management can be such a struggle for children and teens with Asperger Syndrome (AS). How can parents and educators work together to help children with AS in this vital area?

Visual Schedules

Because most individuals with AS are visual thinkers and learners, it is important to provide them with visual schedules. At home, the parent and child should create these together. There should be a schedule for morning routines, one for after school, and one for weekends. The schedule should be focused on specific tasks along with the time the task should begin. For example: 7:15 wake up, 7:20 eat breakfast, 7:35 get dressed, 7:45 brush teeth/wash face, 7:55 check weather on weather.com, 8:00 walk dog, 8:15 get lunch and backpack/check homework, and 8:25 walk to bus stop. You can make multiple copies but your child should have his or her own copy. For younger children, make schedules with pictures.

The next step is trying out the schedule: looking at it, following it, and making adjustments if necessary. The child needs to look at the schedule frequently and follow it. You may need to remind your child to “check your schedule” as new routines take time to learn. The original schedule may need to be re-worked as glitches appear or new routines need to be incorporated.

Watches, Clocks, and Timers

The next important step is for your child to start wearing a watch. The watch should be carefully chosen with your child, especially if the child has marked sensory issues. The watch should be waterproof, and as comfortable as possible. Your child should start to wear the watch all the time so they can overcome any sensory issues and not lose it by taking it off and on.

Now the fun begins! Parents and teachers can begin to ask the child to be responsible for reminders for the family or classroom about time-related issues. For example parents can have their child remind the family when it is time to leave for school, time for dinner etc., or to feed the family pet at a certain time of day. Teachers can ask the child to remind the class of when it’s time for recess, lunch, music class, etc. For some kids this may become a preoccupation, but from what I have seen this dies down after awhile.

Another tool children need is an alarm clock. Again, it is important to choose one that will work for the individual child. Involving the child in the decision can make a big difference in whether the alarm will be effective, and whether the child can learn how to set the alarm independently. For one person, a Japanese clock shaped like a penguin, with an alarm saying “Do your best!” in Japanese, was appealing enough to be effective.

Another helpful tool is a timer. One choice to consider is a “time timer” sold as occupational therapy equipment, and showing a red field on the dial for time remaining. For another child, a particular appearance (e.g. a cute chicken or a professional-looking sports stopwatch) or preferred alarm tone may be the critical factor. Children can set timers for themselves for TV shows or video games; when the timer goes off, so does the TV or computer. Timers are also useful for homework assignments; when the timer goes off it is time to switch assignments. It is important to work with teachers to find out how much time should be spent on each assignment. Kids can even keep track on a chart of how much time they have spent on their assignments. This will help both teachers and parents decide what is a reasonable amount of time for individual children to spend on homework. Families and teachers can encourage skill development by asking the child to estimate how much time they think an assignment will take to complete, and then compare their guess with the actual time.

Continuing to Develop Skills

Over time, it is important to add some new routines and responsibilities to the visual schedules. For example, children can learn to set their own alarm clocks using their morning schedule as a guide. If the new routines don’t work right away, it’s okay to adjust the schedule; it may take a few adjustments to get it right. Children do not master time management skills overnight. However, it is highly worthwhile for parents and educators to invest our time and ingenuity to teach them. The better their time management skills become, the better prepared they will be for college, work, or an independent adulthood.

Guía Básica Para Escoger a un/a Defensor/a Para su Hijo/a

En muchas ocasiones los padres creen que pueden comunicarse y negociar mejor con un/a defensor a su lado.

Stephanie Leblanc es defensora de educación especial que se especializa en niños con el Síndrome de Asperger y otros trastornos del espectro autista. Además es socia activa de varias organizaciones profesionales y acaba de unirse a la junta directiva de SPaN. Stephanie vive en Hopkinton con su esposo y es madre de cuatro hijos - uno de ellos tiene autismo. Se puede llamarla a 508-625-2209 o visitar su página web www.autismspectrumadvocacy.com.

Christine Riley es defensora de educación especial que trabaja con todas las discapacidades. Se graduó de Marymount University en Arlington, Virginia y recibió capacitación a través de FCSN y participó en el programa SEAT. Además es mediadora con años de experiencia. Christine es socia de AANE y forma parte de la junta directiva de SPaN. Vive en Cape Cod con su esposo e hijo. Se puede llamarla a 508-428-2288 o visitar su página web www.capecodadvocate.com.

Para más información sobre SPaN (Special Needs Advocacy Network) o para descargar la guía de defensores, visite www.spanmass.org.


Esta guía fue traducida por Charlie Remy, socio de AANE.
Congratulations to the Winners of the 2010 AANE A+ Awards for Excellence in Teaching Students with AS

Barbara L’Italien, who organized the event, Sue Campbell (winner), & Senator Ken Donnelly

Cheryl Boylan (winner) & student

Aide to Rep. Mary Grant, Aide to Senator Fred Berry, Ryan Plosker (winner) & Barbara L’Italien

Aide to Senator Tom Kennedy, Aide to Senator Tom Kennedy, Christine Curry (winner) & Barbara L’Italien

Paul Ridge, June Ridge (winner) & Catherine Mayes

June Ridge receiving her award from Barbara L’Italien

The Matthew Dandurand Memorial Fund Annual lecture for teens with AS took place on April 1 at Elms College in Chicopee, Massachusetts. Zosia Zaks, author of Life and Love: Positive Strategies for Autistic Adults, was this year’s speaker. Pictured at left with Ken Dandurand, Matthew Dandurand’s father, is Matthew Curtis, winner of this year’s Matthew Dandurand Award for Exceptional Effort. The lecture and award celebrate the courageous spirit of Matthew Dandurand, who died at age sixteen on August 13, 2005.

Congratulations to Matthew Curtis Winner of AANE’s 2010 Dandurand Award for Exceptional Effort
AANE Presents the 2010 Laugh Out Loud Gala!

On May 1st, 2010, nearly 500 friends and supporters of AANE came out for a fun-filled evening of laughs, raising over $400,000 for AANE’s programs and services.

Award-winning author Michael Palmer, MD, auctions off a chance to become one a character in his next novel.

“...I have had the honor of meeting so many parents who felt like I did. Suddenly, I do not feel so alone... Each and every letter I received from a mother said the same thing: ‘You wrote my story.’ My healing began with a call to the Asperger’s Association of New England.”

- Shonda Schilling, 2010 Gala Honorary Chair and New York Times Bestselling Author of The Best Kind of Different: Our Family’s Journey with Asperger’s Syndrome.
Keep the Laughter Going!

AANE will be celebrating its 8th annual gala on April 30, 2011. If you are interested in sponsoring this event, please contact Kelly Genois at 617-393-3824 x 20.
The Glenholme School
*A Devereux Center*

An exceptional boarding school for students with special needs ages 10 to 18 and postgraduates; The Glenholme School offers an individually prescribed learning environment with a steadfast academic curriculum. Using our effective individualized services, we apply a positive behavior support model focused on development of social skills and lifelong strategies for success.

Open enrollment for Glenholme Middle School and High School; and the 2010 Summer Camp and the Glen Ridge Postsecondary Programs

81 Sabbaday Lane, Washington, CT 06793
860.868.7377 www.theglenholmeschool.org
A Massachusetts Approved School

---

Camp Akeela

An overnight camp in Vermont supporting the social growth of boys and girls.

www.campakeela.com

Camp Akeela is a coed, overnight summer camp in Vermont for children and teens with Asperger’s and NLD.

We focus on building a community in which campers feel great about themselves, make friends, try new things and have fun!

866-680-4744
info@campakeela.com

---

Child & Family Psychological Services, Inc

Comprehensive Services for Children and Adults

Services Include:
- Neuropsychological Evaluations
- Psychological Evaluations
- Psychopharmacology
- Social Skills Group
- Child Behavior Management
- Consulting & Training

Michael Goldberg, Ph. D., Director
Timothy Martin, Ph. D., Neuropsychology Director
Kirk Lum, M.D., Medical Director

Braintree | Holliston | Norwood
781-551-0999 | www.cfpsych.org

---

Grace Myhill, LICSW
Psychotherapist and Group Leader

Grace offers individual therapy, groups and workshops for adults

Offices in Watertown and Wellesley
Daytime, evening, and weekend hours

617.504.3116 | GMYHILL@GMAIL.COM | WWW.GRACEMYHILL.COM

---

Lifespan Services, Inc.

Neuropsychological Assessment and Consultation Across the Lifespan

www.LifespanNeuropsychology.com • 781-348-2258
Thank you to our advertisers!

Mental health residential treatment & Transitional living services for young adults

Program Features:
- Safe, Comfortable and Highly Professional Treatment Environments
- Preserves Individual Dignity through Respect and Compassionate Care
- Offers the Highest Levels of Service Possible
- Young Adults 18 +
- Highly individualized care and personalized service
- Clients may be admitted to any level of care (when appropriate)
- All programs based on our internally developed Social Integration Model
- Customized activities-based treatment experience
- Complimentary one year aftercare

We Treat:
ASPERGER’S SYNDROME · AUTISM SPECTRUM DISORDERS/Mild Adult Autism · Schizophrenia · Bipolar Disorder · Anxiety Disorders · Schizo-affective Disorder · Bipolar with Psychosis · Co-occurring Substance Abuse or Addiction · Thought Disorders · Mood Disorders

Our Levels of Care:
Intensive Residential Treatment · Transitional Living/Life Skills Programs · Community Residential Homes · Day Treatment · Supported Housing

Two Locations:
Pasadena Villa – Orlando
14 private & semi-private rooms
2 Community Residential Homes
Transitional Living/Life Skills Programs

Smoky Mountain Lodge – Tennessee
29 private rooms with private bath

www.PASADENAVILLA.com
625 Virginia Drive, Orlando, FL 32803 • Phone 877.845.5215 • Fax 407.329.3300
Education Consulting, Advocacy & Legal Services, LLC

Pamela S. Milman, Esq.
Daniel Mikolajewski, Esq.
999 Broadway, Suite 301
Saugus, MA 01906
Phone: 781.231.1DEA (4332)
Fax: 781.231.FAPE (3271)
Email: ecals@comcast.net

www.educationandjuvenilelaw.com
Thank you to our advertisers!

Classes Offered In:
• Martial Arts
• Social Skills
• Music
• Executive Function
• Groups of no more than five or six per instructor

Contact Us
781-619-1518
www.bostonafterschooladventures.org

Contact Us
781-619-1515
info@ablspartners.org
www.ablspartners.org

Contact Us
781-619-1548
lmeehan@iccddpartners.org
www.ablspartners.org
Find help. Find answers. Find hope.

Jewish Family & Children’s Service
Supports for People with AS

- Independent Living
- Life Skills Coaching
- CJP Disabilities Trust

Caring for Generations
JF&CS
Jewish Family & Children’s Service

Jewish Family & Children’s Service is the leading provider of comprehensive human services, delivering personalized and integrated care that improves people’s lives.

JF&CS Headquarters  |  1430 Main Street  |  Waltham, MA 02451  |  781-647-JFCS (5327)  |  jfcsboston.org

An advertisement is not an endorsement of programs or services.
Thank you to our advertisers!

SUMMIT CAMP & TRAVEL
For boys and girls with AD/HD, Asperger Syndrome, NVLD and/or mild social or learning issues

- Complete recreation, waterfront and athletic activities
- Specializing in therapeutic recreation since 1969
- Professional direction – low staff to camper ratio
- Commitment to personal growth through creative expression
- 3 and 2 week residential sessions (ages 8-17)
- 1 week mini-camp (ages 8-14)
- 19, 18 and 13 day travel programs (ages 15-19)
- Exciting adventure, discovery and super-teen programs

Destinations for 2010 include:
- 19 day trans-Canada trip
- 13 day colonial US bus tour
- 18 day Costa Rica nature and ecology expedition

Our trips are professionally supervised and managed. While at exciting destinations, our older teens are involved with the skills of travel and daily group living: money and time management, decision-making and group interaction.

Summit Camp
Honesdale, PA
Growth, Independence, Maturity, Increased Social Skills, Lasting Friendships
For information call 800-323-9908 info@SummitCamp.com www.SummitCamp.com

PERSONAL Disability Consulting, Inc.
Pragmatic Solutions to Everyday Problems

Lee Rachel Jurman
Lead Disability Advocate
Advocacy, Coaching and Ongoing Support for Adults with Aspergers and Their Families
tel: 617-879-6039 www.personaldisability.com

Career Development Coaching
for adults with Asperger’s & NLD

Career exploration • Job readiness • Job support
Call for a Free Introductory Session. Offices in Lexington & Stow, MA
Barbara Bissonnette, Certified Coach • 978-298-5186
Barbara@ForwardMotion.info • www.ForwardMotion.info

THE VICTOR SCHOOL
is accepting limited applications for the school year. Enrollment available for students in grades 8th—12th.

2010—2011 School Year
Wendy Rosenblum, Director
Heidi Factor, Assistant Director
380 Mass Ave. Acton, MA 01720
Tel: 978-266-1991

Ψ Miles Tarter, Psy.D.
Clinical Associate, Harvard Medical School
Neuropsychological Psychodiagnostic Assessment Educational Testing
University Neuropsychology, Inc.
929 Massachusetts Ave., Suite 01
Cambridge, MA 02139
Voice (617) 877-5978
Fax (206) 666-3687
mtarter@mac.com
DRAMATIC PLAY YIELDS DRAMATIC RESULTS

Experience theatre & music as means to express yourself;
Self esteem building as you explore the art of theatre
Social-thinking groups. (Multiple levels available)
Beginning…..September 2010
Theatre arts games and techniques: Read your audience:
Learn about body language: Group building exercises: and
more…
Director: Mary Spinosa-Wilson, RN, BSN, DTI
Wilson.family.home@verizon.net ; 978-302-0985
For more info, registration and an intake interview

Learn about body language: Group building exercises: and
Experience theatre & music as means to express yourself;
Theatre arts games and techniques: Read your audience:
Self esteem building as you explore the art of theatre
Director: Mary Spinosa

BARBARA D. J ACKINS
Attorney at Law
Legal Planning for Special Needs
♦ Special Needs Trusts
♦ Guardianship
♦ Public Benefits
PHONE: (617) 489-6140
FAX: (617) 484-0501
SUITE 101
385 CONCORD AVE.
BELMONT, MA 02478

Devereux
Massachusetts
60 Miles Road
P.O. Box 219
Rutland, MA
508-886-4746
www.DevereuxMA.org

Emphasizing social skills and
life skills for youth with
Asperger’s and PDD
Treating and educating children, strengthening families, changing lives.

The Groden Network
Your Autism Experts
www.grodencenter.org

JOB TRAINING PROGRAM FOR YOUNG
ADULTS WITH ASPERGER’S SYNDROME
Funded by U.S. Department of Labor & Training
Conducted by the Groden Network of Programs
Start Dates: July 1 and November 1, 2010
Duration: 7 months
Eligibility Criteria: Primary diagnosis of Asperger’s Syndrome, High School Graduate, Ages 18 – 29
Program Goals:
♦ To assist in development of job-essential soft skills;
♦ To discover individual interests and passions for ideal job, college placement, or self-employment;
♦ To place the person on the path to a fulfilling career.
To apply, contact admissions coordinator,
Danna Spencer at 401-274-6310 x1101.

Western Mass Social Thinking Groups
For children and adolescents
Communication Therapy Associates

We also offer individual therapy for children and adults.
Carla A. Bernier, CCC/SLP
Abigail B. Jaffe, CCC/SLP
One Roundhouse Plaza, Northampton, MA
www.comtherapy.com 413-586-1945 office@comtherapy.com

An advertisement is not an endorsement of programs or services.
What the AS Community Needs to Know About the New Mental Health Parity Law
by Dave Harmon

The recently passed Massachusetts Mental Health Parity Law, or MHPL, requires certain insurers who provide mental health diagnostic and treatment benefits to cover the diagnosis and treatment of certain “biologically-based” mental conditions to the same extent that they cover the diagnosis and treatment of physical disorders. The law makes it illegal for certain insurance providers to place higher deductibles, annual benefit limits, lifetime dollar caps, or service limitations that differ from the limitations on the coverage of physical conditions on the coverage of qualifying mental disorders.

The parity law covers the full range of inpatient, intermediate, and outpatient services available for the treatment of mental disorders, so that treatment may take place in the least restrictive clinical setting. Only mental health services provided by licensed mental health clinicians are reimbursable.

The Mental Health Parity Law provides parity for the following biologically-based mental disorders: Schizophrenia, Schizoaffective disorder, Major depressive disorder, Bipolar disorder, Paranoia and other psychotic disorders, Obsessive-compulsive disorder, Panic disorder, Delirium and dementia, Affective disorders, and any other biologically-based mental disorders appearing in the most recent edition of the Diagnostic and Statistical Manual of the American Psychiatric Association (the DMS, currently the DSM IV or fourth edition) that are scientifically recognized and approved by the Massachusetts Commissioner of Mental Health in consultation with the Commissioner of Insurance.

Effective July 1, 2009, four new conditions were added to the list of biologically-based mental disorders: Eating Disorders, PTSD (Post-Traumatic Stress Disorder), Substance Abuse, and Autism. The new law does not cover “Autism Spectrum Disorders,” but covers Autism-related conditions, which fall under the umbrella of Pervasive Developmental Disorder (PDD) in the DSM IV. The only diagnoses that are specifically listed in the DSM IV are Autistic Disorder, Rett’s Syndrome, Childhood Disintegrative Syndrome, Asperger’s Syndrome, and PDD-NOS.

Does this mean that certain diagnoses will be accepted and that other diagnoses will be rejected by insurance companies? No one really knows for certain yet. One can only hope that mental health practitioners use the proper Current Procedural Terminology (CPT) codes to maximize coverage, and that insurance companies do not deny services based on the inaccurate and obsolete DSM IV diagnostic criteria. Families and providers must be prepared for any and all denials due to this lack of clarity and definition. Any denials of this type should be appealed in writing to your insurance company. If the first appeal is denied, you should follow your company’s guidelines and appeal again. This second appeal may be reviewed by an independent panel.

It is also critical that you and your mental health provider are able to show that the mental health service to be provided is “medically necessary.” While a disorder or treatment may be covered under the parity law, insurance companies still have the ability to set the criteria and define which services are and are not considered to be medically necessary. So it is very important to work with a mental health provider who is skilled and able to demonstrate that services provided are necessary. For example:

- **Neuropsychological testing** will now be covered as a medical service, but will only be covered if it is deemed to be medically necessary by the insurance company. Therefore, it is very important that you and your provider properly frame, document, and justify the need for this testing.
- **Cognitive Behavioral Therapy** is considered by many to be very helpful for children, teens, and adults with AS. CBT is now considered an outpatient mental health service, and will be reimbursable under mental health parity.

**More limited coverage for non-biologically based mental health disorders**

The law now also provides minimum coverage for non-biologically based mental health disorders: a minimum of 24 outpatient visits during each 12 month period, and a minimum of 60 days inpatient treatment. Carriers cannot impose other limitations or cost-sharing (such as co-payments) on treatment for these mental disorders, unless the same requirements apply to physical conditions.

**What special rights do children have?**

For children under the 19, the law provides additional safeguards with respect to “non-biologically based” mental, behavioral, or emotional disorders (in addition to the protections for biologically-based disorders). Specifically, the law requires health plans to provide coverage to children:

1) For non-biologically-based mental, behavioral, or emotional disorders that substantially interfere with or substantially limit functioning and social interactions, where:
   a) The child’s primary care physician, pediatrician, or a licensed mental health professional has made the referral for diagnosis and treatment of the disorder, and has documented the substantial interference or limitation, or
   b) The substantial interference or limitation is evidenced by conduct including, but not limited to,
      i) An inability to attend school,
      ii) The need for hospitalization, or
      iii) A pattern of conduct or behavior that poses a serious danger to self or others.

2) If a child turns 19 while undergoing treatment, the health plan must continue to provide this coverage until the course of treatment is completed and while the benefits contract covering the adolescent remains in effect. The plan is allowed to charge a premium for these extended benefits, if the child’s eligibility for coverage would otherwise end at 19.

**Coverage of treatment for substance abuse**

Massachusetts law requires that coverage of alcoholism and/or chemical dependency treatment include 30 days inpatient care and $500 worth of outpatient benefits. However, when treatment for these problems occurs in conjunction with treatment for mental disorders, the patient is entitled to broader coverage.

**What insurers must comply with the MHPL?**

The Mental Health Parity Law applies to all of these health plans:

- Group Insurance Commission (GIC) for government employees and retirees.

*Article continues on page 42: “Mental Health Parity Law.”*
The Magic of Technology

The Magic of Technology begins in my computer classroom when a technically-savvy student, who is a bit socially awkward, and who keeps mostly to himself finishes programming his computer game. I then post the game on my websites. With a simple upload to the internet his classmates, friends, and family now have access to the game. The game is played, and it is a success. A class star is born, and the Magic has happened again. As a high school computer programming teacher, I see this happen all the time, and am constantly impressed by the high status in which students hold the creators of technology. Continually, I am reminded of the transformational powers that technology has to offer.

I first experienced the phenomenon in the late 1970’s when I was introduced to computer programming. I was a good student, but my educational progress was stymied by slow reading skills. Despite my handicap, I was always an adventurous student, and decided to sign up for a computer programming course. I was instantly captivated. I found computer programming completely absorbing, but to my amazement, something else happened when I looked at the computer screen. I was able to look at the screen, and follow the flow of the words with greater ease than I had ever done so before. It was an empowering feeling. Later in life, I realized that I must have some form of dyslexia.

Both the students and I were not physically changed, but through the help of technology, we transformed ourselves into more confident and successful people. The students became essential sources of information for their classmates, and computer programming helped them find potential career paths. I was empowered with a new tool in which to base a lifetime career. Most importantly, for both of us technology helped increase our self-esteem, which is so important.

It is wonderful to listen to the students reply to their classmates’ questions. They generously share their programming discoveries. Their technical expertise can brilliantly pull them through high school and College, but I am afraid despite their passion and generosity their collaborative abilities can fall short of today’s business demands. Software projects can be very big and very costly. Companies need for their engineers to be excellent listeners, to work out solutions collaboratively, and to adhere to business best practices. Therefore, computer programming is a talent, and like all other talents, needs to be nurtured, and developed.

Here is how to start your student with the right kind of training. The following are the names and descriptions of some of the programming environments that I use. All of the tools listed are free, and have lots of online support and help for the uninitiated student and parent.

A great place for kids to start is with Scratch. I have seen kids learn Scratch with adult support as early as 5 or 6 years old. It has been created by the MIT Media Lab, Lifelong Kindergarten group, and can be found on the Scratch Web site at http://scratch.mit.edu. It is a visual programming environment and toolkit, in which kids make games, animate stories, create interactive art, and share with others on the net. Scratch opens a new world of expression and collaboration. When I last looked at the Scratch website it had close to ½ million projects created by 331,607 registered members. Kids are scratching and communicating worldwide. The website has plenty of help material for all types of learners, ranging from simple written instructions to wonderful how-to videos. The group continues to improve and update Scratch. The newest version has the ability to control WeDo Lego’s through its environment. Come to a Scratch class or meetup to learn and see the magic first hand.

For those students who want to create a more traditional computer game, there is Game Maker. It is very popular with the boys. Game Maker can be found at http://yoyogames.com. Students take to Game Maker almost immediately and intuitively. Its creator, Mark Overmar from the University of Utrecht in the Netherlands, generously supports a large Game Maker community through the yoyogames website. The website provides a place where Game Maker programmers and users can play, make, share, and help one another with their game making ventures. I use Game Maker in tutoring and in my 9th grade programming classes. My students continuously amaze and delight me with what they produce.

For students who want to create animated virtual worlds, Alice is an excellent environment from Carnegie Mellon. You can find it at http://alice.org. The inventor of the Alice Project was Randy Pausch, the author of the Last Lecture. It is especially popular with girls. It is an object oriented programming environment designed to create 3D animated virtual worlds. One version of Alice is specifically geared towards engaging junior high school girls in computer programming. I use Alice with my first level Java students, to help them learn object oriented concepts in a fun and painless way. Alice has an excellent support community on the Web, impressive tutorials, and an assortment of good books to assist in the learning process.

For advanced students I recommend java. A great place to start gathering information is at http://java.sun.com. Once the student has learned the language fundamentals, I like the training to be team oriented, and to simulate real-world business conditions. Ideally, a team of students collaboratively agrees on a project that creates a software product or solves a real-world problem that produces a software package. Products can range from game creation, to open source projects, to writing a program for AANE. Who knows, one day a group of entrepreneurial students will spinoff into a successful business?

The Magic of Technology is there for the taking. It is a matter of matching the right technology to the right student.

Go ahead, take it, have fun, and start now!
Creating a Team to Create & Support Your Student’s IEP

by Bonnie Glickman, M.Ed., NCC

An Individual Educational Plan (IEP) is a formal structure for achieving the educational goals of students with learning differences. IEPs are written collectively by a team of teachers, parents, and professionals involved with a student’s welfare, based on concerns raised by parents and/or teachers, usually backed up with specific diagnoses that arise out of standardized evaluations. Frequently they address multiple issues, identified by a variety of professionals. Usually, an IEP is a statement of a set of quantifiable goals for the student to achieve, followed by a description of the support that will be given to help the student achieve the goals. When developed well and implemented conscientiously, an IEP can translate the insights of educators and parents, medical and psychological experts into teaching practices that will be effective given the unique learning profile of the child.

Creating a well-functioning educational team to both write and monitor an IEP can be especially important for a child with Asperger Syndrome (or another closely related autism spectrum diagnosis such as HFA, PDD-NOS, NLD), because these children have a communication weakness. They are less likely than neurotypical children to be able to be good self-advocates, to report important school information to parents, to share important home information with people at school—or even to recognize the need to keep other people in their lives informed. Students with Asperger Syndrome (AS) do best when the key adults in their lives take the initiative to communicate regularly and openly with each other. In addition, since AS is a pervasive developmental disorder—i.e., one affecting multiple areas of functioning—these children often have complex profiles, and therefore require ongoing oversight and tweaking of their educational programs, accommodations, and interventions.

Why take the time?

Without regular communication among the key adults in a student’s life, it’s all too common for parents and educators to play the “blame game” rather than channeling their energy into problem prevention, problem resolution, and fostering a student’s successful development. Over the years, as an educator and consultant, I can attest to the fact that sharing information on a regular, cooperative basis amongst team members helps stop the blame game, which is based on counter-productive assumptions such as:

♦ Blaming the child: This student is lazy/rude/could do better if s/he only tried.
♦ Blaming the parents: These parents ought to push this child more/set better limits/make sure the student is doing homework. This child is falling asleep in class—why don’t those parents get this kid to sleep on time? These parents are so pushy/unreasonable/over-reactive/overprotective
♦ Blaming the educators: The teachers are not trying hard enough. Why doesn’t the guidance counselor do more for my child? The principal has no idea what the teachers are doing with my child. Why won’t the school give my child OT/PT/speech and language therapy? My kids’ teachers are so uncaring/incooperative/unfair!

Frequent, open, respectful communication between home and school prevents the build up of such incorrect assumptions, and defuses mistrust, frustration, and anger. Good teams provide a built-in forum to put such issues on the table in non-confrontational way, to dispel misunderstandings, and to examine (and re-examine) whether the student is, in fact, getting adequate services relative to the diagnosis and the goals of the IEP—instead of playing the blame game.

Regular communication between home, school, and other professionals also gives early warning when a student is struggling emotionally or behaviorally, or that a student is getting poor or failing grades. Proper follow-through, a “given” for any well-constructed team, would ensure that parents be notified shortly after a student’s grades start to slip, or shortly after student has stopped turning in homework (or handing in poor quality homework), or shortly after behavior has become a concern. Then the team can take prompt action to limit the damage and turn the situation around. This is far preferable for all concerned than waiting until a quarterly progress reports shows slumping grades or other concerns.

Creating a smooth-functioning team with an ethos of mutual respect, support, and creative problem-solving can be a challenge. Team members generally start off with differing perspectives, overlapping areas of expertise and sometimes a sense of challenge to personal or professional dignity. To develop and then implement an effective IEP, positive effort is required to establish mutual respect amongst the parties. Students with AS can be challenging to parent and to educate—and they don’t come with operating manuals! When problems arise, usually neither parents nor educators are to blame. However, all team members can contribute to a student’s improvement and success if they are willing to accept one another’s insights and assistance, brainstorm solutions, and think outside the box.

When all involved consider themselves to be on a single team, and come together to pool what they know about the student, there is much more likelihood that the IEP will be geared to the actual needs of the student, and implemented effectively. If the professionals who are charged with the implementation of accommodations in the IEP are directly involved in its creation, it is more likely that they will understand why the accommodations are part of the plan, and therefore be better able and more motivated to implement them.

A team-based approach brings together the required expertise to synthesize a comprehensive plan for the child, but it also serves to help all the adults who play a role in the student’s life. Fully functional teams help all the members to stay on target, and to support each other, as well as the student, to accomplish stated goals of the IEP. Creating and maintaining the team does take time—but it is time well spent. Picking up the pieces or repairing the damage stemming from poor communication also takes time, and it is not nearly as enjoyable or rewarding.

Team Members’ Roles

From the age of 14 years on, students are legally entitled to attend their own team meetings. (However, it may be wise to invite younger students to attend for a short time, to prepare them to participate in meetings constructively as teens.) There are also many advantages to including students in at least some meetings, or for part of meetings, if there is adequate preparation and skillful leadership. For example, many students may be able to bear unique witness to their struggles in accessing the curriculum, as well as learn self-advocacy. Please see the accompanying article for detailed examination of successful inclusion strategies.

Parents are their children’s primary advocates. Regular team meetings allow parents to bring their insights, concerns, suggestions, requests, and ideas to the school’s attention, pro-actively and in-depth. However, parents should be careful not to tell educators...
how to solve a problem or meet the student’s needs at school. Educators know the rules, the culture, the resources, and the people in their school system; they need to be the ones to generate solutions that will work in their school, albeit in consultation with parents.

One person essential to a team is an effective leader. The school may designate a special education administrator (e.g. “Inclusion Facilitator” or “Case Manager”), a school psychologist or social worker, a guidance or adjustment counselor, or a vice-principal to lead the team. Ideally, the leader should be someone who has some mobility and some clout in the school, who feels an interest in the student’s well-being, and who has expertise and experience with AS—or at least an open mind and an interest in learning more about AS. Whatever his or her precise title or position, the team leader should be an educator able to convene the team, to facilitate regularly scheduled face-to-face meetings (once a month is excellent), and to facilitate communication among team members between meetings (e.g. intra-school and home/school communication).

In addition to the team leader, the parent(s), and the student, there can be good reasons to include one or more additional educators from the school. In the case of an elementary school student, for example, the primary classroom teacher and the one-to-one aide may be core team members. A guidance counselor or resource room teacher may play a key role in the life of a teenager, and thus belong on his or her team.

Other professionals representing many areas of expertise may be involved in an IEP team, either on a regular basis or just on occasion when their particular expertise or particular knowledge of the student is needed. They may participate by attending meetings in person or by phone, or by providing information to the core team members through written reports. Professionals may participate in areas from diagnosis and testing, to teaching and therapies.

Once initiated, an IEP may need some level of oversight in each of these areas:
- A pediatrician can provide medical history, developmental factors and any medical condition (physical or sensory deficits, allergies, chronic illness, injuries, hospitalizations) that impacts student capability.
- A therapist helps all parties to understand emotional issues of the child as they relate to school functioning, family issues, or peer issues.
- A psychologist (ideally a neuropsychologist) puts intellectual, emotional and psychological potential into context, especially relative to the student’s academic achievement, output, social skills, ability to read non-verbal cues, processing speed, executive functioning and attention factors.
- A psychopharmacologist or psychiatrist who prescribes medications for student can explain the impact of these medications on a student’s mood or ability to pay attention, and school performance.
- Parents bring the family and home perspective, give family history, information on sibling and parental interaction, and make known the difficulties the student encounters when not in school, including organizational skills, level of distractibility, ability to adhere to routine, and ability to initiate and finish homework. Parents can relate what the child does during non-school time—friendships and hobbies (or lack thereof), signs of stress that may not be manifest during the school day.
- Special Education (or SPED) administrators know what resources are available in the school system and how they can be brought to bear on behalf of the student. They are usually the ones who make decisions on how much funding a school system has to support the accommodations of the IEP. The buck often stops with them and they are often the keepers of the bottom line where expenses are concerned.
- SPED teachers deliver remediation and individualized instruction, either in self-contained or inclusion classes according to the accommodations specified in the IEP. SPED teachers may team teach and do planning in conjunction with regular education teachers, as well as with other specialists involved in student’s IEP.
- Regular education teachers teach heterogeneous classes where specific accommodations of an IEP may need to be incorporated into planning and delivery of services for the student.
- Guidance counselors are instrumental in choosing courses, as well as identifying teachers who deal best with similar students, and in planning for the future. They may act as case managers, and/or provide a designated “safe adult” or go-to person for a student. They may direct the student to after-school activities, and may create a group or invite the student to participate in an existing group. They may act as a liaison between home and school.
- School principals or vice-principals are involved in administrative and disciplinary issues. They are responsible for what happens within their school. Teams should look at the school’s discipline codes and think about whether expectations need to be modified for students with AS. To avoid counter-productive reactions to student behaviors, every adult who may encounter the student will need some level of awareness about AS, and know where to turn for information, support, or problem resolution.
- An organizational coach (sometimes a resource room teacher) works with students to improve executive functioning (organizational skills; ability to initiate, break down, and complete tasks; e.g.: writing down homework assignments, taking home necessary materials, completing multi-step assignments, turning homework in).
- A tutor works with students on specific subject or skill set.
- An occupational therapist helps students with many issues having to do with school success including sensory integration, proprioceptive (body awareness) activities, motor planning.
- A physical therapist works with student on gross and fine motor coordination, balance and coordination, and strength.
- Speech and language therapists work with students on expressive and receptive language, social skills, and social pragmatics. (Articulation is less often an issue for students with AS.)
- A social coach (sometimes a trained/supervised aide) works with students to apply social skills in settings outside the speech therapy room.
- Other possible team members or contributors to team include the school nurse and/or an athletic coach.

How a Team Works
A team supports a student by creating an IEP in which all accommodations are arrived at and implemented based on an agreed-upon set of goals, using agreed-upon techniques and consistent vocabulary. By working together, parents, teachers and professionals strive to create a cohesive, integrated plan that reinforces the same concepts, skills and attitudes for student both at home and at school. Working cooperatively, teams can share information so that planning for a student takes into account the myriad, disparate issues that students with complex profiles have.

Writing the IEP is just the beginning of the team’s work;
the team also needs to monitor the implementation of the IEP throughout the school year, making adjustments as necessary. Therefore, a good team creates a communication system to share critical information promptly, so that the student is not allowed to fall behind academically, emotionally or behaviorally for any length of time. Ideally, there should be three layers of communication.

1. Ideally, a monthly face-to-face meeting of the core members of the team.
2. A daily check-in by handwritten journal or individualized checklist (e.g., a notebook traveling between home and school in the backpack of an elementary school student, sometimes filled out by an aide) or a weekly phone conversation or email message from school to home, probably more appropriate for most students in the middle school years. (The choice of email vs. phone should accommodate the preferences of the educator who is the point person—whichever is realistic given this person’s daily schedule and habits.)
3. Emergency communication as needed, by phone or email, from a parent to a designated person at the school, such as the team leader, or from that person to the parent(s).

There should also be regular communication among educators, and as needed with the outside professionals. By including outside professionals, the ongoing issues at school can be incorporated into the work that tutors, coaches, and therapists do with the student. In turn, these professionals can inform the school and the planning process of issues or insights that might otherwise go unnoticed.

Examples

In my practice, I have been part of many good teams and have seen examples of the benefits of cooperative teamwork. For example:

♦ A student’s psychopharmacologist placed him on new medication whose side effects could have affected mood, energy level, and school performance. The psychopharmacologist informed other team members about the medication and its possible side effects. The other team members were then able to plan ahead how to handle the potential repercussions. If the team had lacked that information, they would have wasted a lot of energy trying to figure out why the student was behaving differently, and trying to undo the damage caused to the student’s academics and peer relationships. Because this team communicated on a regular basis, they made sure that this student’s needs were anticipated and supported. They were also able to report back to the psychopharmacologist how the student’s behavior changed on the new medication. Students spend more waking hours in school than anywhere else. A team that was made aware of what to look for was able to convey information that was used in determining whether that medication was having its intended effect and whether side effects were affecting school performance.

♦ Parents informed the team of a disruptive family event (in this case, a death in the family, but it could well have been illness, loss of parental job, death of a family friend or pet, new sibling, separation or divorce, move to a new house or community). This information was shared (confidentially on an as-needed basis), and professionals planned a course of action to support the child. (Parents could also relay a student’s poor night’s sleep, change of routine, difficulty with homework, or travel plans, so that educators can anticipate, plan, and intervene accordingly.)

♦ A therapist discovered and reported to the team that a child was struggling at school but had not told any other adults of

Visit AANE’s website to view our video, Reuben: Portrait of a High School Student with Asperger Syndrome for an inside look into the life of a teenager with AS.

http://www.aane.org/about_aane/aane_video_reuben.html
Don’t Forget to Invite the Student! Including Students with AS in Meetings
by Amanda N. Kelly, M.S.Ed., BCBA & Catherine Mayes, Educational Advocate

According to the National Dissemination Center for Children with Disabilities, “to write an effective IEP for a child with a disability, parents, teachers, other school staff—and often the child—must come together at a meeting to look closely at the child’s unique needs.” As noted in Bonnie Glickman’s article above, students are legally entitled to attend their own meetings beginning at age 14. Too often, however, when school personnel and families think of an IEP team, they may think of parents, classroom teachers, special education classroom teachers, the principal, the special education directors, the school psychologist, counselors, and perhaps the Behavior Analyst or other consultant—but not invite the student with Asperger Syndrome (AS)—the very person whose life will be most affected by the team’s decisions, and for whose sake the team is being convened in the first place.

There may be reasons why parents or educators hesitate to invite students with AS to team meetings, including the risk of the student misinterpreting what the adults say at the meeting, or the adults misinterpreting what the student says. How-ever, with careful preparation, and a skillful team leader, there are important advantages to having a student attend at least part of a meeting, or at least some meetings.

1. First of all, other team members benefit from seeing who the student really is and how the student really functions. Hearing directly from the student can carry far more conviction than hearing about something from a third party.
   a. It is especially helpful for the student to be able to state what s/he finds helpful or unhelpful at school—which may dovetail with parents’ concerns, but be most credible coming from the student.
   b. It is also very helpful for the student to be able to articulate his or her vision of what s/he wants for his or her own future. The student’s own vision statement will be the basis of the delivery of transition services during the high school years, but elements of it could be brought into focus even before age 14 as a team gets to know not only a student’s needs and challenges, but also his or her interests, talents, and achievements.

2. The student gains an opportunity to learn about the people working on his or her behalf, and what each person’s role is. Team members could become go-to people when the student needs assistance at school.

3. The student can also benefit from an opportunity to practice self-advocacy, and be empowered by the experience of speaking up and being given a respectful hearing.

4. Especially as students move into adolescence, their buy-in to their educational program becomes critical. Everything is being done for the sake of the student’s future, but everyone’s efforts will be more effective to the extent that the student understands why accommodations or interventions are being offered, and takes active ownership of his or her own goals and educational program. Like most humans, students are far more likely to cooperate and participate when people seek their opinion and are responsive.

The IEP process seeks to answer many questions: What do we hope to accomplish? What are the students’ strengths? In what areas does the student need the greatest support? It seems we know many of the questions to ask, but can often overlook the person who we should be asking; the person who matters most. Once we become aware of this oversight and make efforts to include students in the IEP process, then perhaps they will no longer be the forgotten member of the team!

IDEA federal special education law (at §300.321) describes the IEP team as including the following members:

♦ The parents of the child;
♦ Not less than one regular education teacher of the child (if the child is, or may be, participating in the regular education environment);
♦ Not less than one special education teacher of the child, or where appropriate, not less than one special education provider of the child;
♦ A representative of the public agency who is qualified to provide, or supervise the provision of, specially designed instruction to meet the unique needs of children with disabilities; is knowledgeable about the general education curriculum; and is knowledgeable about the availability of resources of the public agency;
♦ An individual who can interpret the instructional implications of evaluation results;
♦ Other individuals who have knowledge or special expertise regarding the child, including related services personnel as appropriate (invited at the discretion of the parent or the agency); and
♦ The child with a disability (when appropriate).

How Students Can Participate

Students can learn to draft their own objectives, although the way and degree to which a student participates will depend on the age and ability of the student. For some students, graphic organizers will provide sufficient support for organizing thoughts and ideas. Other students may benefit from preparing a list of statements or questions. When preparing for participation in the IEP process, students should be encouraged to comment on at least three sections:

1. Vision Statement/Strengths
2. Needs/goals

While drafting objectives may enable a student to have some involvement in the development of the IEPs, students can increase their contribution by attending meetings to voice concerns and to participate in critical discussions. It is important for the students’ to feel supported. Some students may want to present at the beginning of the meeting and then leave. (This also gives parents the opportunity to talk frankly about issues that the student might have a hard time hearing about.) Other students may be comfortable remaining for the duration of the IEP meeting. It is important to allow breaks for the student during the meeting, if needed.

Preparing Students to Participate in Meetings

♦ Teachers can assist by providing students with a way to organize their thoughts: graphic organizers, Venn diagrams, visual representation.

Article continues on the next page.
Likewise, parents and educators can prepare students by familiarizing them with key vocabulary and concepts they are likely to encounter during the IEP process. Discuss with the student what to expect during the IEP process. Video modeling in advance has been shown to produce more rapid acquisition and greater generalization than coaching provided in the moment (Charlop-Christy et al., 2000). Determine the students’ preferred means of communicating during the meeting. For some students speaking can be difficult, and they may prefer an alternate mode of communicating such as through visual, textual, or auditory means. Provide opportunities for students to participate through the use of video, audio recordings, and by presenting permanent products/work samples.

Seeing and Hearing is Believing

Educational advocate Catherine Mayes reports what happened when a 17 year old student was finally invited to his own team meeting:

During the past year, about a dozen teens attended meetings where I was the advocate. Preparation and a willingness to be flexible about how the meeting progresses is critical for making it successful for the teen. Painting as clear a picture as possible ahead of time about what happens at a meeting is also important. Advocates can help by looking critically at what the discussion is going to be, and choosing the part of the meeting, and the length of time, the teen is present, to ensure success.

X is a 17 year old student with AS who attends school in his community. He is innocent, funny, quirky, anxious, and struggles socially and academically. His mother was initially uncomfortable with the idea of him being present at his TEAM meeting. She thought he would become too anxious, and would say inappropriate things if he attended the meeting. Or worse, she was afraid he would agree to whatever the school offered because he wouldn't understand the subtle implications of what the school might suggest to him. His mom and I decided to have him meet with both of us to discuss the pros and cons of him being at the TEAM meeting.

He was happy to learn that he had an advocate (me). When we met, he had a lot of opinions and feelings about school. He was confused and upset that his teachers were doing things in a certain way. He had some resentment about not being consulted about his school program. He said that he hated the kind of job he was assigned in his work/study program and wanted to do something else, but hadn't expressed these feelings even to his mom.

We drew up a list of his concerns. Then I asked him if he would like to go to the TEAM meeting. He wanted details: who will be there, where will I sit, what if I get angry, and will they listen to me? He was also concerned because he had a class at the time of the meeting, and asked if it was OK for him to miss his class.

It was imperative that he felt some control over his situation so he could tolerate the meeting. Although he didn't say it directly, I made an assumption that a major concern for him was what he would do if he got overwhelmed in the meeting. I explained that if he came, he only had to stay for as long as he was comfortable; he could leave at any time. We arranged a signal for him to use if he needed to leave, and I promised to watch his back. I also told him that since he had told me all his concerns, that if he decided at the last minute he didn't want to be at the meeting, I could present his concerns to the school—and I really meant it. This seemed to make sense to him. I think he also knew that I really heard his anxiety, as it was visible in his demeanor and body movement.

At the meeting, he sat between his mom and me. I passed him a note reminding him he could leave at any time, and checked in with him several times during the meeting to make sure he was ok. He was great! He asked a lot of questions, and he used the TEAM meeting to clear up some things he didn't understand.

What happened at X's meeting that was really important was the TEAM finally heard him. His anxiety was palpable, and the educators saw it. When he asked to change the work team he was on, they agreed. They genuinely hadn't known that he was unhappy. When he spoke for himself I could see that everyone listened more intently than when his mother or I spoke. In my opinion, his participation helped to shift the way the school understood him.

A month later, we reconvened. X was there—as nervous as before, but he came.

Resources


Amanda N. Kelly, M.S.Ed, BCBA is currently the Coordinator of ABA Services for the SEEM Collaborative. She is a BCBA Mentor for Masters Degree students at Simmons College, an Adjunct Professor at Antioch University and is completing coursework for her Ph.D. in Applied Behavior Analysis from Simmons College.

Catherine Mayes is the parent of a young adult with AS, and an educational advocate in private practice, based in Southeastern Massachusetts. She also works part time at Mass Advocates for Children, and is Coordinator of Plymouth County Teen Programs for AANE under a generous grant from the Edwin Phillips Foundation. You can contact her at catherinesmayes@aol.com.
Help In Times of Need

Animals that help people in times of need can be spirit (guides or helpers).

When my leg was hurt, I saw a wolf in a zoo and felt connected to it when it stared at me. Later the creator healed me with the help of the wolf giving me some of its strength. When I looked back, I see that the wolf was really a hidden gift in disguise.

The wolf is a strong protector and guardian of its pack. It has many social standings just like us. It can be a teacher, a leader, family, a babysitter, and many more titles. People that we know and strangers that become friends that help us in times of need can also be spirit (guides or helpers).

When I was sick in the hospital, the creator healed me through the prayers of a priest that I knew and the prayers of all the parishes around. I have many friends that were strangers to me and I do not regret my past decisions.

By Allison Brody, in collaboration with David Harrington

Allison Brody is a second-year student enrolled in Chapel Haven’s Asperger Syndrome Adult Transition Program (ASAT) in New Haven, Conn. She is an English major at Southern Connecticut State University, where she is studying for a bachelor’s degree in creative writing with a specialization in poetry. She is originally from Hopewell Junction, New York. “I love the outdoors and animals. My goal is to work with animals. I also am figuring out how to publish my poetry,” Allison reports. She also reports that “Chapel Haven is a great place for social interaction.”

Sharleene Hurst exhibited in AANE’s 2007-2008 Seeing with a Different Eye touring exhibit. A self-taught artist, she is a member of the Newburyport, MA Art Association and the New Hampshire Art Association. She turned to art when she was a child as an escape from her struggles with rheumatoid arthritis, autism, and dyslexia. In the 1990s she served three terms in the NH State Legislature. She thinks of each of her paintings, whimsical blends of surrealism and the abstract, as being similar to a “mental vacation.” She also creates sculpture and jewelry. See: http://www.ebsqart.com/Artists/cmd_19405_profile_portfolio.htm.

Support AANE by purchasing a package of greeting cards featuring artwork by AANE member Gary Hudson.

Contact Kelly at: Kelly.Genois@aane.org or (617) 393-3824 x 20
**AANE Program Update: Children’s Services**

Jean Stern, M.Ed.
Director of Children’s Services
(617) 393-3824 x 308
Jean.Stern@aane.org

Summer workshop offerings include Making Daily Life Work At Home and Bike Riding 101 for parents of children with AS. Please note that when you are looking for summer camp options, they are now listed on the website at this link, [http://www.aane.org/asperger_resources/social_skills.php](http://www.aane.org/asperger_resources/social_skills.php). Monthly Topic Nights for parents will start up again in the fall along with the full array of new workshops. Our phones are open over the summer. We now have over 900 parents on our on-line support group. Please email Brenda Dater if you are interested in joining. Always feel free to contact us if you need assistance. Have a great summer.

Brenda Dater, MPH, MSW
Coordinator of Children’s Services
(617) 393-3824 x 311
Brenda.Dater@aane.org

AANE says goodbye to Caryn Meyers with a surprise wedding shower in celebration of her upcoming July 7 wedding before she leaves on sabatical for the summer.

**AANE Program Update: Adult Services**

Jamie Freed, MSW, Director of Adult Services
(617) 393-3824 x 24; Jamie.Freed@aane.org

Max Sederer, MAT, Adult Services Program Manager
(617) 393-3824 x 12; Max.Sederer@aane.org

Debbie Geheran, Coordinator of Adult Services
(617) 393-3824 x 25; Deborah.Geheran@aane.org

As we move from spring to summer, we will continue to offer numerous Social Groups: an ongoing Book Club, Speaker Series, and Anime Club, as well as a variety of Pizza and Game Nights and the return of the Hiking Group. We will once again be cheering on the Red Sox and gathering for our 4th Annual Conference for Adults with Asperger’s Syndrome and Related Conditions - Know Yourself: The Key to a Better Life 2010 with Keynote Speaker, Psychologist Nick Dubin, Psy.D.

Our support services continue to grow as well. Beyond the variety of open and closed in-person support services for our Adult Members, AANE now has well over 200 Parents of Adults on their Online Google Discussion Group. In addition, AANE is actively enrolling for Spouse Groups and Grandparent Groups.

The AANE’s LifeMAP (Life Management Assistance Program) has continued to expand the geographic area covered by coaches, now servicing Southern New Hampshire in addition to the Greater Boston, Central and Western Massachusetts regions.

We are also always looking to extend the scope of our Adult Services. We are developing a Worcester area Pizza and Game Night to add to our 4 other current locations covering the Eastern Massachusetts region. If you would like to contribute ideas toward future Adult Social Programming, please do not hesitate to contact AANE staff.

**Message from AANE’s Associate Director Robin Lurie-Meyerkopf**

Hi Everyone,

It has been a busy few months for me and AANE! Since January I have traveled to Rockport, ME; North Conway, Bedford, Manchester, Portsmouth, Atkinson and Farmington, NH; White River Junction and Bellows Falls, VT; Barrington, RI; Weston, Brookline, Newburyport, Hamilton/Wenham, Longmeadow, and Dorchester, MA. As you can see I get around. We also hosted a two day conference in Boston for professionals from high school and College called Asperger Academy. This was such a success that we held a one-day Asperger Academy for parents in the spring in Waltham, MA. These conferences help all of us learn the importance of preparing our AS students for college. Last summer we held our first Cape Cod Conference with Jed Baker. It was so popular that we have now planned our 2nd Cape Cod Conference. This time we are hosting Teresa Bolick Ph.D. and Nick Dubin Psy.D. To find out more or to register for this conference, please go to our website at [www.aane.org](http://www.aane.org). I also teach classes for the UNH continuing education department and enjoy these classes very much. I am looking forward to planning our next few months and am always ready to help families and adults in any way I can. I continue to enjoy my work here at AANE and hope that we are providing you and your loved ones with support and understanding.

Sincerely,
Robin Lurie-Meyerkopf
Associate Director AANE
work for several years at the Wellesley Cable Access Channel…
and guess what? I make game shows there! I’ve even done “Are
You Smarter Than A Fifth Grader?” I also applied for an internship
at WGBH – you know, PBS channel 2. My ultimate goal is to be
the producer of a game show on national television – and yes, I
said producer, not host. I’m strictly behind the scenes! The point
I’m trying to make is that special interests can lead to jobs doing
what you love! Despite all this, sometimes it’s OK to let people
with AS know that you’d like to talk about something else. I
can’t always pick up on what you’re thinking without you saying
anything, so if you don’t tell me directly, I’ll never know that you
don’t want to hear a lengthy review of everyone who’s hosted
“Family Feud.” I’ve heard people say that they’re uncomfortable
being direct, but it’s really what I need.

That leads me to the other S – Social Rules Are Hard. I have
a hard time adjusting to different places. I work at the Wellesley
Library, shelving the books. You’ve ever wondered who puts
the books back on the shelves after they’re returned? I’m one of
them. It’s pretty boring, but it’s a job.

While working at the library, I’ll sometimes run in to people
I know who have come into the library to check out a book.
When I see these people, I say hello to them, but I had to learn
to use a quiet “library” voice. If I didn’t learn that, I would
say “Hey, it’s you!” in the middle of the library, which is NOT a
good thing to do…certainly not when they pay you! You might
not think of how people talk to each other in terms of rules. I
have to – otherwise, I’d never do it.

That takes me to the first R – Rules Are Very Important To
Them. One story that sums up a lot about me and about AS was
when I was in middle school. Do you like eating lunch in the school
cafeteria? I sure didn’t. For starters, it was big and loud, but the
worst part was that every day, when lunch was over, the Assistant
Principal would stand up in front of everyone with a microphone
and dismiss each table one by one. When people starting getting up
without being dismissed, or when they talked over the teacher who
was trying to tell them to be quiet, it made me incredibly upset and
frustrated. The rules weren’t being followed, everyone was too loud
for me, and it just got to be too much.

In addition to rules being broken, this upset me in another
way. The first E is for Ears Hurt When Things Are Loud. That’s
true in my case, but for people with AS, it could be any sense
that bothers them – too much light, or smell, or a certain taste.
When things are too loud for me, it hurts me. To this day, when
I’m in the car and someone honks the horn, I’ll be startled
and say “What just happened?” Another example? When I
was writing this speech, I brought my laptop computer to a
Starbucks. I’d never be able to focus on writing at home, but it
wasn’t easy at Starbucks either. The people were chatting, there
was music in the background, and the coffee grinder would
start every few minutes and drive me crazy. You might not even
notice the coffee grinder. If you do notice it, it might be the only
sound you notice. I notice every thing. When I was in eighth
grade, I really had trouble with sensory input. I would
notice the school bell, the smell of the markers on the white board, the
voices of certain teachers…everything. I ended up having to put
my head down on the desk to completely block out visual input.
I still was listening, even if nobody knew it.

Of course, noticing everything can wear you out. The other E
is for Every Day Tries Very Hard. I used to come home from school and fall dead asleep, every day. It’s not that that day was unusual, it’s that it just took me an enormous amount of effort to get through a day at school without collapsing on the floor, completely unable to function. Things that are easy for a lot of people take extra effort for me. I had to take breaks in the middle of the day to keep myself going. If someone with AS asks if they can take a break, let them. It’s not about being unfair — they really need it.

How do I make it easier for me to get through a day? Routines. G is for Gets Mad When Routines Aren’t Followed. When I was a little younger, I would tell people — only partially joking — that I had an internal schedule that had to be followed. If something happened that didn’t match up to what I thought was going to happen that day, I would lose control. When I was in third grade, my teacher decided to team up with another teacher and play an April Fools joke. They would switch places for a day. They thought it would be funny, and I’m sure some kids thought it was. I didn’t think it was funny. When I walked in and saw a different teacher then the one I was used to, I ended up in tears, no matter how many times the assistant teacher explained that it was just an attempt at a joke. I must not have been the only kid who was crying, because by the end of the day, the teachers had gone back to their usual classes and apologized.

By now you’re probably wondering how I remember events that probably happened eighteen years ago. The second R is for Remembers Things Very Well. As I’ve said, I have a special interest in game shows. Well, I’ve come pretty close to memorizing who hosted every version of every game show ever made… and not just in America either! I just retain the information. That’s true for a lot of people with AS. I myself remember text better than pictures, but there are people whose memories are visual — they can remember every detail of what they’ve seen. I remember text really well, so I frequently can quote books. One of my favorite books of all time is The Hitchiker’s Guide To The Galaxy series by Douglas Adams. That might come close to being a second special interest — I’ve read the books, watched the TV show, listened to the radio show, read the comic books, saw the movie the day it came out, and so on. I think they’re hilarious, and frequently, when something happens that reminds me of a scene from The Hitchiker’s Guide, I’ll end up quoting chapter and verse. I could probably recite most of the episodes from beginning to end.

Finally, we come to A – Always Mean Well. I’ve talked about things that might sound annoying – crying during school, turning off the TV at a Super Bowl party, excessively quoting my favorite book, and so on. Well, I don’t mean to be rude by doing any of these things. I just don’t quite realize that people are annoyed by it. It helps me when people remind me that they don’t like what I’m doing, or understand that my brain just works differently. You might have experienced something like this at some point. Have you ever been in a place where it’s too loud? Have you ever started talking about something you like, only to realize that the person you’re talking to doesn’t care? Of course people without AS can have all these feelings and experiences — people with AS probably just have it to a greater degree. Thank you for listening, and I hope that you understand Asperger’s Syndrome a little better now.

Mental Health Parity Law (Continued from page 32)

♦ Massachusetts-licensed commercial health insurers.
♦ Blue Cross and Blue Shield of Massachusetts.
♦ Massachusetts-licensed HMOs.
♦ Small group health plans regulated by Massachusetts insurance authorities.
♦ Non-group health plans.
♦ Student health insurance (for higher educational institutions).

The following plans do not have to comply with this law:
♦ Self-insured employer group health plans.
♦ Large insurance companies not domiciled in Massachusetts.
♦ MassHealth.
♦ Medicare.

What is not covered by the parity law?

♦ Insurers are not required to cover mental health services for persons incarcerated in jail, prison, Department of Youth Service facilities, or other correctional settings.
♦ Insurers are not required to pay for those “educational services” that a school must provide as part of its special education program. However, if there is a medical component to a special education plan, the insurer should still pay for those services which are medically necessary.
♦ Insurers are not required to cover services provided by the Department of Mental Health.

Summary

While the mental health parity law offers some gains to the AS community, the law still has its limitations and requirements, which must be fully understood. For instance:

♦ The new Mental Health Parity Law will provide additional mental health counseling and treatment services for individuals who meet “biologically-based” definitions of mental disorders.
♦ The new law removes discriminatory caps, deductibles, and service delivery limitations, in order to bring “parity” to mental health service delivery.
♦ All mental health services and treatment provided must still meet the definition of “medically necessary” as defined by their health insurance company. Prior to receiving services, the client and provider need to make contact with the insurance company, describe symptoms, justify the need for services, agree on a treatment plan, obtain necessary referrals, and then receive approvals and authorization from the insurance company.
♦ Mental health professionals will need to provide additional information to the insurance company on a regular basis, to justify the continuation of on-going services.
♦ Families are well-advised to develop relationships with skilled mental health professionals who can not only provide quality services, but can also act as effective advocates who know how to secure mental health coverage and reimbursements for their clients.

Dave Harmon is a financial estate planner, AANE board member, and President Emeritus of the AANE Board of Directors.
In memory of Dr. Henry & Ms. Susan Abrams
Mark Abrams

In memory of Matthew Dandurand
Pattie Beitel
Lisa Fitzpatrick
Anonymous

In memory of Carolina & Antonio DeSpirito
Karen DeSpirito

In memory of Irene V. Galdston
Deborah Meringolo
Joan & Irwin Robinson
Mr. & Mrs. Kenneth Rothstein
Jack & Thelma Sahn
Helen Schectman
Anonymous
Anonymous
Anonymous

In memory of Irene Galdston,
beloved mother, grandmother, sister, cousin and very special woman.
She will be missed by all.
Carol & Stan Feingold & Family

In memory of and in honor of Irene Galdston
Stefi Rubin & Fred Marchant

In memory of Kenneth Gosting
Bill Barbour
Larry & Terry Comp
Marie Lane Hart & Dana Steinberg
Jean & Dick Kinder

In memory of Amelia C. Harrell
Marilyn M. Cage
John Kirvin

In memory of Charles Knaus
Robert Knaus

In memory of Leda Lurie
Robin Lurie-Meyerkopf & Richard Meyerkopf

In memory of John F. Mahoney, Sr.,
father of Joanne Flaherty
Fred Affsa
Doreen Affsa
Michael & Paula Connelly
Lauren Daley
Nancy & Clive Durose
Patricia Flaherty
John J. Hawkins
Alice D. Hickey
Ali Hickey
Judith A. Hickey
Arthur & Pat Hyder
Lauren M.
Ann L. Kennedy
Kate C. McDonough
Cheryl & Jack Nolet
Patricia & Tom Pannino
Bill & Mary Phelan
Quincey Retiree Association, Inc.
John & Mary Reardon
Eileen P. Riggs & Family
Henry & Kathy Russell
Anonymous

In memory of Selma Lee Markowitz
Martha Markowitz, Ph.D.

In memory of Cynthia Noonan
Darlene Atkinson
Nancy Lincoln
William & Jennifer Moeckel
Surendra & Reeta Mukerjee
Kristin Provencher

Carol Rocco
In loving memory of Cyndy
David Noonan

In memory of Alice (Hyland) Parker
of Springfield, MA
The Carrazza Family of Longmeadow, MA
Claire Cohen-Stelzer
The Flagship Dental Group
Beverly & Richard Fonner
Tim Kirchmann
Dan & Lisa Stevens

In memory of John Rekemeyer
Michael Cramer
Pete & Ellie Rekemeyer

In memory of Rene Soucy
Jean M. Cook
Thomas & Cheryl Eggware
Robert & Claire Gagnon
Florence R. Gagnon
Denise Gagnon & Joseph D’Arrigo
Michelle & Robert Gilmore
The Harling Family
Brian & Christine Harty
The Jacques Family
Jo Ann Meyer
Ed & Kathy Reinbold
Mr. & Mrs. Ed Sadoway
Lauren West

In loving memory of Mrs. Lillian M. Stone
of Little Neck Road, Ipswich, MA
Sandra R. Nightingale

In memory of Eileen Torchio
Stephen Knudsen

Harry & Mary Lou Allen, in honor of Virginia Allen
David Barach, in honor of moi, and all that the AANE has done to help me figure it out, and get to the point where I can educate & inspire others...

Susie & Don Beck,
in honor of Yvonne & Larry Bright
Fred Berman, in honor of Dania’s excellent presentation at the Cambridge Homeless Services Planning Committee
In honor of Suzanne & James Borstein
In honor of the Camilli Family
Caroline Cusolito, in honor of Alyssa Casey -- Happy 13th birthday!
In honor of Evan Chomas
Lee & Bob Dixon, in honor of Margs Dixon
In honor of Soussan Djamashi, Ph.D.
In honor of The Donovan Family
Erika Dreznier, in honor of Stephanie Loo
John & Beverly Folz, in recognition of Carla & Hans Brigham
In honor of Jeff & Laurie Lasky
General Catalyst Partners, in honor of Steve Levy
Michael & Kristin Goldberg, in appreciation of the efforts of Carynn Meyers
Leslie & Jim Goodwin, in honor of Colleen Deluski,
Heidi Brousseau, Abby Williams, Donna Hartmann & Nancy Morrissette (our children’s teachers)

Cindy Hodgdon, in honor of Gina Gallagher
Nomi Kaim, in honor of Dania, Jamie, and all the extraordinary staff of AANE, for their generosity, compassion, patience, profound understanding and inclusiveness. You have given me the greatest gift of all: a place where I can genuinely belong. Thank you!
Beth Kaufman & Brad Kramer, in honor of Jillian Hansbury & Jennifer Buller, teachers at the Heath School in Brookline, MA
Tim, Patti, Ian, Owen & Emily Law, in honor of the staff at AANE who helped our family in a crisis of understanding what was happening and what we were facing. We were very lucky to have AANE when we needed you all.
In honor of Craig Levine
David Lax & Ilana Manolson, in honor of Bill & Susan Maxfield
Irving Lesnick, in honor of Grace Myhill’s birthday & Jake Myhill’s high school graduation
Kayla Littlejohn, in God’s name for the cause of Asperger’s Syndrome
Miriam & John Macht, in honor of Stephanie Loo for being so helpful to our family whenever we call her
Andrea P. McCullough, on behalf of all children with Asperger’s
Mary McFadden & Larry Stifler, in honor of Eva Bach Mendes who volunteers to run groups for significant others in the Boston area.
In honor of Heather Milligan & Family
Abbe & Anthony J. Morrongiello, in honor of Sam Zarzoor
Ben A. Nap, in honor of Doug & Judy Labs
Ben & Joanne Niedermeyer, in honor of Steve Edelstein & Grace Peng
Terese Pawletko, Ph.D., in honor of the fine work AANE does in the Boston area.
In honor of the occasion of his Bar Mitzvah
Grace Potts, in honor of Jamie Maxfield

Ed & Sheila Rogers, in honor of Jean & Lew Stern, two of our favorite people on the planet
Jan Saglio & Ken Galdston, in honor of the AANE staff
In honor of Laurene Smith
Brendan J. Swords, in honor of Ben Perelmuter, who recently celebrated his bar mitzvah
Sandy & Rick Thau, in honor of Ruth Levine Arnold
In honor of Leslie Treadwell & Family
Patricia Varon, in celebration of Isaac’s 26 birthday!
Rose Weinstock, in honor of Jamie Freed
Benaree Wiley, in honor of Shannah Varon
Elsa Abele, CCC-SLP
A HEARTFELT THANK YOU to ALL OUR GENEROUS DONORS!
A HEARTFELT THANK YOU TO ALL OUR GENEROUS DONORS!

Education, Foxborough Regional Charter School
Karen Ratkovits
Donald Reczek
Marcia, Ralph & Michael Regner
Lori Reinbold
Heidi & George Remy
Ellen & Mark Renadette
John & Jean Rich
Frank Robbins
Susan Roberts & Andrew MacKinnon
William Robinette
Elizabeth Rogers
Richard Romaine -- Romaine’s of Northborough
Nancy Roney
Dr. Allan Rooney
Bruce Rose
Paul Rosenberg
Dr. Daniel W. Roseann & Dr. Barbara H. Roseann
Judith Roth
Daniel Brett Rounsaville
Karen Rowe
Julie Ryan
Anna Sarno Ryan, M.D.
Lisa Sabacinski
John Sabino
Nancy Saltsky
Ofra Sarid-Segal
Tracey Savage
Antionette & Nina Scavone
Randy Schacht
Andrea Scheidler
Julia Schneiderman & John Wiswall
Phyllis Schultz & Matt Gromet
Peter & Estelle Schuntermann, M.D.
John Scullane
Ronald & Patricia Seeley
Charles & Eleanor Selig
Susan & Barry Shamus
Ruth Sharpe & Roy Bellush
Lila Shayan
Kathleen Sherman
Suzette Shilts
Peter & Jennifer Shor
Eleanor G. Shore
Penny and Don Shukan
Side by Side Supported Living, Inc.
Bill & Barbara Sikes
Richard Silverman
Mr. & Mrs. Herbert Simons
Tim Sindelar
Carol Singer
Henry Skillman
Polly Slavet
Jonathan & Monica Small
Ruth Smith
Daryl Smith
Jan Snitzer
Michael & Cara Snyder
Bozena Sobiech
Amy and Jeff Socolow
Rob Sokolove
Marc Solomon
Douglas Sondak
Nancy Sonnabend
Stephen Sonnabend
Carol Spofford
Katherine Spencer-Molloy
Sarah Stahl
Linda Stanley
Julia Steed Mason
Susie & Mike Steinberg
Harvey Steinberg
Marcia Stern
The Stillman Family
R. Newcomb Stillwell
Carol Stone
Brenda & Greg Stone
Sandra Storer
Barbara Stromsted
Marcy & David Stuart
David & Jame Sugar
Mary Tadda
Beth Taplack
Annalisa Tidball
Susan Taylor
The Taylor Family, Danville, NH
Andrea Tepper
Pamela Tetreau
Matthew Therien
Elizabeth Thissell Turenne
Susan and Rich Thompson
Elaine & Arnold Trehube
The Tudor Foundation
Alison Uretskey
Judith Ursitti, CPA
Peter Valberg
Shannah L. Varon
Michael Varteresian
Maureen Vautraun
Susan Vecchi
Sangeeta Verma
Michele Visconti
Mary & Peter Volpe
Amy Voorhes & Selwyn Notelovitz
Peter Wadsworth
David & Carol Wagner
Wendy Wagner
Crystal Walters
Thomas & Christine Warger
Robert M. Washburn
Bill & Cyndi Webber
Kim Weeber
Amy Weinstock
Shelby Weitzel
Sara Werder
Jane Whelen Banks
Betty & Jim Wickis
Nicola & Curtis Wilbar
Michael Wilcox
Richard & Phyllis Wilker
Alice H. Williams
Margaret Wilson
Debbie & David Winnick
Alan Winnick
Barbara Wirth
Paul Witham
Irene Witt
Janice M. Wolpert
Charles G. Wright Endowment for the Humanities
Paul Yamartino
Laura Yellen, Massasoit Community College, Helping Hands Club
Carolyn Young
Paul Yu

THANK YOU TO OUR DEDICATED VOLUNTEERS & COMMITTEE MEMBERS!

Elsa Abele
Jody Acford
Mary Ann Ascione
Matthew Arnold
Eric Aron
Margarita Ascione
Jill Avery
Veronica Bacon
Alma Bair
Gina Beaney
Mary Berman
Lucy Berringer
Nancy Berringer
Julie Bettis
Miriam Biuri Scriver
Patty Boornazian-Macdonald
Sue Brooks
Megan Burgay
Edith Burns
Maria Carrasco
Lorraine Cavallo
Natalie Charles
Kathy Clark
Kathryn Collins-Wooley
Deb Connerty
Fred Conrad
Eileen Costello, M.D.
Jennifer Cronin
Sangeeta Dey, Psy.D.
Supriya Dey, Psy.D.
Sara Diaz
Michael Duffy
Rachel Duffy
Carol Ann Edwards
Alex Eustice
Cathy Falcione
Dennis Feigen
Lisa Flagen-Shay
Erin Flaherty
Lynn Flaherty
William Flaherty
Sam Frank
Betzaida Fuentez
Cindy Gallant
Steven Garfinkle
Elishe Ghitelman
Bonnie Glickman
Maria Gomez
Judy Goon, MS, OTR/L
Shelley Green
Cynthia Greene
Phyllis Greene
Danny Gromet
Ann Marie Gross
Dan Gross
Ashley Harmon

Association of New York State
Ann McLaughlin
Kathleen McLeive
Rachel Medrek
Laura Messersmith
Roger M. Meyers, “...of a different mind” Consulting Service
Marilyn Micco
Debbie Mikels
Diane Mikush
Diane & Douglas Miller
Melinda Miller
Fiona Miller
Cyrus Miller
William Miller
The Mills Brothers
Douglas Milne
Celia Moore
David Morf
Todd Moss, Turner Construction Company
Mary & Bob Murphy
Philip Murphy
Alyson & Peter Muzila
Jennifer Nash & Don Bronstein
Donna Neely
Virginia News
Paul Newhall
Janice Newman
Roseann Nickerson
Laura Nordstrom
Graeme Noseworthy
Genevieve Novo
Mary O’Brien
Joanne O’Connell
Kevin Brian Offer
Old friend of a parent whose son has Asperger’s
Marlene & Michael Olin
Anne-Marie O’Neill
Daniel L. Ouellette
Ann & Paul Padden
Michael and Luke Palmer
Saul Pannell
Jan Patton
Nancy Pearlman
Doris Peckner
Jennifer Peebles
Christopher Peltier
Grace Peng
John Pepe
Sue Pepper
Stephen Perkins
Helen Perone
Bruce Phillips
Suzanne Phillips
Marianne Phinney-Liapis
Kevin Plummer
Jenny Pollak
Mr. David M. Pollak & Dr. Emelia J. Benjamin
Marion Pollock
James Poulos
Carolyn Powell
Alan Price
Mary Beth Prosnitz
Susan Pursell
Cara Rachlin
Daniel Rahil
Susan Rascol, Director of Special

Thank You to our GeneRous Donors!

Paul Yu
Paul Yamartino
Charles G. Wright Endowment for the Humanities
Janice M. Wolverton
Irene Witt
Paul Witham
Barbara Wirth
Alan Winnick
Debbie & David Winnick
Margaret Wilson
Debbie & David Winnick
Alan Winnick
Barbara Wirth
Paul Witham
Irene Witt
Janice M. Wolpert
Charles G. Wright Endowment for the Humanities
Paul Yamartino
Laura Yellen, Massasoit Community College, Helping Hands Club
Carolyn Young
Paul Yu

THANK YOU TO OUR DEDICATED VOLUNTEERS & COMMITTEE MEMBERS!

Elsa Abele
Jody Acford
Mary Ann Ascione
Matthew Arnold
Eric Aron
Margarita Ascione
Jill Avery
Veronica Bacon
Alma Bair
Gina Beaney
Mary Berman
Lucy Berringer
Nancy Berringer
Julie Bettis
Miriam Biuri Scriver
Patty Boornazian-Macdonald
Sue Brooks
Megan Burgay
Edith Burns
Maria Carrasco
Lorraine Cavallo
Natalie Charles
Kathy Clark
Kathryn Collins-Wooley
Deb Connerty
Fred Conrad
Eileen Costello, M.D.
Jennifer Cronin
Sangeeta Dey, Psy.D.
Supriya Dey, Psy.D.
Sara Diaz
Michael Duffy
Rachel Duffy
Carol Ann Edwards
Alex Eustice
Cathy Falcione
Dennis Feigen
Lisa Flagen-Shay
Erin Flaherty
Lynn Flaherty
William Flaherty
Sam Frank
Betzaida Fuentez
Cindy Gallant
Steven Garfinkle
Elishe Ghitelman
Bonnie Glickman
Maria Gomez
Judy Goon, MS, OTR/L
Shelley Green
Cynthia Greene
Phyllis Greene
Danny Gromet
Ann Marie Gross
Dan Gross
Ashley Harmon

Association of New York State
Ann McLaughlin
Kathleen McLeive
Rachel Medrek
Laura Messersmith
Roger M. Meyers, “...of a different mind” Consulting Service
Marilyn Micco
Debbie Mikels
Diane Mikush
Diane & Douglas Miller
Melinda Miller
Fiona Miller
Cyrus Miller
William Miller
The Mills Brothers
Douglas Milne
Celia Moore
David Morf
Todd Moss, Turner Construction Company
Mary & Bob Murphy
Philip Murphy
Alyson & Peter Muzila
Jennifer Nash & Don Bronstein
Donna Neely
Virginia News
Paul Newhall
Janice Newman
Roseann Nickerson
Laura Nordstrom
Graeme Noseworthy
Genevieve Novo
Mary O’Brien
Joanne O’Connell
Kevin Brian Offer
Old friend of a parent whose son has Asperger’s
Marlene & Michael Olin
Anne-Marie O’Neill
Daniel L. Ouellette
Ann & Paul Padden
Michael and Luke Palmer
Saul Pannell
Jan Patton
Nancy Pearlman
Doris Peckner
Jennifer Peebles
Christopher Peltier
Grace Peng
John Pepe
Sue Pepper
Stephen Perkins
Helen Perone
Bruce Phillips
Suzanne Phillips
Marianne Phinney-Liapis
Kevin Plummer
Jenny Pollak
Mr. David M. Pollak & Dr. Emelia J. Benjamin
Marion Pollock
James Poulos
Carolyn Powell
Alan Price
Mary Beth Prosnitz
Susan Pursell
Cara Rachlin
Daniel Rahil
Susan Rascol, Director of Special
**Thank You to Our Dedicated Volunteers & Committee Members!**

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elaine Harmon</td>
<td>Murray Ostrov</td>
</tr>
<tr>
<td>Christopher Hayes</td>
<td>Grace Peng</td>
</tr>
<tr>
<td>Ann Holzman</td>
<td>Fran Perlman</td>
</tr>
<tr>
<td>Trish Huff</td>
<td>Kathleen Pigott</td>
</tr>
<tr>
<td>Barbara Ives</td>
<td>Jill Purpura</td>
</tr>
<tr>
<td>Kathryn Jantz, MSW</td>
<td>Steve Purpura</td>
</tr>
<tr>
<td>Connie Johnson</td>
<td>Katrinka Quirk</td>
</tr>
<tr>
<td>Eileen Johnson</td>
<td>Taylor Raftery</td>
</tr>
<tr>
<td>Nomi Kaim</td>
<td>Charlie Remy, MLSIS</td>
</tr>
<tr>
<td>Lucy Keeney</td>
<td>Chris Robbins</td>
</tr>
<tr>
<td>Robin Keller</td>
<td>Judy Robinson</td>
</tr>
<tr>
<td>Abram Kelly</td>
<td>Vivian Rodriguez</td>
</tr>
<tr>
<td>Cindy Kelson</td>
<td>Daniel Rosenn, M.D.</td>
</tr>
<tr>
<td>Mike Kingsbury</td>
<td>Barbara Rosenn, Psy.D.</td>
</tr>
<tr>
<td>Jodi Kipnis</td>
<td>Anna Ryan</td>
</tr>
<tr>
<td>Peggy Kriss</td>
<td>Janet Saglio</td>
</tr>
<tr>
<td>Karen Lean Boyd</td>
<td>Allison Sargent</td>
</tr>
<tr>
<td>Belinda Lee</td>
<td>Julie Savoyski</td>
</tr>
<tr>
<td>Elizabeth Leonard, M.D.</td>
<td>Jodi Scaltreto</td>
</tr>
<tr>
<td>Anna Lert</td>
<td>Curt Schilling</td>
</tr>
<tr>
<td>Lesley Levine</td>
<td>Shonda Schilling</td>
</tr>
<tr>
<td>Toby Liebowitz</td>
<td>Robert Schmidt</td>
</tr>
<tr>
<td>Gerrick Lindberg</td>
<td>Nancy Schwartz, MSW</td>
</tr>
<tr>
<td>Alexander Link</td>
<td>Phil Schwarz</td>
</tr>
<tr>
<td>Larry Link</td>
<td>Marci Shaffer</td>
</tr>
<tr>
<td>Lisa Lokshin</td>
<td>Eric Shamus</td>
</tr>
<tr>
<td>Dorothy Lucci, CAGS</td>
<td>Susan Shamus</td>
</tr>
<tr>
<td>Mike MacIntosh</td>
<td>Stephen Shore, Ed.D.</td>
</tr>
<tr>
<td>James Maguran</td>
<td>Carol Singer</td>
</tr>
<tr>
<td>Diego Mansilla</td>
<td>Ruth Smith</td>
</tr>
<tr>
<td>Adam Markell</td>
<td>Thomas Smithyman</td>
</tr>
<tr>
<td>Martha Markowitz, Ph.D.</td>
<td>Steve Snitzer</td>
</tr>
<tr>
<td>Bill Maxfield</td>
<td>Audra Socinski</td>
</tr>
<tr>
<td>Jamie Maxfield</td>
<td>Jenny Solomon</td>
</tr>
<tr>
<td>Stephanie Maze-Hsu</td>
<td>Nancy Somnabend</td>
</tr>
<tr>
<td>Diane McGrath</td>
<td>Eric Stern</td>
</tr>
<tr>
<td>Elizabeth McLaughlin</td>
<td>Llew Stern</td>
</tr>
<tr>
<td>D. Scott McLeod, Ph.D.</td>
<td>Elizabeth Stringer Keele</td>
</tr>
<tr>
<td>Bonnie McManus</td>
<td>Dave Stuart</td>
</tr>
<tr>
<td>Dan McManus</td>
<td>Marcy Stuart</td>
</tr>
<tr>
<td>Carolyn Meadows Marquez</td>
<td>Helen Tager-Plusberg</td>
</tr>
<tr>
<td>Eva Mendes</td>
<td>Krsyss Tarara</td>
</tr>
<tr>
<td>Jane Mildred</td>
<td>Dan Tatar</td>
</tr>
<tr>
<td>Melinda Miller</td>
<td>Mike Thibodeau</td>
</tr>
<tr>
<td>Nasha Miller</td>
<td>Adrianne Tompkins</td>
</tr>
<tr>
<td>Lynne Mitchell</td>
<td>Suzanne Tompkins</td>
</tr>
<tr>
<td>Joe Moldover</td>
<td>Linda Van Duyne</td>
</tr>
<tr>
<td>Tony Monteiro</td>
<td>Shannah Varon, MBA</td>
</tr>
<tr>
<td>Alessandra Morceo</td>
<td>David Velten</td>
</tr>
<tr>
<td>Coleen Motyl-Szary</td>
<td>Sangeeta Verma</td>
</tr>
<tr>
<td>Monique Myers</td>
<td>Shelley Viles</td>
</tr>
<tr>
<td>Grace Myhill</td>
<td>Richard Villavicencio</td>
</tr>
<tr>
<td>Nisha Narvekar</td>
<td>Rick Walba</td>
</tr>
<tr>
<td>Allison Nevins</td>
<td>Brianna Welcome</td>
</tr>
<tr>
<td>Erin O’Malley</td>
<td>Barbara Whalen</td>
</tr>
<tr>
<td>Ginger O’Malley</td>
<td>MaryEllen Williams</td>
</tr>
<tr>
<td>Maura O’Malley</td>
<td>Niki Wilson</td>
</tr>
<tr>
<td>Meghan O’Malley</td>
<td>Janet Yedinak</td>
</tr>
</tbody>
</table>

**AANE Board of Directors**

Nancy Schwartz, MSW, President  
Phil Schwarz, SB Vice President  
Ann Marie Gross, BA Secretary  
Jan Saglio, MA, Treasurer  
Jody Acorf, Esq.  
Lucy Berrington  
Sangeeta Dey, Psy.D.  
Steven Garfinkle, MA  
Judy Gooen, MS, OTR/L  
Dave Harmon, MSW, MBA, CLU, ChFC  
Dorothy Lucci, M.Ed., C.A.G.S.  
Elizabeth McLaughlin, Esq.  
Scott McLeod, Ph.D.  
Melinda Miller  
Grace Peng, BS  
Janet Price, M.Ed.  
Barbara Rosenn, Psy.D.  
Daniel Rosen, MD  
Susan Shamus  
Ken Shulman, Esq.  
Shannah Varon, MBA  
Michael Forbes Wilcox, MA  
Hank Miller, President Emeritus  
Stephen Shore, Ed.D., President Emeritus

**AANE Staff**

Dania Jekel, MSW, Executive Director  
Robin Lurie-Meyerkopf, M.Ed., Associate Director  
Diane Burke, Controller  
Kelly Genois,  
Director of Fundraising  
Jean Stern, M.Ed.,  
Director of Children’s Services  
Brenda Dater, MSW,  
Coordinator of Children’s Services  
Yolanda Kolinski,  
Director de Programas para la Comunidad Latina  
Stephanie Loo, M.Ed.,  
Director of Teen Services,  
AANE Journal Editor, Grantwriter  
Erika Drezner, MSW,  
Coordinator of Teen Services  
Catherine Mayes, Coordinator of Plymouth County Teen Services  
Jamie Freed, MSW,  
Director of Adult Services  
Max Sederer, MAT,  
Adult Services Program Manager  
Debby Geheran,  
Coordinator of Adult Services  
Gail Kastorf, M.Ed.,  
Vocational Trainer  
Nataliya Poto,  
LifeMAP Program Manager  
Nisha Narvekar, LifeMAP Intern  
Eva Mendes, Intern  
Audra Socinski, Intern  
Brianna Welcome, Intern  
Lisa Graffeo, Administrator  
Carynn Meyers,  
Administrative Assistant,  
AANE Journal Production Editor  
Mary Ann Medlar,  
Database Manager  
Steve Snitzer, Moderator of Parents of Adults Online Group  
Matt Conrad, Web Master  
Bekan Knox, Packet Coordinator  
Ynn Flaherty,  
Family Grants Administrator  
Erin Flaherty, Special Projects  
Grace Myhill, Spouse Services  
Mary Ann Monheimer,  
Spouse Services

---

We extend our sympathies to New Hampshire member Jodi Scaltreto and her family on the passing of her father, Joseph Scaltreto, in May.

We would also like to take this time to give special thanks to Jodi, who has served as our thank you letter volunteer for the past three years. Jodi’s dedication to the vital task of writing the thousands of thank you letters for new memberships, renewals, and donations is unmatched, and very much appreciated by AANE!

We offer our condolences to the Schwartz-Levinger family on the passing of their family member Jerome Lavin.

Thank you to Barbara Ives for her years of volunteering as co-Director of AANE’s Maine Chapter.
AANE Celebrates St. Patrick’s Day with Traditional Irish Music

On a Saturday afternoon in March, in celebration of Saint Patrick’s Day, a group of musicians gathered at AANE’s Watertown office to entertain over 50 members of our community with traditional Irish music. There were the recognizable guitar and flute; plus the more unique Celtic harp; the bodhrán, or Irish frame drum; and the bones, which are two animal bones or carved pieces of wood that click together rhythmically when played. Many thanks to the talented Gary Hudson, Kevin McDermott, Moira Kelly, and Bill Perry!

In addition to performing, Gary Hudson is a maker of flutes and bodhráns, and has shown his instruments at AANE’s Seeing with a Different Eye touring art exhibit.

Martha Garcia, a twelve year old with AS, was inspired to draw this enchanting picture while listening to and observing the Irish musicians.
Asperger’s Association of New England
85 Main Street, Suite 101
Watertown, MA 02472-4409
www.aane.org

Changing Perspectives, Changing Lives

Asperger's Association of New England
85 Main Street, Suite 101
Watertown, MA 02472-4409
www.aane.org

Changing Perspectives, Changing Lives

AANE’s Annual Fall Conference
for Parents, Educators, Professionals, & Adults with AS
Asperger Syndrome Connections
September 24 & 25, 2010
8:30 am - 4:30 pm

Keynote Speakers:
♦ Dr. Eileen Costello, pediatrician and co-author of
Quirky Kids: Understanding and Helping Your Child Who Doesn’t Fit In - When to Worry and When Not to Worry
♦ Scott Michael Robertson, Vice President of the Autistic Self Advocacy Network, and adult on the autism spectrum
♦ Dr. Ami Klin, Director of the Autism Program at Yale University School of Medicine, author, and researcher
♦ Jason Katims, Executive Producer of “Parenthood”, a popular TV show portraying a child with AS, and father of a teenage son with AS

~ Plus 50 workshops over two days ~

Regis College
235 Wellesley Street
Weston, MA

AANE’s Fourth Annual
Adult Conference
for Adults with AS & Related Conditions
Know Yourself: The Key to a Better Life
July 31, 2010
9:00 - 5:50
Northeastern University
360 Huntington Avenue
Boston, MA 02115

Keynote Speaker:
Nick Dubin, PsyD

AANE’s Second Annual
Cape Cod Summer Conference
for Educators, Professionals, & Parents
Supporting & Empowering Young People with AS
Thursday, July 29, 2010
8:00am - 4:30pm
Cape Codder Resort & Spa
1225 Lyanough Road
Route 132 & Beane’s Way
Hyannis, MA

Teresa Bolick, PhD
Nick Dubin, PsyD

Get up-to-date information on all of AANE’s upcoming events, and register online at a discounted rate at:
http://www.aane.org/upcoming_events/aane_event_list.html.