THE VAC SHACK
Evan, St. Louis
Autism Awareness Day
April 14, 2011

Two AANE members, Michael Wilcox and Elizabeth Avery, spoke at the Massachusetts State House for this year’s Autism Awareness Day program. Please see the facing page for Michael’s inspiring speech.

AANE Educator/Professional Training

Training educators and other professionals is one of the most important services AANE can provide to help children, teens, and adults with Asperger Syndrome. Many educators and professionals attend AANE conferences, but that’s not the only way to tap into our expertise.

Did you know that:

• AANE’s Director of Training, Robin Lurie-Meyerkopf, M.Ed. and AANE Consultant and Trainer Jean Stern, MS, have conducted trainings at schools and conferences all over New England.
• Brenda Date, MSW MPH, our Director of Children’s Services, is conducting trainings for museum educators at the Museum of Science, the Children’s Museum, and the Museum of Fine Arts.
• AANE Executive Director Dania Jekel, MSW and our Adult Services Staff also conduct trainings for professionals at colleges, mental health clinics, hospitals, and police departments.

We got a special training opportunity last summer, when the Massachusetts Department of Elementary and Secondary Education selected AANE to present an intensive summer institute on “Meeting the Academic and Non-Academic Needs of Students with Asperger Syndrome.” Thirty-two public school educators from across Massachusetts gathered at Assumption College in Worcester for four days in August, for an intensive program designed and led by Robin and Jean. Institute participants learned through presentations by Robin and Jean and three guest speakers, through reading, homework assignments, videos, group discussion, and in-class exercises. Guest speakers included an adult with Asperger Syndrome, pediatrician Eileen Costello, and Bonnie Glickman, M.Ed., M.Sc.

All participants started work on culminating projects designed to put their new learning to work in service of their students and school communities. Institute participants also attended one day of Asperger Connections 2010. Later in the fall, they gathered again at Assumption College in October to share their final projects with one another. AANE is applying to offer a 2011 Summer Institute. Interested Massachusetts public school educators please contact Robin.Lurie-Meyerkopf@aane.org.

• Children and teens with Asperger Syndrome can be challenging to teach and parent.
• Adults with AS can offer challenges to college personnel, vocational/rehab counselors, employers, mental health professionals, and first-responders.

Does your staff need an on-site training or a professional development workshop? Do your clients need a workshop on living successfully with Asperger Syndrome?

To discuss the specific needs of your school, agency or clients, please contact Robin.Lurie-meyerkopf@AANE.org at 617-393-3824 x 11.
Michael Forbes Wilcox
April 14, 2011
You’ve Got to Have A Dream!
If you don’t have a dream
How you gonna have a dream come true?
Words to live by, from the song “Happy Talk” Rodgers and Hammerstein’s South Pacific.

I am delighted to be here today to represent the Massachusetts Special Commission Relative to Autism. Part of our job is to dream. The rest of it is just hard work. The Commission was created by the Legislature, and the 31 Commissioners were all appointed by Governor Deval Patrick.

The Commission is charged with reviewing all services offered to autistic individuals living in the Commonwealth that are provided, regulated, or funded by state agencies. The Commission will produce a report to the Governor and the Legislature, in September, which will summarize its findings and make recommendations for improvements. Some of these changes may be possible to implement by Executive Order; others may require legislation.

The Commission is relying on four subcommittees to do research on specific topics. The membership of these subcommittees is drawn from the wider autism community, and reflects the diverse interests of this broad community. In the same way that the Commission is composed, members of the subcommittees represent autistic individuals, parents, family members, educators, legislators, state agencies, clinicians, and other advocates.

The subcommittees are working groups that will meet and work together to produce reports on their respective areas of focus. They will deliver these reports to the Commission for review and possible inclusion in the Commission’s final report.

The four subcommittees are focused on four different age groups, including the period of transition from school to adulthood: Birth through age 5, School Age, Transition, Adult.

Meetings of both the Commission and the Subcommittees are open to the public, and you are encouraged to attend.

We have an expression in the self-advocacy community; “Nothing about us without us!” I was eager to be a member of this Commission because I wanted to add the perspective, and the voice, of an autistic person. I want to do whatever I can, both on the Commission, and as part of my autism self-advocacy in general, to make life just a little bit easier for those who come after me than it has been for me. This is the same dream that I believe all the members of the Commission and the Subcommittees share: to make this Commonwealth a better place to live for autistic individuals, and therefore for all of us, and for everyone who lives in our community.

The variety of organizations represented both on the Commission and here in this room today is evidence of how we all recognize that we are all in this together. Autism comes in a variety of flavors. In fact, there are so many forms of autism that it may not be obvious to that proverbial anthropologist from Mars just exactly what it is that we all have in common.

Some of us, like Elizabeth and me, will be able to stand up in a room in the State House and tell you what it’s like to live as a stranger in a strange land. Others of us will never be able to do this.

Yet, the neurology of our condition is such that there is much that joins autistics in common cause. What we share is more important than what makes us different from each other.

We all suffer (and I use that word advisedly) from sensory overload issues. We all face enormous challenges when it comes time for transitions, whether it be in moving from one part of the day to the next, or in moving on to the next phase of our lives. We all share the frustrations of living in an alien world, as we try to achieve our own aspirations, whether those aspirations involve simply getting from one end of the day to the other, or in achieving some cherished life goal.

We all take pride where we can find pride. We all endure suffering when we must. We all struggle as best we can. We all rejoice over our accomplishments, both big and small. We are all unique. There is no way to compare the subjective experience of one person with that of another.

I thank you all for being here today to support me and to support the dream and the work of the Commission. I want nothing more, and nothing less, than to see that future generations of autistic individuals do not have to endure quite as much agony as I did in my time. I had to learn, through trial and error, how to get by in this incomprehensible world. We can, and we MUST do a better job of providing support for autistic people and to those who care for them.

Again, thank you for being here, to share in this dream. Because,

You’ve Got to Have A Dream!
If you don’t have a dream
How you gonna have a dream come true?

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**New Anti-Bullying Law in Massachusetts**

By Mary-Ann McCabe

**co-ordinator of children’s services**

MaryAnn.McCabe@aane.org

Research has shown that children with disabilities are two to three times more likely to be targets of bullying than non-disabled peers. The new Anti-Bullying Law in Massachusetts requires that school districts address bullying in a student’s IEP if the team determines that the student needs additional support to develop the ability to avoid and respond to bullying beyond the school-wide programs. There is a lot more information on the new law at [www.doe.mass.edu/bullying](http://www.doe.mass.edu/bullying), but here’s a quick overview:

- Districts around the state are required to inform parents about their new Bully and Intervention Plan.
- Familiarize yourself with your local school district’s anti-bullying plan. What curricula are they using? How are the students introduced to these curricula? Make an effort to attend an information session, or view the plan on your school district’s website.
- The new law specifically requires teams to address bullying in the IEP for all students with Autism Spectrum Disorders (AS included), because of their disability it is a disability affecting social skills. There must be a team member who is knowledgeable about the anti-bullying curriculum when discussed at a meeting. The specific areas of the IEP where bullying can be addressed are:
  a. Parent concerns/vision statement
  b. Present levels of performance
  c. Goals and measurable short-term objectives
  d. Accommodations
  e. Special ed. and related services (service delivery grid)
  f. Extracurricular and nonacademic activities
  g. Transportation

Examples of provisions for these areas can be found at [www.doe.mass.edu/bullying/considerations-bully.html](http://www.doe.mass.edu/bullying/considerations-bully.html).

The team should also consider whether there might be a need for specialized training or consultation for staff working with a student.

Maintain a written log of all incidents. Meet with leadership and teachers to discuss concerns. Communicate concerns with school district in writing.

Students can be vulnerable as targets and/or as aggressors because of the unique needs resulting from their disability. Fortunately, this new Massachusetts law recognizes these issues. It is now up to us as parents, and advocates for our children, to work with the schools to ensure that this new law is implemented properly, to ensure a safe school environment for all students.


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**The Bits and Pieces**

by: Natalie Weaver

I can look inside myself, and not understand what it is I see; but, all of it, the bits and pieces, the confusion, it’s all me.

For artwork by Natalie Weaver, please see p. 19. For another poem, see p. 11.
Dear AANE Members and Donors,

This spring has been a time to celebrate many milestones for people in our ever growing and evolving community, including a birth, a wedding, and many graduations. Throughout this issue of the AANE Journal we offer you inspiring speeches from our spring Gala, striking visual images, some poetry, and many hopeful stories from the lives of adults with AS—starting with the story of Evan, whose picture graces the cover.

From an early age, Evan had a intense special interest in vacuum cleaners, and his mother took him all over the country to attend vacuum cleaner conventions. Recently, his mother reported:

Evan is doing really well. About a month ago, he moved himself to a small town outside of St. Louis where he has a couple of friends from the Vacuum Cleaner Collectors Club. One of them was selling his vacuum cleaner shop and Evan stepped right in. He is now a business owner, is doing ordering, sales and repairs, and is loving being his own boss.

Congratulations, Evan! What a great reminder of how important it is for people on the spectrum to develop their strengths and interests as essential ingredients of a successful life.

We are delighted to announce that our October 14-15 Asperger Connections 2011 conference in Marlborough will once again feature “Seeing with a Different Eye,” a juried exhibit of work by our own adult artists. Congratulations to past AANE exhibitor John Williams, whose artwork appeared on the cover of last fall’s issue of the Folk Art Messenger, published by the Folk Art Society of America. John is now represented by the Outsider Folk Art Gallery in Reading, PA, and exhibited some of his work at the Outsider Art Fair in New York City in February.

We also hope to mount some art exhibits in our beautiful and spacious new office, which has a lot of freshly painted wall space. The new office includes a library corner with comfy chairs, a sunny conference room, and a large new Training Center for parent workshops, adult social activities, and professional trainings. We are still right near Watertown Square, close to many bus lines, and have plentiful free parking.

For the past two years, we have been very fortunate to have Kelly Genois as our Director of Fundraising. Kelly is leaving in order to begin her graduate studies in scriptwriting at the Boston University School of Communications. We will miss her, we wish her every success.

We are also saying good-bye to AANE Board Member Liz McLaughlin. By serving as Board Secretary, and on our Governance Committee, and working on our by-laws, Liz greatly strengthened the governance and stability of the organization. We will miss the way her intelligence, her legal background, and her sense of humor have added zest to many board discussions. We welcome to the board three new members: JJ Allaire, who has contributed so much to our IT committee; Michael Appell, who will contribute his know-how to our Development Committee, and Doug Rainville, who will take over the vitally important job of Board Treasurer.

For photos from AANE’s Gala, please see the inside back cover. We congratulate and warmly the 2011 co-chairs, Natasha and David Chomas, Lynn and William Flaherty, and Jill and Steve Purpura for the unstinting work and generosity that made this such an outstanding event. We extend special thanks to Julie Betters, who has donated her professional skills as a graphic artist to make our Gala look great. We are delighted that Jill and Steve have agreed to co-chair the 2012 Gala with Deb and JJ Allaire.

We wish all of you a wonderful summer—please don’t hesitate to call us, whether share good news or for assistance in hard times. We look forward to seeing many of you at the adult conference in July or the Cape Cod conference in August, and in then again when our community reunites in Marlborough, Massachusetts in October for Asperger Connections 2011.

Sincerely,

D. Jekel
Dania Jekel, MSW
Executive Director

N. Schwartz
Nancy Schwartz, MSW
Board President

JODY ACFORD SPIRIT CONFERENCE
Know Yourself: The Key to a Better Life with Rudy Simone
Saturday, July 23 2011 at Northeastern University

This AANE conference is exclusively for adults with Asperger Syndrome and related conditions.

Register now at www.aane.org

Our community was greatly saddened by the sudden death earlier this year of AANE Board Member Jody Acford, Esq. Jody was an exceptionally generous and caring woman. One way her family has chosen to honor her memory is through sponsoring AANE’s annual summer conference exclusively for adults with Asperger Syndrome and related conditions. The family’s generosity will make this conference more affordable and accessible to many low-income adults in our community.
About a year ago, I was driving with my three boys, and we were talking about Tim Page’s book Paral...

“Why AANE?”
BRENDA DATER, MPH, MSW
AANE DIRECTOR OF CHILDREN’S SERVICES

We listen.

A mom of a high school senior came to us greatly concerned for her teen’s well-being. Her daughter was extremely anxious about life after high school. She had spent countless hours watching helplessly as her daughter ate compulsively, without any sense of fulfillment. By the time she spoke with us, her daughter had gained 32 pounds in one year. We delved into why this was happening and what might help. She left feeling like the wobbly ground she’d been on for the past year was being replaced by a solid foundation—she had a plan.

We build community.

Here’s how one parent explained what AANE means to her family. “My son is an AANE member and attends social groups for young adults. He called me this evening to let me know that he was going to go with another group member to watch the Celtics’ game at a local restaurant. He arrived home eager to share the events of his evening. I am sitting here now crying tears of joy. My son is 22 years old and this is the first time in his life that he’s had social success! AANE has provided our family with something that 20 years of special education could not!”

We advocate.

Asperger’s is an invisible social disability. We recently had an adult with Asperger’s walk into a fast food restaurant after it was closed and trigger the alarm. He was confused because the door was open and the lights were on. When the police showed up, the man couldn’t look the officer in the eye. Instead, he showed his AANE wallet card, which explained what Asperger’s is and how the officer could help. The officer changed his approach from assuming this young man was a suspect to offering assistance. AANE acts as a bridge. We decode the larger social world for people with Asperger’s, and interpret the behavior of the Asperger’s community for the larger world.

We provide innovative programming.

After a recent workshop on “Knowing Your Brand of Asperger’s,” a parent of an adult wrote, “I want to thank you for conducting the workshop on Aspie Brands. Our son rated it a 20 on a scale of 1-10.” Through LifeMAP, our 1:1 coaching program, a parent told us the following, “My son who is away at college would get upset every time I tried to talk with him about hygiene. Because he’s comfortable with his LifeMAP coach, he was able to talk with her about his questions, and he listened to her explanation.” She is helping to expand his world.

We help you learn.

AANE walks alongside adults with Asperger’s and the family members of children and teens, as they face the ups and downs of daily life. Parents call us when they read an article or watch a program about Asperger’s, when school calls requesting the parent pick up their child, when their child is bullied, or when they just need a reality check. So much of raising a child with Asperger’s is learning to recognize and appreciate remarkable qualities while knowing how to respond to the challenges that crop up each day.

So how do we give people their sanity back when they feel as if their lives are out of control?
It’s essential for families to feel competent in their understanding of Asperger’s and to build an emotional reservoir for support during the unavoidable highs and lows of trying to build connections.

When we moved to the Boston area in the middle of my son’s 4th grade year, I was terrified that he wouldn’t find any other kids to connect with. One of the smartest things my son did was to disclose to his class near the end of the year to help them understand him. A couple of days after my son’s presentation, another mom came up to me. She said she was glad that her son was in class with my son. I got excited because I thought I knew what was coming next: the offer for the ever-elusive play-date. My heart soared and a smile started to form across my lips as she kept talking—and then I heard her words. She said, “It’s good for him to be exposed to someone with Asperger’s.” I didn’t see that coming. I didn’t see my son being a “good or interesting experience”. I had wanted another child to choose him. I wanted another boy or girl to see him as an equal—not a community service project. No one can take away that hollowed-out feeling you get in the pit of your stomach—but AANE understands what it’s like to have it, and walks beside you as you go through it, and celebrates with you when it changes. Parents and adults often come to our workshops or programs feeling burdened, worn out and discouraged. But despair can turn to hope. After a workshop on emotional regulation a participant wrote, “Thank you, thank you, thank you! This class was a gift!”

At AANE we believe that everyone with Asperger’s is amazing just the way they are. People come to us for a variety of reasons: to learn about Asperger’s, to figure out where they fit, to get validation for the challenges and strengths that live side by side in a person with Asperger’s, to connect to someone else living this life and to become confident and empowered in order to advocate and support each person living with Asperger’s to live meaningful, connected lives, no matter their age.

Just as AANE will continue to walk alongside adults and families—providing a welcoming place to learn and connect—we are grateful to have you walking alongside AANE this evening. Thank You.

Dear AANE,

Thank you for providing such a life raft in this stormy bottomless ocean.

A Parent

Post from a parent

I am wondering if “losing all services” is referring to the fact that public schools are mandated to provide certain services to children under the education for people with disabilities laws that colleges and workplaces are not required to provide. For that reason, my son is choosing to spend one extra year at his public high school. This has allowed my son to take fewer academic courses each year and fill his schedule with more electives (music, woodworking, photography) and some specialized services (counseling, tutoring, etc.) The electives are a place to socialize, to learn team work, and to gain skills that can be used to enhance the recreational part of his adult life (e.g. playing an instrument means he can join a community band and meet people.)

The lighter academic load distributed over more years helps to reduce anxiety by making the work load more manageable. The individual tutor helps with organizing and being responsible for school work and is also a time block that he can use to meet with his social worker and transition co-ordinator. The tutor means I can let go of managing his work at home and that has improved our relationship and relieved me of a huge burden.

Post from AANE parents of teens Google group. Contact Erika.Drezner@aane.org to learn about joining the group.
My Brother Charlie
2011 Gala Fund-a-Need Speech
by Meg Chittenden

My big brother Abram, who I’ve always called by his middle name, Charlie, has Asperger Syndrome (AS), and tonight I want to share with you our story—a story that may in some ways remind you of your own. It’s a story of a family striving to make sense of a child’s physical needs, and to help him to grow and be his best self.

Charlie—where are you Charlie? There he is.—Charlie is one of my favorite people in the world. He’s three years older than I am, but we were one year apart in school and we’ve always been very close. When we were kids we played together constantly, and later he was the person I went to, to have those big discussions about life, God, and the world—you know. I knew that whatever was on my mind, I could go to him and he would consider it with me seriously without any kind of judgment. No matter what I’ve done in my life, Charlie has always supported me wholeheartedly.

When I was a sixteen year old exchange student in Switzerland, my brother Charlie sent money in the mail sometimes because he said that he thought that I could probably use it more than he could. How many teenage boys do you know that would do that for their little sister? I love Charlie so deeply, and it’s been hard to see him face so many challenges throughout his life. Charlie and I grew up in a small town in the time before Asperger’s was widely recognized, and sometimes I wonder what it would have been like for us if we had had the information and the resources that we now have, thanks to AANE, when Charlie was growing up. But as it was his perplexing amalgam of gifts and challenges remained a mystery to us. And I feel like now in retrospect, given what we know now about Asperger’s, the diagnosis would have been fairly obvious. We’ll see what you think.

So, Charlie has been with me from the beginning. Literally, from the beginning, he was there when I was born. I’m told that the next day when people asked him what he thought of this miracle of birth and of his new baby sister he said, “Well, someone has a lot of laundry to do,” which was an astute observation for a three-year-old but might have been in some ways a preview of Charlie’s tendency to focus more on facts than on feelings, if you know what I mean.

Charlie has always been extremely bright and articulate. Even so, school has been challenging for him. He did all right in the Montessori school that we attended until he was eight years old, but then we moved to a new state and we enrolled in a more conformity-oriented public school, and within the first week at our new school Charlie had been sent to the Principal’s office because apparently the teacher had seen him daydreaming at his desk and had come over and said, “Are you going to do the work or just sit there?” Now Charlie thought—in true Asperger’s style—he understood the words but not necessarily the tone—but he actually thought she was giving him a choice—so he considered it, and he said, “I think I’ll just sit here,” and, you know, was then surprised to find himself in the Principal’s office. You can imagine how confusing that was for a second-grader. So, similar misunderstandings of teachers continued to plague his early schooling years.

He has always had very intense special interests: one could maybe call them obsessions. And one such interest when we were still in elementary school was genealogy. He was totally captivated, particularly by our Scottish heritage, and this led to a particularly painful period in my own childhood in which I was forced to endure the excruciating squawk of poorly played bagpipes through the thin wall between our rooms. It was hard, but luckily that was a short-lived time. But he also memorized the plaid of every single clan. He made a wall-sized chart of all the different Scottish monarchs throughout time. He experimented with haggis, which if you don’t know what that is you don’t want to know. And he also would perform all 87 verses of the Ballad “The Battle of Otterbourne” for anyone who would listen, which as you can imagine was a pretty select audience. But I think by verse 79 it started to thin out. But it was impressive—good memory.

His eccentric interests combined with the didactic way in which he was sometimes prone to pontificate, did not necessarily always endear him to his peers. And, as we moved into our middle school years, his difficulty forming positive social connections became more pronounced. Some people might have turned to intellectual pursuits altogether, but Charlie is by no means misanthropic. Despite his social challenges, he has always been very interested in and concerned with the people around him. And so he found less conventional ways to engage in the social posturing that takes up so much of the middle-schooler’s consciousness. For example, he took up journalism. He would arrive at the middle school dance equipped with a notebook and a pen, and rather than standing self-consciously against the wall of the gymnatorium during the slow dances, Charlie would work his way through all the couples, meticulously documenting who was dancing with whom for every dance. Then he’d take this home and he’d analyze the information, and create some spreadsheets and some graphs, and bring those into school on Monday. And you know, he did get a fair amount of attention for this work, but I can’t say that it was really altogether positive attention. And that was around the time when I started to hear a refrain that became all too familiar during our school years together: “You know, your brother is like so weird.” It always surprised me how many people thought that was a good conversation starter with me, like where do you go from there? “The weather is really nice, thanks.”

Charlie has also always loved a good argument. Not like a heated emotional rant, but a cool efficient—but-merciless verbal sparing, that’s what he’s into. I have to say, as his little sister, this hasn’t always been enjoyable for me. And one thing that it’s taken me my whole life to fully grasp, and I still sometimes forget, is that Charlie is perfectly happy to argue a position that he himself does not hold. And this is another thing that hasn’t actually always served him well. In high school, his freshman year Latin teacher was a staunch feminist, and Charlie himself is a feminist. However, this did not stop him from engaging her in what he would have called lively debate around which sex was superior. And I guess once, after a particularly heated exchange on this topic she demanded that he write her a letter of apology.

Charlie and Meg as kids

Charlie has always been extremely bright and articulate. Even so, school has been challenging for him. He did all right in the Montessori school that we attended until he was eight years old,
And this he did. It was very gracious and remorseful. The trouble was that if you read the first letter of each sentence going down it spelled our WOMEN ARE INFERIOR. He assured me that she was going to find this just as clever and funny and he did. He was wrong.

After high school Charlie tried to make it work in various different colleges, but it never seemed to quite work out for him. And it was almost as though the more independent he became, the more crises he seemed to face. By that time he had developed a keen interest in computer programming, and he usually had some kind of computer programming project under way on his own. And often when he had such a project under way he would neglect to do some of the basics necessary for daily life. Like eating, sleeping, paying bills, taking out the trash, going to work—just details like that were hard for him to manage. So as a result he got and lost a series of jobs. He was married. He divorced. He even managed to get into some pretty serious legal trouble. He needed that card that Brenda Dater was talking about. That would have really come in handy.

And as our family rallied around him again and again to help him through yet another crisis, it all started to feel strangely predictable, yet at the same time utterly confounding. Here was Charlie, this brilliant, loving, talented, kind young man, trying to make it in the world on his own, yet sliding three steps back for every one step forward. He’d been assessed by various professionals since he was a teenager. He’d been diagnosed with this and that. Medicated, chastised, encouraged—but nothing seemed to help. Things went from bad to worse for him, and it got to a point where we didn’t know where else to turn. Finally, when Charlie was 32 years old, someone suggested that he might have Asperger Syndrome. And that is when we found AANE. Through AANE we were able to get an accurate diagnosis, and to start down the road towards developing a true understanding of Charlie’s challenges.

The people of AANE have truly become like a surrogate family for him. They offered him the same kind of unconditional love and support that a family offers. And what’s more, they helped all of us to be able to find the resources and the information that we need to be effective in approaching the challenges associated with Asperger’s. They’ve helped Charlie find consistent work that builds up his strength. They’ve encouraged him to develop his incredible artistic abilities. And perhaps best of all, they’ve connected him with other people who enjoy arguing for the sake of argument as much as he does, which has been wonderful. In all seriousness, it feels like now at last, through AANE, Charlie finally has the supportive social network that seemed to elude him throughout most of his life. And now he steps out into the world with such confidence that the same little boy who used to run into an alley and hide rather than risk having to converse with someone on the street, can now form lasting friendships with strangers that he meets on the train. It’s an amazing transformation and we thank AANE.

In closing I’ll just state briefly: my husband and I are blessed to be the parents of a wonderful baby boy who is just a few months shy of his first birthday, and I have no idea what the future holds for him. But when I look down at his beautiful sleeping face, I wonder about what joys and challenges lie ahead for him. It gives me great comfort to know that AANE is out there helping to support children and families who are navigating the ups and downs of growing up with Asperger’s.

Thank you.

Eva Mendes was an intern at AANE for one and a half years, where she led groups, conducted individual therapy, and coached LifeMAP clients. She wrote this piece at the request of one of her clients, based on a conversation during one of their therapy sessions. Eva recently completed a Masters in Arts in Clinical Mental Health Counseling. She plans to stay in the Boston area and continue working with adults with Asperger Syndrome.

You can contact her at eva.mendes.aane@gmail.com
My Year of Transition
by Charlie Remy, MLS

2010 was a year of tremendous changes and milestones for me. While finishing my graduate studies in library science at Simmons College in December 2009, I started the dreaded job search. It couldn’t have been a worse time to find a job - millions were unemployed, library budgets were either frozen or cut, and those who were on the verge of retirement decided to stay put in their jobs because they realized that they truly couldn’t afford to retire.

I ended up applying to over 300 jobs during an eight month period. I was a finalist for four jobs. As you might know, searching for a job can be a full time job in itself. I spent hours looking for jobs online, crafting cover letters unique to each institution, and, when I was a finalist, preparing for presentations. It was a dehumanizing process - you’re made to feel like nothing more than a piece of paper: you don’t have enough library experience, thousands of people across the country have recently graduated with your same degree, and, oftentimes, you don’t hear back from the search committee for several months. Checking the mail each day always revealed a pile of rejection letters. The unpredictable outcome and impersonal nature of the job search process can be particularly stressful for an Aspie.

In June I was finally offered a job at Western State College of Colorado. The library director called me less than two days after my in-person interview on campus to make the offer. I was so relieved. I told her that I needed to think about it, but I knew that my options at that point were limited. I gracedfully accepted the opportunity. Ironically, in the following weeks, I received calls from five or six other libraries where I had applied, asking me for phone interviews. It felt good to tell them that no, I couldn’t continue with the application process because I now had a job.

In August my father and I drove from Maine to Gunnison, Colorado. It was fun - we visited two academic libraries on the way and had good conversations. I was fortunate to have his help with the big move. For the first month, I lived in campus housing while my apartment was being readied. My father spent a week with me out here. When he left I cried and was sad for a day but then I realized that I was doing the right thing for myself, both personally and professionally. The sadness quickly went away.

Gunnison is a town of about 5,200 in the middle of nowhere, western Colorado. Denver is four to five hours away and Santa Fe is a four and a half hour drive. I have never lived in such a geographically isolated place in my life. The two main employers are the college and the hospital. It’s located in a valley surrounded by mountains and protected National Forest Service land. It’s one of the coldest places in the country; on some winter nights the temperature dips down to negative 30. What I love about this place is how sunny it is. It’s sunny every day with hardly a cloud in the sky. No more endless cloudy days like in the Northeast. I live in town so I rarely need to use my car. I can walk to work, the library, the bank, the grocery store, etc. It’s a great feeling to be free from the need to use a car every day.

I love my job at Western. I am the Electronic Resources Librarian which means that I manage the library’s database subscriptions and help with other technological initiatives. Working at a small library allows me to do a lot: I work about ten hours at the reference desk per week, I sometimes do library instruction sessions with classes, I decide which materials to purchase for our collection, I meet with faculty to determine their needs, and serve on a few committees. My boss calls me the “one man library” because I am eager to do so much beyond my job description.

I want to highlight how important it is to have a good boss. Nancy Gauss has worked at Savage Library for over 20 years and became the director about three years ago. She is truly the ideal boss. She is democratic, non-hierarchical, patient, accepting, frequently praises her employees, encourages us to pursue different opportunities both on and off campus, and is a friend. I feel very comfortable with her and can tell her anything because I trust her. After two months of working at the library, I decided that it was time to disclose to her. I wanted her to know that I have Asperger’s Syndrome because I hoped it would help her to better understand me and my sometimes odd behavior like not understanding subtle social cues, occasionally making inappropriate comments, and having a low tolerance for frustration. I told her that A.S. can be the cause of a lot of my eccentric actions but it’s not an excuse. I asked her to please tell me right away if I am doing something wrong or inappropriate. The great thing about telling her this is that she has continued to treat me with respect and dignity. It’s as if she never knew I had A.S. I’ve decided not to disclose to my other coworkers yet until I get to know them more. I don’t mind disclosing to anyone but I cannot control how they will react. I prefer to get to know a person first so that I am assured that they can handle it.

A.S. affects me in my work environment every day. I always need to remember to use tact and diplomacy when communicating with others; hence, I need to think before I talk or write. Since the summer I have been working hard on avoiding meltdowns when I become frustrated, anxious, or upset. So far it’s working - when I become upset, I try to walk away from the situation and calmly collect my thoughts. I realize that I cannot have a major meltdown at work without jeopardizing my job or professional standing. Nancy is always good about telling me to “let it go” and not worry about things that I cannot control. I work a compressed schedule (four ten hour days each week) which allows me to have three day weekends. This is very helpful because I get extremely tired toward the end of the week due to excessive stimulation, the need to concentrate, and general anxiety. Having an extra day allows me to get more rest and enjoy my time outside of work. Getting used to a 40 hour work schedule has been difficult. I no longer have as much time to partake in my hobbies such as consuming news. I get way behind in my personal reading but am not letting it get to me like I did before. I try to maintain a strong work/life balance.

My social life is slowly but steadily improving. I seem to be making new friends every week. Early on in my job, I met a student worker whose sister happens to have A.S. We have become good friends and I feel like she understands
me quite well. I eat in the college’s cafeteria every night, which is a nice social environment. I often eat with students who are friends of mine. My liaison work for the library has introduced me to countless faculty members, some of whom I consider friends. I also keep up with old friends from across the country and internationally via phone. I spend hours on the phone during my weekends — it’s truly my connection to the world outside of Gunnison.

As mentioned earlier, I have achieved many milestones since I moved out here. I have registered a car in my name, bought my own insurance, live on my own in an apartment, cook entire meals for myself when I have to, and will be filing my own income taxes next month. I’m lucky to have supportive parents who are only a phone call away if I need help. The thought of cooking for myself while the cafeteria was closed during winter break caused great anxiety. It ended up working out fine — I called my parents and they instructed me on how to cook meals. I ate out in restaurants only twice in a three week period.

In late November I did something that I never, ever thought I would do: I started attending a church. One night when I was in the cafeteria, I saw a faculty colleague of mine. He invited me to join him and this woman for dinner. She turned out to be the pastor at the church that he attends. They both invited me to come to a service and I decided to take them up on it. The Gunnison Congregational Church United Church of Christ is the most liberal and progressive church in town. It’s less than ten years old and meets in a space on the college’s campus. The pastor is openly lesbian and sets the tone: everyone is welcome and accepted for who they are. The first time I attended a service, I was overwhelmed by the people who came up to me and introduced themselves. It was so kind and genuine on their part. I’ve been attending ever since.

Part of me can’t believe that I’m regularly attending a church. Both of my parents had long ago relinquished their religious ties. Although religion was not a part of my upbringing, values and ethics were always emphasized. I think this is good because I don’t have the emotional baggage that so many people do, caused by negative church/religious experiences. I went to a Catholic high school since there were few private schools in my area. After I graduated, I said to myself that I’d never attend a church service again. Attendance of the occasional Masses held at school was obligatory and I found them to be empty and meaningless with the school not living up to the social teachings of the church. I am a part of GCC-UCC because the people there share my values for social justice and acceptance of diversity. It’s a great source of community. When I stayed here and worked during winter break, a couple invited me over to their house to celebrate Christmas. Instead of being completely alone in my apartment, I got to know some great people over a delicious Christmas dinner. I’ve already been asked to greet people as they are coming in and lead the worship service. I feel truly valued for who I am in this unique community.

Although there is a great distance that separates me from my parents, it doesn’t make me sad or anxious. I talk with them on the phone multiple times a day, which helps to bridge the gap. In October they came to visit me here. We spent several days in New Mexico and had fun together. I will see them again when I attend a library conference in Philadelphia at the end of March. Part of why I’m not struggling with this distance is because I’ve been away from home many times before. I went to college in North Carolina, studied in Chile, and went to graduate school in Boston. I think that distance from family and close friends can help a person to grow. It forces you to learn how to do things you never needed to do before, makes you more independent, exposes you to new people and cultures, and makes you appreciate your loved ones all the more.

I want to conclude by stating how fortunate I feel to have full time, professional employment in my chosen field. Many of my classmates from graduate school still continue to search for employment one, two or three years after they graduated with their degrees. There’s not a day that passes by that I’m not thankful for what I have. I am learning a lot on the job, networking with colleagues from different libraries, and doing what I truly love. For an Aspie facing daily challenges, being constantly surrounded by information is like living in paradise.

Charlie welcomes your questions and comments. Please email him at csr03@maine.rr.com

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### Through Different Eyes

**by Natalie Weaver**

It’s hard,  
being misunderstood;  
being judged,  
when you did all you could.

You tried your best,  
but you didn’t succeed.  
Attacks and criticism,  
now proceed.

You try to explain,  
to your friends in vain;  
but they don’t feel,  
your anguish and pain.

It’s times like these,  
that you realize,  
that you see the world,  
through different eyes.

For more artwork by Natalie Weaver, please see p. 19.  
For another poem, see p. 4.
What is Wrong with Faces?

by Nouchine Hadjikani, M.D., P.H.D.

Brain imaging is commonly used in research on autism spectrum disorders (ASD). However, many caveats need to be kept in mind when considering findings reported in these studies.

1. ASDs are neurodevelopmental disorders, and their presentation may change over time (e.g. through compensation of disturbances, or the appearance of secondary disabilities).

2. By definition, people with ASDs represent a spectrum, and great care must be taken to define which part of the spectrum (which “color”) was examined in each research study. Did the researchers examine young, nonverbal kids, or adults with Asperger Syndrome? Results from either studies will be of great interest, but will obviously reveal different profiles, and conclusions from one study may not be applicable to the other.

3. Information processing in individuals with ASD can take very different paths than in neurotypicals, and we must therefore ensure that the tasks used are processed similarly by all participants, people with ASDs and controls, or if they may differ, be aware of it.

Communication and social interactions are impaired in individuals with ASDs. Klin et al. (2002) have documented the well-known observation that individuals with ASDs have a strong tendency to avoid eye contact in social situations. Seeing the eyes is important to our ability to recognize people. For example, note how a black strip over the eyes is sufficient to conceal identity in a medical textbook photo, or how some people wear big dark sunglasses in order to avoid being recognized. The reasons why individuals with ASDs do not look at the eyes are not clear yet. Moreover, these reasons may vary across subgroups of individuals with ASDs. We are currently conducting research to try to better understand this phenomenon.

Faces, Eyes, and the Cortex

About a decade ago, many studies had reported that individuals with ASDs were lacking brain activation in an area of the brain that is specialized in face identity recognition, known as the fusiform face area (FFA). The authors concluded that individuals with ASDs saw faces as objects (vs. people), which in turn led to their impaired social behavior.

Our group questioned these results for a number of reasons. First of all, we knew that face perception was happening not only in one area of the brain, but rather in a network of different areas (Figure 1). Second, we were at the time working with people suffering from prosopagnosia, an inability to recognize faces due to a damage to the FFA. (For a vivid description of that neurological syndrome, read the title essay in The Man who Mistook his Wife for a Hat by Dr. Oliver Sacks.) These people were suffering from a lack of FFA activation, yet their other behavior was not at all reminiscent of an autistic behavior.

We combined all that evidence, together with the knowledge that there was a tendency for individuals with ASDs not to look at the eye-region of faces, in order to design an experiment where we could be sure that our participants would actually look at the faces presented to them. We put a red cross in the center of the image, located in the region between the eyes, and instructed the participants to look at the faces and attend to the red cross. Our results confirmed our expectations: the FFA of participants with ASDs responded as well as the FFA of neurotypical controls. Since then, several groups have reproduced these results, including in two studies that showed a correlation between the time spent in the eyes and the amount of FFA activation, a phenomenon present both in people with ASD and in neurotypicals. However, we noted that other areas of the brain that are spontaneously engaged in face perception for neurotypical individuals seemed not to be activated for those with ASDs. Those areas included the somatosensory and motor areas of the brain that are important to feeling and producing facial mimicry, as well as areas belonging to what is known as the mirror neurons system.

Mirror mechanisms were first described in monkeys, but have since been shown in humans in a large number of studies. These mechanisms seem to be at the basis of our capacity to understand other people. Humans are a very social species, and our survival and evolution depend upon our capacity to interpret complex social situations, and to send and receive subtle social signals. Mirror mechanisms produce motor representations in our brains that reflect the actions and the emotions we observe in others. Because we know the results of our own motor representations, we can access, through mirror mechanisms, a direct understanding of what others do or feel. Our results seem to indicate that these mirror mechanisms are not spontaneously engaged in face perception for subjects with ASDs.

We also performed another study where we compared the thickness of the cortex in ASD and closely matched neurotypicals, and found that the same areas that we have found to be less activated were also thinner in ASD. This is, of
course, only a snapshot in time, in a study which examined young adults with ASDs, and we do not know whether our observations reflect the cause or the consequence of the syndrome; in either case, however, it is part of a vicious circle that needs to be broken (Figure 2).

Experiments Using Face-like Stimuli

One important question we need to address is whether faces are in fact “special stimuli” that people with ASDs than by neurotypicals process using different brain pathways. One of the research problems is that faces are always social stimuli, making it is difficult to differentiate between what brain activity is in response to the face as an object, versus activity in response to the expression or social content of the face.

We addressed this challenge by using face-like stimuli for our experiments: objects that immediately remind us of faces, even though they are objects and there is no social interaction intended in them (see Figure 3). Using this type of stimulus with neurotypical participants, and using a method called magnetoencephalography allowing a very precise recording of the timing of brain activation, we have shown that activation in the FFA occurs for these objects in the same time period as it does for real faces (around 170ms). This result is very interesting, because it showsthat our brain detects something that has a face-like configuration very quickly, suggesting that it is more a reflexive than a cognitive process. We are now conducting the same experiment in participants with ASDs, to see whether these objects also elicit this response faster, slower, or at the same speed. We hypothesize that we might find two groups:

1. One group composed of individuals who actively avoid looking at faces; we expect that they will show an early response to faces and maybe also to face-like objects.
2. Another group who are indifferent to faces (not particularly caring to look at faces); we expect that they will have a later response time.

We hope that we will be able to share the results of this research with you soon.

Another aspect of emotion perception that we have been studying is Body Expression of Emotion (BEE). Most of research done on emotion has been done using facial stimuli. However, since Darwin’s time we have know that body posture is another very important means of communicating emotions. In consequence, we decided to ask the following question: Do individuals with ASD also show difficulties in understanding emotions when these are expressed by the body?

For these experiments, we asked actors to take a posture of fear for some photographs, or to just perform neutral actions for others (miming things like pouring water in a glass, or talking on the phone). We blurred their faces so that their emotion could only be read on their bodies. We presented these two groups of pictures to a group of neurotypical subjects, alternating the photos of fearful and neutral body expressions. We used fMRI (functional Magnetic Resonance Imaging) to measure the location and intensity of brain activation for each photo. We found that the presence of fear in the body expression modulated a number of brain areas quite similar to those involved in face perception, and including mirror neurons areas, as well as the motor cortex (preparing for action: fear fosters flight). However, when we did the same experiment with participants with ASDs, we did not see this modulation. Both groups showed similar activation for neutral actions, but subjects with ASDs did not demonstrate increased activation when viewing fearful bodies. We concluded from that study that individuals with ASDs have difficulty understanding emotions whether they are expressed through the face or through the body. That may be due to some problem in activation of the mirror neurons system.

Implications for Possible Treatment

We think that our data may be relevant for behavioral therapy. We know that the brain is a plastic organ, meaning that exercise can modify it—a bit like the way that physical exercise can modify muscles! Mirror neurons are involved in imitation, and a training of imitative functions might help people with ASDs to develop a better understanding of other people’s actions, emotions, and behavior. It is important to realize that the brains of individuals with autism just function differently than neurotypical brains (not better, not worse), and that people with ASDs need a tremendous amount of energy to make sense of things that are considered innate and spontaneous for the rest of us. The goal is not to try to make ASD brains function like neurotypical brains (an impossible goal), but to give people with ASDs the tools to be able to learn to participate more smoothly in our society, and minimize their suffering in a world where social codes are sometimes so difficult to crack. We hope that future research will help us to better understand the effect of behavioral therapy on behavior, and on the brain.

Nouchine Hadjikani is an Associate Professor in Radiology at Harvard Medical School/MGH/MIT, and also conducts research at the Brain Mind Institute of the Swiss Federal Institute of Technology. You can find out more about her work at http://nmr.mgh.harvard.edu/nouchinelab.
Teens with Asperger’s Syndrome & Unstable Relationships
by Adam Pearson

A teen’s first steps into the dating world can be just as unsettling for the parent as for the teen, if not more so! Teenagers, by nature, are highly vulnerable to being misled by peers. This, however, does not negate the necessity of socialization, especially for people with Asperger Syndrome (AS). Nevertheless, socialization with the wrong people can be even more damaging for people with AS than for neurotypical people (NTs), as people with AS have difficulty understanding the line between appropriate and inappropriate social behavior. This can become an even bigger problem when dating, because people with AS are less likely that NTs to detect red flags that may be indicative of the other person’s mental health issues or social instability.

I was diagnosed with AS when I was in the 2nd grade. I was very high functioning though, so I was able to go to a regular school. My social life, however, only expanded slowly, as I grew older. I started socializing with girls in junior high and had one relationship in high school. I will describe that relationship in this article.

I will call the girl I went out with Laura. Laura had some issues of her own. She had bipolar disorder, plus severe mood swings. Her behavior was erratic to the point that most neurotypicals would have run the other way. At first, when Laura acted clingy and moody, I assumed she was only slightly moodier than most girls, and did not see her behavior as a red flag. I did not recognize that it wasn’t within normal bounds for Laura to call me in the middle of the night crying, threatening to break up with me because I only saw her on Saturday and Sunday but not Friday. Nor was it normal for her to act as if I cheated on her just because I spent some time hanging out with my friends. When I went away on a trip, Laura demanded that I send her a letter every day. Once she got angry at me for wasting ten minutes buying lunch—time I could have spent with her. Eventually, when she learned that I would be going away for a week to see my family, she started crying months ahead of the trip. While I was away on that trip, and learned that Laura had cut herself, I finally got a clue.

After around six months of my seeing Laura, my family started to catch on to the fact that I was not in a good situation. My grandparents had only met Laura once and, while not voicing their disapproval to me a the time, later revealed that they thought that both Laura and her mother were very controlling. My mother was the most bothered by the relationship. Her initial ways of dealing with it were very ineffective—that is, reacting emotionally. Eventually though, she came up with a good idea and, instead of attempting to force me break up with Laura, gave her a rope to hang herself with.

For a while, I was not allowed to see Laura on the weekends, but my mother made an exception. She would allow Laura to throw my 16th birthday party and invite all of my friends. My friends hadn’t met Laura before that, and my mom guessed that if they all saw how she behaved, maybe they could talk some sense into me. During the party, Laura had a random attention-seeking breakdown, made some mean remarks, and made endless demands on everyone there. It was more embarrassing to me than it would have been private. Much to my mother’s relief, I broke up with Laura a few days after the party.

Looking back, I don’t think I was ever deeply in love or even deeply infatuated with Laura, so I can’t use that as an excuse for my folly (at least not solely). I believe my lack of knowledge of interpersonal relationships at the time contributed to how long I stayed with Laura.

I tell this story to warn parents of the extra dangers teens with AS face in the dating world. I was lucky because no serious harm came to me or my family, nor did I adopt Laura’s behavior in my subsequent relationships. However, there are lots of emotionally, mentally, and physically abusive partners out there who could make life a living hell for teens with AS, many of whom have low self-esteem and limited social knowledge or experience.

I can imagine many people are reading this and thinking, “What an idiot, I have Asperger’s, too, but I’m not stupid enough to date someone like that.” Please note that I am not trying to say that Aspies do not have the ability to judge character. However, appropriate interpersonal behavior does not come as second nature for Aspies, as it does for NT’s. Rather, we learn it through studying it. If you have AS, I would highly recommend using the internet as a resource for clues as to whether or not there are red flags in your relationship. Also consult your trusted friends or mentors. If you are parent of a teen with AS who is concerned your teen is headed down a road similar to mine, I would recommend communicating with your teen in a non-intrusive, nonemotionally-charged way. The article “Tips for Parents of Teens with Aspergers” by Stephanie Loo (available on the AANE web site) provides sound instructions on how to communicate with your teenager.

I would like to end my account on the note that although socialization with the wrong people can have negative consequences, not socializing at all has equally negative consequences. I know how it feels to sometimes just want to spend all your evenings alone, away from those who may not approve of you because you’re different, but no man (or woman) is an island. As most of you who are reading this article right now have probably discovered, socialization is beneficial in the long run. Sometimes, though, you need to use your resources (such as the AANE website) to insure that you are socializing in a positive way.

Adam Pearson is currently in college. He hopes to be a professional fiction writer someday.
**Asperger Syndrome and Sexuality**

*by Lucy Berrington*

*Note: Names and identifying information of some interviewees have been changed.*

Sexuality and intimate relationships are a very sensitive and very private matter for most people, and perhaps even more so for people with Asperger Syndrome (AS). Very little is known about the sexual attitudes, feelings, practices, or experiences of people with AS. Yet this is also an important factor in many people's lives. In preparation for AANE and MGH YouthCare’s June 2011 conference on AS and sexuality, we asked journalist Lucy Berrington to write this article.

Would anyone say true love came easily? Probably not. For those on the autism spectrum, however, intimate relationships are especially elusive. People with Asperger Syndrome (AS) tend to have fewer social opportunities than neurotypicals, and are likely to grapple with heightened anxiety, troublesome sensory processing, and difficulty interpreting nonverbal cues (including the language of love). Any of these factors can reduce their chances of romantic success.

“Intimate relationships can be very difficult for people with Asperger Syndrome,” says professor Stephen M. Shore, Ed.D., author of *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*, “mainly because the dating scene is full of the hidden curriculum: all these rules that everyone else seems to know but which are not talked about. It’s hard to play the game.”

Many people assume that Aspies (people with AS) don’t want to play the game, that dating and sex are a low priority for them. Some people with AS, including animal behavior scientist Temple Grandin, have described themselves as asexual. The “asexuality” of people with autism, however, may not necessarily represent an absence of sexual desire. Many may feel, based on experience or suspicion, that attempting to form and maintain intimate relationships is too physically or emotionally uncomfortable, or the social barriers insurmountable. Such personal struggles are compounded by a general societal inability to know how to think about disability and sexuality, denying people on the spectrum a supportive context.

“The sexual profile of individuals with Asperger’s syndrome indicates that they have sexual needs and drives comparable to those of the general population,” say Linda Baker and Lawrence Welkowitz in *Asperger’s Syndrome* (Routledge). “They have fantasies but lack experience, generally because interpersonal difficulties prevent easy progression into sexual relationships. One study participant summarized the problem by saying, ‘Situations with lovers are very awkward. It seems as though my loneliness and lack of experience show on my face... One can’t help but feel inferior and unhappy.’”

For those with AS, finding a long-term partner does not in itself mean coming to terms with one’s sexuality. British counselor Maxine Aston, the author of *Asperger’s in Love* (Jessica Kingsley), conducted a survey of 45 adults with AS (39 of them male) and 35 of their neurotypical (NT) partners. She found that about half the NT wives and girlfriends reported no shared sexual contact with their partners. (NT) partners. She found that about half the NT wives and girlfriends reported no shared sexual contact with their partners.

Standing between the men with AS and their potential lovers were a range of troubles: difficulty initiating sex and interpreting nonverbal cues, anxiety around sex, sensory discomfort and, perhaps above all, the naturally solitary inclinations of many people with AS. “As sex is a form of communication, it is this that causes the problems,” writes Maxine Aston. Having AS, she says, “can lessen adults’ need to share the physical satisfaction that achieving an orgasm can bring them with a partner. Physical satisfaction can just as easily be achieved and enjoyed in solitude, very much like the other special interests and needs in the life of the person with Asperger syndrome.”

Nevertheless, some adults with AS achieve sexual contentment with others. It seems reasonable to hope that the current generation of people diagnosed with AS in childhood—the recipients of long-term social skills support and other interventions—will mature into more sexually confident and satisfied adults than previous generations. While any particular outcome can never be guaranteed, the necessary skills can be to some extent learned, and sexual troubles pre-empted or alleviated. “Adults with AS can do better at this if they have awareness of their differences in this area, and a real desire to change. If you couple these together there can be a lot of hope,” says Stephen Shore.

When it comes to couples, there are three possibilities, each offering its own challenges and potential. There are couples where both partners have AS, couples where one partner is more neurotypical, and couples where one partner has AS and the other partner has some other kind of difference. The relationships vary widely in the levels of satisfaction experienced by each partner. Often there is frustration stemming from mismatches in terms of the partners’ needs, style, and ability to express and receive affection. Couples who are not aware that AS is in the mix are particularly likely to experience conflict or dissatisfaction. This is why AANE offers workshops and both online and face-to-face support groups for NT partners and for couples where one or both partners have AS or a related condition.

Dr. Tony Attwood sees many couples where a person with AS is paired with a very nurturing NT partner. In some cases, the partners are able to accept each other’s differing needs and styles. Other people with AS tend to have more success in relationships with partners who are also on the spectrum, although Stephen Shore notes that, “Sometimes the blind spots of autism line up in such a way that they exacerbate the problem.”

Tony Attwood also suggests that some Aspies do better with partners who themselves have some kind of difference—not necessarily an autism spectrum disorder. “It could be a difference in culture, religion, nationality, or age,” says Shore, whose wife of twenty years is Chinese. “It may be because the other person is not so intimately aware of how one is supposed to behave. Someone of another nationality may have their own challenges integrating into society, so may be more tolerant of differences.”
Even if successful coupledom is in the future of a person with AS, the route there is likely to be atypical. The “dating gap” between Aspies (people with AS) and neurotypicals starts forming early, with children on the spectrum often missing out on the pre-teen social maneuverings that prepare their peers for intimate relationships later on. “Around grades 4 and 5, there started to be social games or practicing,” says Beatrice, a Massachusetts teacher in her early 30s who was diagnosed with AS last year. “Boys and girls being interested in each other and simultaneously repulsed, the phenomenon of girls making and breaking friendships all the time. ‘I hate you,’ ‘You have to hate this person with me,’ and so on. Girls are cultivating social knowledge around how they relate to boys. They gossip, play out the drama of friendship and intimacy, and bring that to relationships later. I didn’t get it and couldn’t participate.” What Beatrice describes is a classic developmental stage from which students with AS may be excluded says Sally Fogel, a sexuality educator who works with individuals, groups, and schools around New England. “My role as a counselor and educator means explaining the norms, helping them navigate the waters, because they likely will not experience it in a typical way.”

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Students with AS may not perceive the texture of teen and adult relationships: their intensity and fluidity, as well as the specific steps involved that elevate a relationship from platonic to romantic. Fogel cites the example of a teen girl in a special school who texted an acquaintance and asked if he’d like to be her boyfriend. The boy enthusiastically agreed, although previously they’d only passed in the hallway. “One goal is to recognize there are steps to be taken before you ask someone on a date. You can’t be her boyfriend unless you know her last name, have called her on the phone frequently, have dated for a certain period, gone to her house and so on. Girls are cultivating social knowledge around how they relate to boys. They gossip, play out the drama of friendship and intimacy, and bring that to relationships later. I didn’t get it and couldn’t participate.” What Beatrice describes is a classic developmental stage from which students with AS may be excluded says Sally Fogel, a sexuality educator who works with individuals, groups, and schools around New England. “My role as a counselor and educator means explaining the norms, helping them navigate the waters, because they likely will not experience it in a typical way.”

What Beatrice describes is a classic developmental stage from which students with AS may be excluded says Sally Fogel, a sexuality educator who works with individuals, groups, and schools around New England. “My role as a counselor and educator means explaining the norms, helping them navigate the waters, because they likely will not experience it in a typical way.”

Students with AS may not perceive the texture of teen and adult relationships: their intensity and fluidity, as well as the specific steps involved that elevate a relationship from platonic to romantic. Fogel cites the example of a teen girl in a special school who texted an acquaintance and asked if he’d like to be her boyfriend. The boy enthusiastically agreed, although previously they’d only passed in the hallway. “One goal is to recognize there are steps to be taken before you ask someone on a date. You can’t be her boyfriend unless you know her last name, have called her on the phone frequently, have dated for a certain period, gone to the movies with her, know what her favorite TV show is.” In Fogel’s workshops and courses for teens or adults (including those offered at AANE) she defines in concrete terms what having a girlfriend or boyfriend means.

Sex education is at least as important for teens with AS as for their neurotypical counterparts. “People with AS don’t have the benefit of learning about sexuality and intimate relationships from their typical peers,” says Stephen Shore, “so they need direct instruction and mentorship.” Parents should be aware to what extent social skills and sex education are offered in schools, and be prepared to supplement that curriculum. “Standard mainstream sex education is not enough for teenagers with Asperger’s Syndrome,” writes the counselor Maxine Aston. “All the issues surrounding attraction, dating, courtship and sex need to be broken down into segments and explained in specific detail.” The book Making Sense of Sex (Jessica Kingsley), by Sarah Attwood, offers clear, inspired coverage of relationships and social growth.

Ideally, sex education starts early and in the home. The use of accurate vocabulary for body parts and processes minimizes obscurity and euphemism, says Sally Fogel: “penis, vagina, vulva, not ‘wee-wee’ or ‘muffin.’” Correct language, she says, serves “to empower kids, convey that this is a part of the body we’re able to talk about. If you’re changing a diaper, say, ‘That’s your penis.’” This begins the process of training children ultimately to advocate for their own sexual independence, safety, and health care. (Tolerating a pelvic or prostatic exam can be problematic for people on the spectrum.) Talking about the body and sex, Fogel says, is “part of the landscape of raising a child. Don’t touch a hot stove; don’t run in the street; the body is private and precious.”

Sexual safety for people on the spectrum goes far beyond reducing the risks of STDs or pregnancy. Teens must learn the difference between public and private conduct, and how to ensure sexual contact is consensual. Mary Newport, a woman with AS and co-author of Autism—Asperger’s & Sexuality, has written about how her “social cluelessness” contributed to her being initiated into sex at age eleven by an adult neighbor.

“As a child I had no boundaries, so I was available to many of the boys in my world,” recalls Beatrice. Consequently, she was teased in fourth grade and, at the age of fourteen, sexually assaulted by a male cousin. “I think he could have and did pick up signals of my resistance, which I couldn’t verbalize, but he didn’t respond to them.” Beatrice suffered a long period of depression. A year later, she gave a statement to the police. No charges were pressed, but the experience “completely fractured” her family.

Adults should clarify for children on the spectrum what constitutes appropriate play. Parents need to acknowledge children’s curiosity about the body, says Sally Fogel, while emphasizing that bodies are private. Information should be sought from books designed for this purpose. All children on the spectrum should be taught to assert themselves unequivocally—“I’m not comfortable; please give me space; stop that, I don’t like it”—and to discuss uncomfortable situations with a trusted adult.

Children with AS need to be taught the sub-clauses of social rules. For example that an affectionate sideways hug serves a very different purpose than a full frontal body hug—and while the affectionate hug works for the aunt you run into at the mall, it has no place in dealings with a school principal or strangers. To ensure that his or her own behavior is appropriate and welcome, the safest approach is to ask: “You seem upset; can I put my hand on your back?” or “Can we hold hands during this movie?” “Ask more than would normally be expected,” says Stephen Shore. “It’s almost like following the protocol of sexual harassment avoidance. Before you make any move, ask permission.”

Parents are responsible, too, for expressing the values they want their children to share: how long people should date before considering themselves a couple, or whether sex is acceptable before marriage. Teachable moments can be offered up by current events (Tiger Woods and Jesse James can be of service here) as well as television sitcoms, movies, and real-life observations.

Fogel uses clips from contemporary romantic comedies to
direction. “What is the difference between being sexual and touch that moves the relationship in an unanticipated way?” Sensory issues can make people on the spectrum more vulnerable to receiving (or giving) inappropriate touch—or, for some individuals, access to someone else’s body is automatically sexual. “Rather than getting a certain fulfillment through touching, it may be to some extent sensory seeking rather than truly sexual,” says Beatrice. “It’s all erotic, right? We don’t often talk about disability and sexuality together.”

Unusual sensory needs should be discussed and negotiated with a partner. For some women with AS, sensory issues—an aversion to handling gel—may affect contraceptive options. Or, an individual with AS may be so sensitive to skin-on-skin contact that he or she must remain partially clothed during sexual contact.

For other Aspies, physical touch may need to be unusual—intense. People who have read the books of Temple Grandin, or watched the HBO movie about her life, are aware of the calming effects of the “hug machine” she invented. AANE members who have heard Dr. Liane Holliday Willey speak may remember how she likes to scrape her forearms hard with an eraser. Stephen Shore once met a woman on the spectrum who said that she really needed a sexual partner to use firm pressure. “If a woman has such a need she has to be very careful because there’s a risk of abuse.”

Author Jerry Newport sees tactile defensiveness in sex as the symptom of a rushed approach to life, a general reluctance to linger—perhaps fueled by general anxiety. “Sometimes we on the spectrum approach everything with a somewhat frantic ‘get it over with and move on’ attitude. The key is to slow down and enjoy, sensually, the entire world around you.” He suggests that sensory defensiveness can be reduced by stroking a pet, exercise, certain medications, deep pressure hugs, or meditation.

Online dating can be attractive to people on the spectrum, because there are no worries about making eye contact or other behavioral traits. For many people, online dating sites offer a way to avoid the anxiety and awkwardness they feel about approaching strangers in a public setting, or the pressures of telephone banter. (“The phone is an evil, dangerous thing,” says Beatrice, not entirely joking. She met her husband through an online support group for depression.) “There aren’t any non-verbals to keep track of and it’s not temporal in nature; an online chat or IM is always there and you can refer back,” says Stephen Shore. “At the same time, there are people out there who might be dangerous.”

Ted, a Long Island journalist with AS, says, “I try to be conscious of it, but my head goes down a lot, which doesn’t bode well when I’m meeting someone.” He has dated several women he met on Match.com and Chemistry.com, relationships that have tended to be brief (the longest lasted five months). At WrongPlanet.net, an online resource for people with autism and AS, people seeking relationships are frank about their quirks and desires: “I’d like to meet a chick within 10 years of my own age who has an appreciation for logic and pragmatism.” “Most people with my rough exterior might see me as disengaged or distant or whatever, but I just think of it as my extensive warm up period.”

People with AS are more at risk of exposing themselves to danger, and more naïve about the opportunities the internet offers for deception. Zosia Zaks has clear recommendations on internet dating and safety in her book (p. 193, see resources below). Dealing with the online social media, the usual warnings apply. Sally Fogel would like to eliminate Facebook and MySpace: “I worry about people with bad
intentions trying to find the most vulnerable person.” Safety trumps privacy, she says: parents must supervise their children, checking every friend request and deleting approaches from anyone they don’t know. Posting an obscure profile picture is safer than one’s own photo. The safest route to dating, Fogel says, is improving peoples’ social skills to the point that they can meet in person, perhaps over a shared interest or at an AANE group.

The experience of gay and lesbian Aspies is complicated by an added layer of societal misunderstanding and judgment. “It combines the stigma of people with disabilities not being thought of as sexual, and the stigma that can still exist against people who are gay or lesbians,” says Sally Fogel. Gay, lesbian, and bisexual people with AS need considerable support. There is anecdotal evidence that Aspies are more likely than neurotypicals to identify themselves as non-heterosexual, although (as with asexuality), the reasons for that may be complex. Beatrice sees her decision to come out as a lesbian in high school as linked to her Aspergian worldview (although she hadn’t yet been diagnosed). People with AS may be somewhat removed from social constructs, including gender. “Other people who didn’t fit the gender norms were sometimes the only community that made sense to me,” Beatrice says. “As someone who didn’t experience myself as ‘automatically’ a heterosexual woman, I can relate to anyone who has found that trying to be someone they’re not takes far too much effort.”

Any significant relationship carries the risk of a painful ending, as when the other person loses interest for reasons that are never articulated or understood—an experience shared by neurotypicals. For those with AS, however, other peoples’ motivation and behavior are particularly mystifying. Ted describes a woman he dated several times who initially seemed to reciprocate his interest: “All of a sudden she did a complete 180. They don’t want to tell you, they come up with excuses. It’s hard emotionally.” Ted (who has so far chosen not to disclose his AS diagnosis to girlfriends) acknowledges he tends to talk obsessively about sports, and suspects women may politely conceal their boredom. He has tried to educate himself via popular culture, with limited results. “I used to watch dating shows like “Blind Date” where you’d see certain guys talk about themselves the whole time. I always try to ask a lot of questions, not dominate the conversation, but sometimes the girls I meet are on the quiet side… I try to be myself, be honest, but it doesn’t seem to work.”

In such circumstances an adult social pragmatics group can be helpful, says Sally Fogel. Ideally this would be designed for individuals with AS, but it is worth investigating courses in dating and conversation skills such as those offered in adult education catalogues (e.g. from Brookline, Newton or Cambridge, MA). Such courses also demonstrate that similar concerns exist for people without disabilities. “While reality or dating shows might clearly show ‘what not to do,’ talking in a group of other singles about their fears, concerns and confusion might be extremely important,” says Sally Fogel.

Romance and sexual intimacy are often hard-won for people with AS. The challenges are real, yet so is the potential for progress. Relatively small successes are meaningful, and can make the difference between a sense of personal failure or growth. “I used to think I was cursed,” says Ted. “When I finally went out with a girl it was just for seven weeks, but it felt like a big burden lifted off my shoulders. If I get into a relationship, great. If not, I’m okay, it’ll happen eventually. I’ve gotten to a point where I’m kind of at peace.” For Beatrice, her growing Aspergian self-awareness is proving the key to success in love. “The biggest and best thing, finally in my second marriage, is that I have dropped so many of the defenses and compensations that kept my disabilities hidden. It’s much easier to meet challenges with a clear picture of what they are. I’ve grown so much with the truth.”

Resources
Books are available through the AANE online bookstore http://www.aane.org/asperger_resources/recommended_reading_spouses.html.

Adults with AS and/or their partners may contact Jamie Freed, MSW, AANE Director of Adult Services to learn about AANE support groups and other services.

Sally Fogel is certified by the American Association of Sexuality Educators, Counselors and Therapists (AA-SECT) and has an M Ed in counseling. smfogel@hotmail.com


Aston, Maxine, Aspergers in Love: Couple Relationships and Family Affairs, Jessica Kingsley Publishers

Attwood, Sarah, Making Sense of Sex: A Forthright Guide to Puberty, Sex and Relationships for People With Asperger’s Syndrome, Jessica Kingsley Publishers

Baker, Jed, The Social Skills Picture Book for High School and Beyond, Future Horizons, Inc.

Baker, Linda J. and Lawrence A. Welkowitz, Asperger’s Syndrome: Intervening in Schools, Clinics, and Communities, Routledge


Newport, Jerry, Mary Newport, and Johnny Dodd, Mozart and the Whale: An Asperger’s Love Story, Touchstone

Newport, Jerry and Mary Newport, Autism-Asperger’s & Sexuality: Puberty and Beyond, Future Horizons

Shore, Stephen M., Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome, AAPP

Stanford, Ashley, Asperger Syndrome and Long-Term Relationships, Jessica Kingsley Publishers

Walker, Chris and Gisela Slater-Walker, An Asperger Marriage, Jessica Kingsley Publishers

Zaks, Zosia, Life and Love: Positive Solutions for Autistic Adults, AAPC

For more books, see http://www.aane.org/asperger_resources/recommended_reading_spouses.html.

For more articles, see www.tonyattwood.com.au/index.
Congratulations, JP!
Easter Seals and Google SketchUp teamed up to launch Sketch-A-Space, a first-of-its-kind online competition that offered people with autism an opportunity to design their ideal dream space using Google SketchUp’s free 3-D modeling software. The Grand Prize and $2000 went to John Paul Saikili, a young adult in the AANE community, for his “Ultimate Video Game Room.” This space features a puffy sofa, cozy carpeting, a calming magenta lava lamp, a HDTV and a surround sound system, a video game vending machine, and relaxing, dimmable lights. John says, “The Ultimate Game Room” is specialized to be a comfortable and relaxing environment for playing video games.” See JP’s design at: www.easterseals.com/sitePageServer?pagename=ntle8_sketchaspace.

LEFT: “Giraffes” by Natalie Weaver
“I drew the giraffes on special paper used for soft pastels, and used soft pastels to color the giraffes. I then scanned the giraffes and had the color increased and printed out on thick, white paper. I then used an X-Acto knife to cut out the giraffes and glued them onto thick, blue paper. I actually printed out 40 of them, cut out 40 of them, and glued 40 of them. In the end, I had 40 greeting cards. The blue paper was long enough to fold into a 5 by 7 inch card. I paint and draw as a hobby and normally do acrylic on canvas or soft pastels on paper. I almost always draw animals.

ABOVE: “The Masked Horse,” painting by Cynthia Cepedia, age 17. Cynthia will soon begin her studies at the Art Institute of Boston, where she plans to major in Illustration and Animation. For a digital drawing by Cynthia, please see p. 7.

BELOW: “Fall Reflections” by Gary Hudson
For more about Gary, please see p. 33.
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WORKAROUNDS FOR ASPERGER SYNDROME

I’m writing this article to help my friends and family—and other people—understand the workarounds I use to manage Asperger Syndrome (AS) and get along with people who don’t have it. This is based on personal experiences; other people with AS may have different stories to tell.

It took me over 25 years to develop these strategies. I’m in my 30s and am still working on some of them. I’m “high-functioning,” was diagnosed at age 29, have been working since age 17, and have a graduate degree. Most people who know me are not aware that I have AS, so I developed these skills in a “sink or swim” situation where everyone assumed I would be neurotypical.

Here are the strategies I use to manage AS in everyday life. At the end of each bullet point, I’ve mentioned ways that other people can make my life easier. I hope people will benefit from these insights.

1. I exercise for an hour or more, four times a week. I exercise because it’s the best way of preventing anxiety from interfering with my life, not because I agree with the dominant culture’s views about fitness. I also solve problems and get ideas while I’m exercising. If I skip networking events to go to the gym, this is why. If I seem fitness-conscious, don’t envy me; I am doing this to reduce anxiety and it is not optional.

2. I take “time outs.” I’m an extrovert, but I start feeling “talked out” quickly. At any group events—especially conferences—I seek out hiding places. I will even use bathrooms and fire escapes if I can’t find anywhere else to go. You should expect to see me avoiding people occasionally. If you see me making a quiet exit, please don’t invite me to rejoin the group; I will come back when I am ready.

3. If I am upset, I prefer not to work it out verbally while emotions are still high. If we have a problem to solve, try not to discuss it while I am still anxious. I’ll probably become defensive if you take that approach. Although I may seem angry, my defensiveness is really an instinctive attempt to get personal space so I can calm down. The best thing you can do is to let me get some time alone to write, clean the house, and/or exercise.

4. I avoid being around kids who are making noise. Because it’s mostly high-pitched sounds that irritate me, I can enjoy going to a rock show but can’t deal with kids crying or trains squealing. This is one of the main reasons I don’t plan to have children: I can’t deal with the noise and distraction. People sometimes make the mistake of assuming I “ought” to want to have children, or that my decision not to do that is self-centered. Although I have several other reasons for not becoming a parent, the main reason is that I just can’t tolerate kids well enough to live with one.

5. Multi-tasking is counterproductive for me; I need to keep things clear and simple. I’d be the world’s worst short-order cook. I like to do physical activities while talking, since moving around helps me listen. Putting a stack of unsorted papers in my in-box is a good way to make me anxious. Making impossible requests is another good way to do that. I am very responsible, so trying to meet unrealistic goals will burn me out. If you see me simplifying and organizing my “to do” list, don’t be surprised. I’m also unlikely to use my cell phone while talking with someone. I would be very grateful if people stopped pressuring me to adopt a lifestyle that requires intense multitasking. For example, people often assume I should be comfortable with having children, teaching college classes, and/or holding two jobs at once.

6. I analyze things people say and do. I’ve become much better at reading cues over the years, especially nonverbal ones; before I was 23, I often missed them. I still spend a lot of time writing in my journal about how people communicate. I learned how to dress well at work, how to negotiate conflicts, and how to work cooperatively by reading books. I’ve even read books on body language. I use some of what I learn to help other people understand and appreciate differences. If I ask you for a reality check, I don’t need sympathy: I just want to make sure I am assessing the situation accurately. You can also let me know if I overlook some important cue.

7. If I want to remember something, I write it down. I bring a notepad with me everywhere (or take notes on a cell phone). If you tell me something, even during a lecture or class, the odds are that I will forget it in less than an hour. Also, if a plan or chore doesn’t make it into my in-box, notepad, or calendar, I don’t usually remember it. I put every task on my agenda into my calendar eventually. Repeated verbal reminders can frustrate me because I know I might forget them. If you think I might forget something you said, write it down or send me an e-mail.

8. I seek out friends and social groups that value nonconformity. Even if I have superficial qualities in common with a group, I will challenge their dominant beliefs sooner or later. Although it might look as if I’m being anti-authoritarian, it’s more accurate to say that I don’t value the group consensus just because it’s the consensus. I’m a natural whistleblower. I can be tactful at work, but in social settings I need to be able to question the status quo to feel comfortable. I have unconventional opinions about multiple social and political issues. Over the years, I’ve grown tired of apologizing for my views, so I seek out friends who will support me. If you see me questioning the status quo, don’t take it personally. I’m not challenging you; I’m challenging your ideas. If you show that you respect my tendency to question the consensus, I am much more likely to make friends with you than I would be otherwise.

9. I like having personal space and can be very protective of it. A request for a hug can be OK, if I’m making friends with you, but any physical contact that is unexpected or doesn’t involve a request will mean that you lose my respect and trust. (This is especially true if you initiate it more than once.) I also avoid holding hands with strangers. If you want me to trust and respect you, don’t initiate physical contact—other than shaking hands—until we’ve at least gone out for coffee.

10. Because I don’t take group values as my standard, but I also value fairness, that makes me politically non-dogmatic. I am much more open-minded than most people I meet, but I also tend to stand up to behavior
that I find oppressive. I believe good fences make good neighbors, but that also means it isn’t my business what sort of garden my neighbor is planting on the other side of the fence. I’m very unlikely to judge you based on your background, but I will judge you if you don’t treat people well—and I may even give you feedback about it.

11. The clothes I wear don’t necessarily mean anything about my identity. I tend to wear a wide range of clothing—unless I am trying to seem predictable, which I do sometimes. Because I am not really invested in having an image that matches a cultural group, I buy whatever I think looks interesting. If you see me wearing something that you think might not be appropriate—or may be wrong for the weather—it’s OK to let me know.

12. I experience the world visually. I also solve problems by using visualization, mind mapping and drawing. I am visually perceptive, remember faces but not names, and notice details that other people do not see. In high-traffic and well-lit areas, this can be very distracting. I’m likely to feel better at a rock show than a street festival. If you ask me to remember how something looks, visualize a solution to a problem, or find directions to a destination, I can almost always do it. I can even remember phone numbers this way.

13. In addition to being visually alert, I’m sensitive to bright light, so if you see me dimming the lighting, wearing sunglasses, or even turning off some lights entirely, don’t be surprised. I’m very uncomfortable with fluorescent overhead lighting and avoid some stores where it is too bright (like Target and IKEA). Asking me if I want the lights turned down is a very positive gesture—especially since most people don’t even think of this.

14. I have very limited depth perception. (I’m not sure how much this is related to the AS.) I spent the first 17 years of my life thinking I was no good at sports because I couldn’t catch a ball, even though I did well in gymnastics and hockey. Now I do athletic activities that don’t require using a ball. This also affects my driving; I’ve gotten much better at merging into traffic, but parallel parking is still a challenge.

15. I’m relatively objective, so I give and receive constructive criticism well, as long as it’s stated in a way that lets me take action. Because I’m idealistic and logical, I like honesty, too. Saying “You are a _____” or “You always _____” isn’t helpful; saying “You’ve been doing _____, and it isn’t working for me” is a better approach.

16. I’m extremely practical and interested in problem-solving. This is true for most topics, including conversations about spirituality. Almost everything I do gets applied to problem-solving sooner or later. If you want me to listen to a story and not offer solutions, let me know; I don’t mind.

17. Time management is challenging for me. I am late sometimes because I underestimate the amount of time required for transportation and getting ready to leave the house. I’ve made a lot of progress with this; in grade school, I was late every morning. Now, it’s much less common. If I’m five or ten minutes late, it isn’t a sign of disrespect—it just means that I didn’t remember to allow time for something.
What does it take to make it in the NT workplace, anyway?
Barbara Bissonnette, Principal
Forward Motion Coaching

An adult with AS whom I’ll call Kevin summed up a big part of the problem. He was crushed after losing his first post-college job in just six weeks. “At school it was about getting good grades,” he said. “At work it’s about figuring out what people want.”

If you are a person who has AS, figuring out what people want probably seems like an impossible task. No matter how hard you try, you just don’t “get” the way NTs (neurotypical people) do. At work, people can say one thing but mean another. They accuse you of not listening, and yet won’t tell you exactly what they want from you. When you guess, you often guess wrong.

It is exhausting to be anxious every day about saying or doing the wrong thing. You want to interact with your co-workers, but don’t know what to say. Sometimes, their conversations seem so trivial or boring that you don’t even try to join in. At other times, you think that you’re being friendly and helpful but are accused of being “rude” or “hard to get along with.” Why all the emphasis on socializing anyway? What is more important: chatting in the lunch room, or getting your work done?

Speaking of getting your work done, the continual interruptions make it so hard to concentrate! You lose track of what you were doing, or forget altogether. The pressure starts to mount. You’re getting confused. Soon, you become paralyzed. You are not sure what you should be doing, so you abandon the current project and return to an earlier task. Later, your supervisor says that you need to prioritize better.

On top of all this, you are assaulted by sights, sounds, smells and textures that are uncomfortable (even torturous) for you, but that no one else seems to notice. Why can’t people turn down the lights, be quiet, and stop eating noxious-smelling food at their desks?

It’s all very frustrating, and sometimes makes you really angry, particularly if you have been fired once (or more than once) and you don’t really know why. What are you supposed to do differently now? It keeps getting harder to explain the employment gaps and short-term jobs on your resume. You shouldn’t lie, but you’re afraid that if you tell the full truth, no one will want to hire you.

Perhaps you are employed, but struggle to carry out job duties. Perhaps you are bored in a position that doesn’t make use of your intellect. Perhaps you have a new supervisor who has changed all the rules, leaving you once again to frantically try to figure out what is expected of you now. Maybe you have earned a promotion where you are required to show “leadership” and now have no idea what to do.

At times you wonder whether you should disclose your AS to your employer. Technically, the Americans with Disabilities Act protects people from discrimination. In the real world, however, it is hard to predict how your manager will react, and proving discrimination can be difficult, time-consuming, and expensive. Still, disclosure means that you can request accommodations, which could improve your performance dramatically.

If you can relate to any of the situations described above, then you have a lot in common with the clients in my coaching practice. They are men and women who, like you, are smart and skilled. Most have college degrees, and some have master’s degrees or doctorates. Some are young people who are just entering the workforce, while others are people in their 30’s, 40’s, 50’s and even 60’s, who have spent years at work in all kinds of fields.

Although they have been diagnosed with AS (or strongly suspect that they have it), each person is unique. For some, holding on to any job is an incredible challenge. Others maintain steady employment. Even those who stay employed and earn promotions often struggle to communicate with co-workers and understand workplace expectations.

All are trying to figure out just what it is that NTs want!

What can you do about it?

As an NT and a former business executive, I act as a bridge between individuals with AS and the neurotypical workplace. Until the day when most companies are “Aspie-friendly,” the burden is on you, the employee with AS, to find ways to fit in. Even if you opt for self-employment, probably you will still have to interact with neurotypical customers, vendors, or employees.

The work of fitting in is not about changing who you are as a person: it is about changing how you approach situations and interact with others, so that you can function more effectively at work. It can be about finding a job that capitalizes on your strengths, while discovering ways to minimize or work around your limitations. People ask me sometimes why NTs are so “mean,” or why Aspergians (people with AS) are the ones who have to do all of the changing. NTs aren’t mean—but they are in the majority. Most of them know little or nothing about AS. Despite the increased attention that AS has received from best-selling books, national magazines, and television programs, the general population (including business people) still doesn’t understand it. Understand it. Myths and misconceptions abound. I still meet people who think that everyone with AS is a genius or is working in the information technology industry. Most believe the stereotype of the loner who “doesn’t like people” and isn’t empathic. Some individuals think that Asperger’s is a personality problem.

Within the workplace, the lack of understanding about AS means that communication gaffes are treated as attitude or behavior problems. Executive function difficulties are interpreted as lack of effort or caring. The individual having
sensory issues is considered demanding and picky. Should it be like this? No. Will it change overnight? No. Will it change someday? Yes. But what do you do in the meantime?

- Choose a career wisely, based on your interests and strengths.
- Learn how to communicate well enough to get along with co-workers.
- Be open to new ways of doing things.
- Ask NTs for help. (They are everywhere, so why not use them?!)  
- Do not allow bad experiences from the past to make you angry and bitter. Instead think about how you want people to perceive you.

Remember, everyone has to fit into cultural expectations and norms. During my corporate career there were times that I had to work with people whom I didn't like, adhere to policies that I thought were silly, and settle for doing work that was just "good enough" instead of outstanding. I experienced periods of boredom, uncertainty, and frustration. I found some senior executives thoroughly intimidating. No job is perfect—but putting up with the hassles can be worth it when you get a regular paycheck, health insurance, paid vacation, and sick time.

This is not to minimize in any way the very real challenges that the majority of people with AS face at work. It is to let you know that whenever groups of people get together, there will be some conflicts, power struggles, and frustrations. NTs have problems on the job, too!

**How to approach change**

Choose one or two areas to focus on at a time. Trying to make too many changes at once is overwhelming. You might need help from a neurotypical who can translate some of the techniques into a plan that addresses your specific needs. This person can be a professional coach, a psychotherapist, or just someone in your personal life whom you trust. Perhaps there is a colleague at work you have a good relationship with, who can help you put some of the ideas into action.

Action is the key when you want to make a change. Usually it is the small, consistent steps taken over time that get big results. You don't have to do everything perfectly, either. It takes practice to master a new skill. The most successful clients I work with are those who are willing practice new attitudes or behaviors, even though they initially feel uncomfortable. What they discover is that the more they do something, the more at ease they become with it.

Motivation is a factor when you are making changes. The best way to maintain your focus and determination over an extended period of time is to set a meaningful goal. When it comes to work, sometimes the big motivator for change is fear—usually fear of job loss. Even if this is your primary
Residence Life
University
Main Street
Collegetown, MA 02454

May 30, 2008

Re: Housing request for College student

College Student is a current patient with a diagnosis of Asperger Syndrome. Although he functions well in an academic environment, there are a number of factors related to his condition that suggest he would be most successful if the university were able to provide a housing placement:

In a single room
At one of the First Year Experience Residence Halls and
In which his resident advisor pays particular attention to Student’s joining in with freshman social activities.

Sensory issues
As is the case with many people on the autism spectrum, certain environmental conditions may cause significant discomfort and stress. In Student’s case, he has very narrow tolerances for noise and light. He prefers to study with background noise such as the TV or radio; however, he can not study or sleep with loud music in the background. Similarly, he prefers to sleep in complete darkness and has trouble falling asleep if it is too bright or if there is a light on in the room. Because of his sensory preferences, Student does all of his studying in his room and if would be difficult to work in a library or other public space.

Social issues
Student functions very well in both large and small group situations. He continues to have challenges in 1:1 social situations as he is not good at reading non-verbal cues in tone or body language. He is not good at negotiating or compromising if he is sure he is in the right. While he has improved enormously in social functioning, I do not feel that he has the social competence to get along in a roommate situation without significant support and facilitation.

Dysgraphia
Student has writing challenges that he has learned to overcome, in part, by the use of voice recognition software (Nuance, Dragon Naturally Speaking). It would be very disruptive to a potential roommate to study while Student is “writing” a paper, and difficult for Student to speak loudly and clearly while worrying about disturbing someone else.

Medication
Student takes medication on a daily basis to control impulsivity and increase his ability to concentrate on a particular task. It would be better for him to keep this private. He will be locking his medication away for safety reason, but it would be best if other people did not have knowledge of or access to these medications.

At the same time I am recommending a single room, I do not want him to be socially isolated. Therefore, I am also hopeful that you will be able to place him in housing with peers. It will be important that he develop positive social relationships with the other freshmen and I sincerely do not want to compromise potential social relationships by “depriving” him of a roommate. I hope you will be able to accommodate Student’s special circumstances by providing him with a single room in one of the First Year Experience Residence Halls, and that you will make sure that his resident advisor pays particular attention to Student’s joining in with freshman social activities.

Sincerely,

Hans Asperger, M.D.

cc: Coordinator of Disability Services, Parents
Vignettes from Two Lives

Spring seems to be coming a little early in Portland, Oregon. I, along with 2 other people, helped a neighbor with her planters. The moorage is taking them to use for landscaping as she is unable to attend her garden at this time. You may not believe how many gardeners live on the floating home. Tasha and Ivan, across the way, grow strawberries and catnip. They also have a palm tree in the backyard. Shelly, a few house down, grows tomatoes. Of course, there is plenty of algae around. On the plus side, any dead leaves or biodegradable residue from any gardening is plopped into the river, to the Pacific. Also, there is no excuse not to go inside to fill a watering can. Scott and I like the moorage and will most likely stay at our rental for another year.

- Michelle Knight

Hi Jamie,

I am so very happy to know you. I remember first meeting you and how despondent I was. I had always thought that I was something different but reading all those symptoms and having them line up in that manner went right through me like a spear. The universe hadn’t played a joke on me, I was the joke.

My own mother thought I was making it up for some reason or other and though that if it were true it was because she had been a bad mother. So many times I thought maybe not, but then it all comes clear. I have sureness now that Aspie is what I am and Aspie is a good thing to be. I know there are so many levels to this Spectrum of which I am a part and being of the superior intelligence region of it my duty is to speak for those who cannot, for the are surely my kin and have similar software to run their brain.

I am finding that in my work the NT’s with mental illnesses are people which I can communicate with easier than those without. Our staff though I must admit is only made up of nurture type NT’s so I get on with them well too.

That I have been brought up to management level pay and will be expanding my Art project into other Regions of Fellowship Health Resources, Inc. has my head spinning. I am doing well at this and being accepted not because I am so schooled at being a false NT but because I am allowed to simply be my Aspie self. It is indeed a “Brave new world which has such people in it.”

I also wish to thank you for your kindness and help and for taking some time to listen to my prattling on in aspiespeak as I sometimes will do.

I look forward to the concert and hope that you will be there. It always means a lot to me to see you.

Sincerely,

G.E.H.

Gary has exhibited work, including a hand-made bodhran (Irish frame drum), at AANE art shows. Many AANE members have also enjoyed Irish music concerts presented annually in March by Gary and some of his musician friends. You can see one of Gary’s paintings on p. 19.
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Mark & Nilima Abrams

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Thank you so much for helping us to furnish our new office!
Creative Office Pavilion
John Nealon Realty
Yale Appliance

Thank you to our dedicated volunteers and committee members!

The AANE Journal is published twice a year: once in the spring/summer and once in the fall/winter. Please submit articles or ideas, stories or poems, drawings or photos, to the Editor at Stephanie.Loo@aane.org.

We are so grateful to the advertisers who help subsidize the AANE Journal. For information on advertising in a future issue, please contact Stephanie.Loo@aane.org.

Articles in the AANE Journal represent the views of their authors, and are not necessarily those of AANE board or staff members. Our aim is to give you information so that you can make your own judgments and decisions.

Production Editor for this issue: Jana Vijayakumar
Thank you so much to our LAUGH OUT LOUD Gala Chairs & Committee Members!

Co-Chairs: Natasha & David Chomas, Lynn & William Flaherty, Jill & Steve Purpura

‘GOODBYE’ FROM KELLY M. GENOIS, DIRECTOR OF FUNDRAISING

I am thrilled to report that, thanks to the incredibly hard work of our committee, the 2011 Laugh Out Loud Gala was our most successful ever, with 450 guests helping AANE raise $420,000. We had great auction items, great food, great speeches, plus great entertainment from comedian Steven Wright.

As of May 27th, I am leaving my position at AANE in order to pursue graduate studies in screenwriting at the Boston University School of Communications. While I am very excited about this new step in my own life, I will miss my many friends in the AANE community. I have thoroughly enjoyed working on three Galas, two annual appeals, and many other fundraising events to support AANE’s outstanding work on behalf of the AS community. I hope to stay involved in some volunteer projects -- look for me at next year’s Gala!

Thank you Committee Members

Deborah Allaire, Jill Avery, Veronica Bacon, Alma Blair, Julie Betters, Elaine Harmon, Connie Johnson, Yolanda Kolinski, Diane McGrath, Melinda Miller, Nasha Miller, Grace Peng, Allison Sargent, Nancy Schwartz & Lori Zegarelli.

Thanks also to our intern Lisa Glasheen, Emmanuel College ’11.

AANE board member and Gala committee members Grace Peng and Nancy Schwartz, Board President, with Michelle Alkon, AANE Coordinator of Adult Services
SAVE THE DATE

Cape Cod Summer Conference
Brenda Smith Myles
Thursday, August 11, 2011
Cape Codder Resort, Hyannis, MA
Register now at aane.org

Jody Afcord Spirit Conference
Know Yourself: The Key to a Better Life
with Rudy Simone
Saturday, July 23, 2011
at Northeastern University
An AANE conference exclusively for adults with Asperger Syndrome.

Asperger Connections 2011
October 14-15, 2011
in Marlborough, MA
with Dan Coulter
featuring workshop galore & ‘Seeing With a Different Eye’ art exhibit.

Asperger Academy for Parents:
Success After High School for College Bound Students with AS
with Jane Thierfeld Brown, Ed. D. & Lorraine Wolf, Ph.D.
November 5, 2011