Anime and manga maven

Anime & Manga Flourish at AANE
(Story on page 3.)

Castle Iza by Atsuko

Dodge Ryu by Atsuko

Anime and manga maven
In July, our adult community gathered at Bentley College in Waltham, Massachusetts, for Know Yourself: The Key to Success 2008, AANE’s second annual conference exclusively for adults with AS and closely related conditions. After the keynote address by author, scholar and parent Valery Paradiž, conference participants attended a variety of wonderful workshops and panel presentations. We are very grateful to our underwriters, the Nancy Lurie Marks Family Foundation, the Shamus Family, and the Massachusetts Developmental Disabilities Council. We also thank our exhibitors: the College Internship Program, Chapel Haven, Barbara Bissonnette/Forward Motion Coaching, Jewish Family and Children's Services, Life Coach Ellen Korin, and the MGH Bressler Clinical and Research Program for Autism Spectrum Disorders.
MESSAGE FROM AANE’S EXECUTIVE DIRECTOR

Dear Friends of AANE,

With input and support from our whole community, AANE has continued to develop at amazing pace over the past few months. In this journal you will meet some new AANE staff members, and hear about some exciting new programs. In fact, so much has happened recently that this publication can’t contain it all! I invite you to see and read more on our web site, in the spring 2009 issue of the journal, or on our brand new blog. You can sign up for the blog from the homepage of our web site, www.aane.org.

The Asperger Connections 2008 conference attracted almost 600 people on each of the two days, and featured outstanding keynote addresses by Dr. Daniel Rosenn on Friday, and from the amazing duo of brothers and authors John Robison and Augusten Burroughs on Saturday. Filmmakers Lizzie Gottlieb and Kaz Gamble also gave moving presentations about their adult brothers with AS. If you missed the conference, take heart: some of the articles in this issue are by conference workshop presenters. Also, this year for the first time you can order a DVD containing the handouts from most of the workshops. (See the publications page of our web site.)

To mention just a few exciting developments at AANE:

- Read about our new LifeMAP program on page 5.
- On December 13th, come hear Nick Dubin speak on Asperger’s Syndrome and Employment: The Ultimate Test.
- Be sure to save the date of January 16th for a talk by Dr. Roy Richard Grinker, author of the fascinating book Unstrange Minds.
- Please join us on May 9th for the AANE spring gala.

Finally, I would like to ask for your continued support. In these tough times, our programs and services are more necessary than ever—and so is your support. Please make AANE your top priority for tax-exempt charitable giving, and give as generously as you can. Use our annual appeal card, or give online. So many families and individuals continue to need our services—and over the coming months, so many first-time callers will be filled with relief when we let them know that they are not alone in facing the challenges of living with Asperger Syndrome, but part of a wonderful community. Thank you for being part of our community. We wish you an excellent 2009—and please keep in touch!

Sincerely,

[Signature]

Please note that 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.

MESSAGE FROM AANE’S EXECUTIVE DIRECTOR

AANE Journal      Issue 3        Fall 2008

Manga and Anime at AANE

Atsuko, a gifted artist and an AANE summer intern, created the graphics on our cover for our teen anime and manga day in August; Jacob Rittari, Stephanie Loo’s son, spoke at that event as well as for our adult anime club’s August meeting. Catherine Mayes recruited manga artist Bettina Kurkoski (Camp Lake) to teach manga madness workshops for teens at the ARC in Plymouth, Massachusetts this fall—just one of the exciting new teen programs funded by our longtime friends at the Edwin Phillips Foundation.

Atsuko is currently a senior in high school, and has been drawing in all her classes since fifth grade, when she was put into a private school. She is planning on becoming a manga artist of some sort eventually, and is currently working on a webcomic that will be called “Lock my Heart.” (And will probably start off by being posted at comicgenesis.com. Updates posted on DeviantArt.) It is a continuation of a short comic that she will, at some point, submit to Tokyopop, and is used to vent her feelings without involving anyone in real life. Atsuko specializes in the manga style, but has recently been experimenting with abstract and street-art styles. Aside from art, she likes trying to do parkour (Look it up!), eating chocolate, and observing people. She dresses like a Japanese Gothic-Lolita, and is learning Japanese constantly. She, of course, has Asperger’s Syndrome, has few friends, but she loves the friends that she does have, and is inspired by them to draw every day. See more of her wonderful work at:


Thank You, Donors!

We depend on you! Donate to AANE any time, online or by mail. Consider a gift in honor of a relative, friend, or educator during the holiday season. Some families invite friends to donate to AANE in memory of a loved one, or to celebrate joyful family occasions. See a list of donors on pages 34-35.

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

We are so grateful to the advertisers who help subsidize the AANE Journal. For information on advertising in the spring issue, please contact carynn.meyers@aane.org.
Dear Friends,

First of all, I want to congratulate AANE’s staff for such a fine fall conference, *Asperger Connections 2008. John Robinson* and *Augusten Burroughs*, along with Dr. Dan Rossen, anchored a simply fascinating event. *Kaz Gamble* and *Lizzie Gottlieb* presented extraordinary films about their adult siblings. A wealth of workshops demonstrated the vibrancy of AANE and our community. Thank you to all those who attended. If you missed it, please join us next fall—or for some of our many classes, workshops, and support group meetings this winter and spring. Look online, or call, for a brochure listing workshops for parents, or for the adult activities schedule.

If you have called AANE recently, you may have noticed that there are a few more extensions to select from when looking for an answer to a question. Indeed, over the past years AANE’s staff has grown—and our office space, budget, programs and services have all grown, in response to the growing size and multiple needs of the AS community.

Last spring, we realized that it was also time to expand and refine our governance structure, so that we could tap into the expertise of a wider cross-section of our community, and coordinate all our efforts more effectively. Over the summer, we analyzed our needs, and invited many people in our community to become more intimately involved in AANE. We are thrilled that many people have accepted our invitation to serve on our new and continuing board committees. We will post a list of all committee members on our web site, but right now I would like to introduce our committee chairs below. Please see page 35 for a full list of members of our Board is of Directors—and feel free to contact any board or committee member with your ideas and concerns.

**AANE Board Standing Committees**

*Governance Committee*, Elizabeth McLaughlin and Nancy Schwartz, Co-Chairs; *Finance Committee*, Jan Saglio, Chairperson; *Strategic Planning Committee*, Dot Lucci, Chairperson; *Development Committee*, Steven Garfinkle, Chairperson

**Other AANE Committees: Program Committee**, Judy Gooen, Chairperson; *Executive Advisors* (works with Dania Jekel); *Educators’ Advisory Group* (works with Jean Stern); *Employment Committee* (works with Gail Kastorf); *Legislative Committee*, Dave Harmon, Chairperson; *DSM V Revision Committee*, David Pauls, Chairperson; *Gala Committee*, Ann Marie Gross, Jill Purpura, & Melinda Miller, Co-Chairs

Each year, to sustain and grow AANE, we raise money through our year-end annual appeal, and through our annual spring benefit gala. We are very appreciative to all those who have helped with contributions and donations—but we still need the continued and increased support of our whole community. AANE provides many free services to the community. We offer free memberships to families experiencing economic hardship, and scholarships so that people in need can attend conferences or workshops. Currently our family grant program has a long waiting list of deserving families—and the need is likely to increase due to the state of the economy across New England. I personally ask that if you are able, please consider donating—or increasing the amount of your gift—so that AANE can continue to serve families in our community who are struggling financially as well as emotionally.

Another way to change people's lives, including your own, is to volunteer. The staff at AANE is supported by dozens of volunteers who donate their time and talents. The annual benefit gala, which raises a significant portion of the budget, is completely driven by volunteer parents. Our Board of Directors and committees consist of volunteer parents, professionals, and adults with AS, all dedicated to our mission. Almost all are personally impacted by Asperger’s. So if you'd like to offer more support to AANE, but don't have deep financial resources, consider donating your time instead. Just contact Volunteer Coordinator *Lynn Flaherty* at ext. 329.

While AANE has grown, our mission and our commitment to our community remain the same. While we have new technologies to serve you, such as webinars, online support groups, and a blog, our staff still answers the phones every weekday to listen—and to provide information, support, and referrals, to help individuals, families, and professionals meet the ongoing challenges of living with AS. With your continued participation and support, AANE will survive the current economic shocks, and continue to be here for every person who calls or walks through the door.

Sincerely,

Hank Miller

---

**TABLE OF CONTENTS**

- Employment and AS .................................................. 5
- Tips for First-Responders ........................................... 7
- New Genetic Findings ............................................... 8
- Poetry ........................................................................ 9
- New Groups Forming .................................................. 9
- Married with AS .......................................................... 10
- Liam Says “Hi” ................................................................ 11
- Seven Insights for Reducing Anxiety .............................. 12
- No es un Secreto: Divulgación ...................................... 14
- Pressing Need for Adult Diagnosis ................................. 16
- Message from Kristen White; Honoring Volunteers ............... 17
- Perspectives Art Exhibit ................................................. 18

**Special Advertising Section** pages 18-24

- School Disclosure Sheet ............................................ 25
- Replays: Turn Problems into Fun ................................. 26
- New Staff, New Projects at AANE ................................. 28
- Connecting to Humans ................................................ 31
- Thank you to our Donors! ............................................. 33
- AANE Board & Staff List ............................................. 34
- AANE Members Around New England ......................... 35
Employment and Asperger Syndrome
Ashleigh Hillier, Ph.D., Assistant Professor of Psychology, University of Massachusetts Lowell.

Graduating from high school and transitioning to the world of work is an extremely important and exciting milestone. However, for many young adults with Asperger Syndrome (AS), employment can present some unique challenges. Despite the vastly increasing numbers of individuals being diagnosed with AS, adult services for this population are seriously lacking. Many young adults with AS live at home, are unemployed or underemployed, or participate in programs that are inappropriate or unhelpful, leaving parents worried about what the future holds for their adult children. Yet individuals with AS bring many strengths to the work place, such as attention to detail, trustworthiness, reliability, and low absenteeism. In addition, aspects of jobs that other employees may find unattractive, including social isolation or repetitiveness, often appeal to persons with AS.

Although demands for employment services for adults with autism spectrum disorders (ASDs) are increasing, currently there are few specialized services available and not much is known about how best to support those with AS. However, there are some strategies which may help empower young adults with AS to achieve rewarding, satisfying employment, and make meaningful contributions to their community and society as a whole. Strategies discussed here will emphasize the fundamentals, or “employment philosophies,” such as helping the individual realize what employment actually means, what jobs are like, and some of the realities of employment. These issues are critical for helping the young adults understand the importance of employment and the magnitude of the role it will (hopefully) play in their life.

Successful Employment: Preparation

Understanding the purpose of employment is critical for ensuring enthusiasm and motivation for the transition to the world of work. If the adolescent with AS does not fully grasp the fundamentals such as how important getting a job is going to be for them and why, a successful transition will be much harder to achieve. For adolescents who are used to having all their needs met by their parents, the idea of having to get a job on their own may be particularly appealing and may not seem urgent. Many adolescents with AS may be reluctant to even think about life after high school, when everything will change and there will be even greater expectations of them. It will be critical to spend time thinking about why it is important to have a job; what it means to have a job; what an employer is looking for in an employee; why being “independent” is important, etc.

Building a positive attitude and excitement about getting a job is also important. The young adult can be reminded of why this transition is so positive, e.g. they will have their own money, they will meet new people, they will learn new skills, they will have something to do during the day, they will increase their self-confidence and improve their self-image, etc. Employment can be talked about as something which will be exciting and enjoyable. Making plans for the future, setting goals adolescents would like to reach, and discussing how these goals can be achieved, will help maintain enthusiasm for employment, and also serve as a reminder that they need to be realistic in their employment expectations.

It is also important that young adults with AS have opportunities to gain insight into the huge variety of job options available and what these jobs are like. Well before high school graduation, adolescents can be encouraged to consider what career paths may suit them. Due to the abstract nature of imagining what a particular job would be like, it can be difficult for anyone to decide what job might be a good match. Constant observation and discussion of what other people are doing while you are out in the community can be helpful. This exercise can help the adolescent recognize the huge variety of possible jobs (e.g. sales clerk, manager, construction worker, engineer, librarian, etc.). Whilst observing others, or engaging in activities, questions can be asked such as: “What jobs are people doing when I go to McDonalds?” “There are the cashiers, the cooks, their managers, people who work where the food comes from (farms, processing plants), workers designing and manufacturing the packaging, building the restaurant, corporate management of the business/franchise, jobs in the banks that provide the financing etc.” “What jobs are involved in making this computer and getting it to me?” Answers could include designing the computer, manufacturing the parts of the computer, buying the parts from other companies that go into the computer, software design, managing the people that do these jobs, sales and marketing, accounting, advertising, shipping, retail, etc. Adolescents can be encouraged to ask themselves questions such as: What would these jobs be like? How would I get a job like that?

Another useful strategy is simply asking people the young adult meets (including friends and relatives) questions about their jobs such as: How did you get your job? What do you like/dislike about it? What qualifications do you need? How much do you get paid? (if appropriate), etc. People may be willing for the adolescent to visit their work sites for job shadowing experiences, where the adolescent can observe people at work for a couple of days. This will help enormously in exposing the young adult to a variety of jobs (not only the individual s/he is shadowing, but also all the others who work there), work environments, and realities of employment. Better still, actually volunteering at a company or organization will enable young adults to get hands on experience and try out different jobs. In addition, they can record these experiences on their resume, and have sources for obtaining references. Even if the volunteer experience is not a great match to the adolescent’s interests, s/he can learn a variety of skills that would be applicable to any job, such as responsibility, punctuality, reliability, interacting and communicating with others. S/he can also learn some of the realities of work such as having to do tasks which are less enjoyable, having to do things the way other people tell you to, only taking breaks at specific times, workplace rules such as no personal phone calls, no internet, etc.

Regarding the job application process itself, after some practice, searching for jobs, completing application forms, and preparing an eye-catching resume may or may not pose particular problems for individuals with AS. The internet provides some very useful resources in these areas and beyond, including free job interest inventories, statistics on various job categories...
such as typical salary and necessary qualifications, lots of examples of resumes, job hunting tips, as well as the websites for various companies and organizations where the individual may be interested in working. However, some young adults with AS may need a lot of support through this stage of the job search, due to their difficulties with executive functioning.

There are some potentially greater obstacles specific to the communication and social skills deficits seen in AS that relate to the job application process. These may include coordinating the job search process, communicating with potential employers by telephone, and identifying and tapping the individual’s social network for employment leads (often the most successful approach to finding a job). To coordinate the job search process, set up a table with columns for job title applied for, when applied, how applied, contact person, follow up date etc. Job seekers with AS can practice using the telephone by first calling relatives and others they know, and slowly expanding this to individuals they know less well, perhaps the doctor’s office or hair salon, and finally to potential employers. A script can be implemented to help the conversation go smoothly and ensure that the young adult gets all the information about the job or the next steps that they need to take. A “spider-gram” can be used to help the young adult brainstorm and identify all the individuals in their immediate and expanded social network.

The job interview may pose the most significant challenge for adults with AS, due to deficits in social skills and in “mind-reading.” Parents and family members can play an important role in conducting realistic mock job interviews, where the young adult can practice appropriate behavior and learn how to answer typical job interview questions such as: Why do you want this job? Why should I hire you and not someone else? What are your strengths/weaknesses?

Successful Employment: Strategies in the Workplace

Once young adults with AS begins their jobs, it may be useful for them or their supervisor to distribute a brief handout to co-workers describing AS and some of the characteristics the individual may present with. This will help co-workers understand the behavior of the young adult, and perhaps be more supportive. Identifying a co-worker who can serve as a mentors is also a useful strategy. Supervisors can be asked whether there are any employees who are familiar with AS or other types of disability, and who might be willing to serve in this role. This person can serve as an initial “go to” person when the young adult needs advice, or if problems arise. The mentor can also help integrate the young adult socially into the workplace, which is critical for job retention and job satisfaction.

Providing supervisors with specific strategies for supporting the employee will also be helpful. Although more employers will be familiar with AS than in the past, they may still have little idea of how to best support someone with AS in the workplace. Strategies used in the classroom remain extremely useful and are often easily adapted to the work place. For example, encourage supervisors to:

♦ Clearly define the job task; what exactly is expected?
♦ Break tasks down into smaller components if possible.
♦ Provide immediate, honest feedback on performance.
♦ Provide as much routine and predictability as possible.
♦ Provide predictable routines as much as possible.
♦ Minimize oral verbal instructions (perhaps provide written instructions), and allow time to respond.
♦ Provide models of the specific job skill.
♦ Allow the individual to complete one task before beginning another.
♦ Provide prioritized checklists and timelines for tasks.
♦ Provide a strategy to communicate when the employee needs help or has not understood.
♦ The individual may not easily interpret body language or sarcasm, read between the lines, etc. Clear communication is critical; lack of communication between employees with AS and their supervisors is a main cause of job termination.
♦ Be sensitive to accommodate any sensory issues the individual may present with that interferes with work.
♦ Explain authority hierarchy, to help prevent co-workers possibly taking advantage of the employee with AS.
♦ Encourage social interactions with co-workers.
♦ Explain the formal and informal rule structure of how things work at that job site. Explain unwritten (often social) rules of the workplace.

Meeting with other adults with AS can also be helpful during this transition. These peers can provide advice and discuss their employment experiences from an AS perspective, and help the individual realize s/he is not alone in experiencing certain challenges. Finding social groups for young adults with AS can be difficult, but they are increasing in number. Also, email chat groups on the internet can be found easily. Building a career brings positive and negative experiences for everyone. Remind the young adult with AS that mistakes and failures are useful learning experiences, to help them maintain a positive attitude towards employment when things don’t go according to plan. Quitting jobs, declining jobs, and sometimes even accepting jobs, can result in negative consequences—but these too can be seen as providing important information and lessons for future decision making.

Although it can be difficult, it is important for parents to allow their young adult children to become more independent, and to treat them as the adults they are. Allowing them to make their own decisions and choices—with guidance—will help them achieve employment success.

Please see: http://faculty.umb.edu/ahlilier/aspirations.htm


Interacting with Persons with Asperger Syndrome: Tips for Law Enforcement Personnel and Other First Responders

by Dania Jekel, MSW, AANE Executive Director

Because the number of people with Asperger Syndrome (AS) and other autism spectrum disorders is very high—there are perhaps as many as one in 250 individuals or higher—it is very likely that police officers, fire-fighters, and emergency medical technicians will encounter many children, teens, or adults with Asperger Syndrome or related conditions in the course of their duties. AANE offers training to help first-responders learn about Asperger Syndrome, how to recognize that a person may have AS, and how to work skillfully when encountering a person with AS. The recommendations below are drawn from our training materials. We encourage parents to use this page to let local police departments, fire departments, and emergency medical services know that they can contact AANE for training.

If first-responders can follow the guidelines below, they can lessen the probability of misunderstandings, conflict, or tragic outcomes.

Recommendations for interaction and intervention:

When you encounter someone who has Asperger Syndrome, or whose atypical behavior makes you suspect he or she may have an autism spectrum disorder, extra patience is required. Try to:

- Talk in a soft, calm voice.
- Try to reassure the person. Say things like: “We will work this out” or “You will be o.k.”
- In talking to this person, use direct, concrete language. Avoid sarcasm, slang, or figures of speech.
- Give simple instructions, one at a time.
- Be as logical as possible; give a clear concise explanation.
- Give the person time to calm down.
- Give the person time to process information.
- Don’t touch someone unless absolutely necessary.
- Don’t assume behavior is intentional. For example, if the person doesn’t follow your instructions, he or she may not understand, or not be able to do what you ask.
- If the person’s verbal response is unexpected, don’t assume he or she is “talking back” to you.
- Do not leave the person alone. With teens especially, there is a suicide risk.
- Try to summon a familiar, trusted adult to help resolve the situation—e.g. a parent, relative, guardian, teacher, youth group leader.

Prevention and Community Relations

- Maintain a “File of Life” and invite families to file information about their members who are children, teens & adults with AS or related conditions. Some departments also have systems that red flag an address where a person with a disability or medical condition lives, so that first-responders are prepared when going out on a call.
- Meet with parents of children individually as needed.
- Hold open community meetings to which you invite adults with AS.
- Police, fire, and emergency medical services can cooperate to hold a “Community Day,” in which when you invite families to bring children and teens with AS to visit a fire station, see the engines and police vehicles, and ambulances. (Contact firefighter Bill Cannata of ALEC at BCANNATA@SNCARC.ORG.)

The Asperger’s Association of New England (AANE) is a non-profit organization located in Watertown, Massachusetts.

- AANE serves all of New England.
- We have a staff of experienced social workers and educators.
- We serving individuals with Asperger Syndrome and related disorders (High Functioning Autism, PDD-NOS, and Non Verbal Learning Disability).
- We offer First-Responder Training.
- Feel free to contact us at 617-393-3824 to discuss training. Ask for Executive Director Dania Jekel at ext. 303, or Adult Services Coordinator Deborah Geheran at ext. 317.

Disclosure Tools

Look at www.aane.org, or contact AANE staff, for:
1. A wallet disclosure card that teens and adults with AS can carry.
2. A car visor/front door disclosure card, for use by the parents of younger children.

Ask if your police department maintains a “File of Life” where families can disclose medical information—or contact AANE for a sample first responder disclosure form that you can take along to open a dialog with your local police department, fire department, or emergency medical service.

AANE Connects with Watertown Police Department

AANE wishes to thank Officers Patty Grady and Sheila Grady-Duguay of the Watertown Police Department, who recently spoke to our Women’s Group about keeping safe, responding to police, and avoiding scams. Bekan Knox and Debby Geheran met with the officers prior to the group presentation, in order to discuss Asperger Syndrome and present the group’s questions. The presentation was extremely informative. And it was a great collaborative effort toward helping those with AS avoid unfortunate incidents with law enforcement, and to avoid falling victim to predators. We hope to work with these wonderful officers on future projects addressing these vital issues. AANE Executive Director Dania Jekel also provided training about Asperger Syndrome to Watertown Police officers.
New Genetic Findings from the Autism Consortium Collaboration

by Kira Apse, ScM, CGC, Autism Consortium Director of Family Research Network; Mark J. Daly, PhD, Autism Consortium Gene Finding Group and Center for Human Genetic Research, Massachusetts General Hospital and The Broad Institute of Harvard and MIT, and David T. Miller, MD, PhD, Autism Consortium Clinical Genetics Group and Division of Genetics and Department of Laboratory Medicine, Children’s Hospital Boston

The Autism Consortium (AC) is an unprecedented research and clinical collaboration bringing together over 60 researchers and clinicians from multiple Boston-area institutions, with a goal of enhancing the care of children and families affected by autism and related disorders. Members of the AC approach this goal by combining the knowledge gained through years of clinical experience with new breakthrough discoveries that come from collaborative research that brings together scientific experts from many disciplines and across many institutions, including: Beth Israel Deaconess Medical Center, Boston University and Boston University School of Medicine, the Broad Institute of MIT and Harvard, Cambridge Health Alliance, Children’s Hospital Boston, Harvard University and Harvard Medical School, Massachusetts General Hospital/ Ladders, Massachusetts Institute of Technology, McLean Hospital and The Floating Hospital for Children at Tufts Medical Center.

Underway for a year, the research and clinical collaboration of these many dedicated researchers and clinicians has already yielded exciting results. The Autism Genome Scan, the largest, most complete, genome scan for ASDs to date, was completed in October 2007, using data made available by the Autism Genome Research Exchange (AGRE), a program of Autism Speaks. Even before its researchers had completed their own analysis, the AC made the data available online to the scientific community through AGRE.

What valuable information has come out of the AC collaboration? Earlier this year, the AC team completed a comprehensive genome scan of more than 3,000 individuals, including 1,441 children diagnosed with an Autism Spectrum Disorder (ASD), and many parents. The idea was to look for tiny missing or extra pieces of their chromosomes. Chromosomes are made of DNA, and a missing piece of DNA could contain genes that—when missing—increase the risk of autism. We all have two copies of every chromosome, and thus two copies of every gene. The genome scan was designed to look for areas of a chromosome where one copy of those genes went missing, also called a partial deletion of the chromosome.

Published in the February 14, 2008 issue of the New England Journal of Medicine, this comprehensive scan identified a small area of chromosome 16 that plays a significant role in ASDs. The entire genome contains over 20,000 genes, while this part of chromosome 16—called 16p11.2—has only about two dozen genes. For unknown reasons, missing that handful of genes on chromosome 16 makes an individual 100 times more likely to have an ASD. In the majority of cases, the deletion was de novo: a newly occurring change in the DNA that the affected individual did not inherit from either parent. The authors verified the clinical importance of their findings through independent observations in the DNA Diagnostics Laboratory at Children’s Hospital Boston, a member of the AC, and at deCODE Genetics, Inc. in Iceland.

The AC team identified five individuals who had the de novo deletion, out of 1,441 with ASDs in the AGRE database. Independent observations at Children’s Hospital Boston DNA Diagnostic Laboratory found an additional five cases of the deletion in clinical genetic testing of 512 patients referred for developmental delay and/or suspected ASDs. An additional independent observation by deCODE Genetics demonstrated three individuals out of 299 on the autism spectrum who had the identical deletion, bringing the total in this three-institution study to 13 patients with the same deletion. Equally striking are the findings of gene duplications in the same region among the patients studied. Seven individuals in the AGRE database, and four individuals from Children’s Hospital, had extra copies of genes on chromosome 16, in a region matching the area where others had missing or deleted genes.

The discovery of new gene deletions and duplications has immediate clinical implications. The same technology used for the genome scan—called chromosomal microarray—is available for clinical use. This type of clinical testing can detect 16p11.2 deletion and duplication, in addition to other genetic changes associated with autism, in diagnosed patients and their parents. Additionally, Children’s Hospital Boston DNA Diagnostics Laboratory offers a customized test of the chromosome 16p11.2 region. Those who might consider testing include parents and family members of an individual with a 16p11.2 deletion or duplication, individuals who had an early version of the chromosomal microarray analysis where the genetic change could not have been detected, and individuals who are not able to have a chromosomal microarray analysis due to financial restraints or other reasons.

Within the next several months the AC plans to publish additional findings from the Autism Genome Scan. Additionally, the AC will publish a study examining results from three clinical genetic tests: karyotype (looking at the chromosomes under a microscope), fragile X DNA testing, and chromosomal microarray, performed at the five participating clinical centers. The results include the frequency of abnormalities detected by the three genetic tests. Chromosomal microarray analysis showed the highest detection rate with about 10% of individuals found to have chromosomal abnormalities associated with ASDs. Additionally, the study examined insurance reimbursement for clinical genetic testing performed for individuals with ASDs. The AC is working to increase insurance coverage for chromosomal microarray testing, and to make it part of the standard of care for genetic testing for ASDs, which currently includes karyotype and fragile X DNA testing.

In ongoing studies, AC researchers and clinicians hope to better understand the different subsets and spectrum of autism symptoms by extensively characterizing individuals with ASDs.
and their families, and to understand the contribution of genetics to specific traits. We are currently conducting a study for families that involves providing blood samples as well as an assessment battery including IQ tests, questionnaires and observations. Parents and siblings, along with the family members diagnosed with an ASD, are invited to participate. The study is conducted at all of our affiliated hospitals throughout the Boston area, or may be performed at a family’s home. At the conclusion of the study, a detailed report of the assessment results for the family member with an ASD will be provided.

For more information, please visit the Autism Consortium website at www.autismconsortium.org, or contact the research team at research@autismconsortium.org or by calling toll free at 1-866-518-0296.

Do You Hear The Music

Listen. New hymns are forming in the laughter of a friend.
Beneath your feet, the grass chants
snatches of songs even you haven’t heard of.
In the meadow, cows are practicing
ancient operas and cadenzas.
The dog beside you is flat picking with its feet
and accompanying itself on the collar.

When the cat claws on the screen, it is really saying it wants a washboard, a banjo, and a whole jug band.
If the fly’s buzz were slowed down, it would be a carol.

Listen. Your silence is a melody.
You will hear its refrain from a stranger, who was taught it by your absent friends.

In the distance, your heart is drumming.
When it arrives, this entire room will become an orchestra.

Listen. Can you recognize that the trees are humming
Happy Birthday and Auld Lang Syne? They have been rehearsing for months waiting to surprise you.

STORM 1977, 2003

Right: Bremen Town Musicians toys

To hear about the latest research on AS and autism, attend the free Wednesday afternoon lectures in the Autism and Developmental Disorders Colloquium Series hosted by the Brain Disorders Initiative at MIT.

These colloquia bring top researchers from across America. They are sponsored by the Autism Consortium and supported by the Simons Foundation and the Anne and Paul Marcus Family Foundation. To get email notice of upcoming lectures, contact lmavros@mit.edu.

Do you want to participate in a study? IRB approved research studies are listed on our web site: http://www.aane.org/make_difference/research_studies.html

New Groups Forming

AANE is offering new groups for people married to or in partnership with an adult with Asperger Syndrome:

♦ Women in relationships with men with AS
♦ Men in relationships with women with AS
♦ Gay men in relationships with men with AS
♦ Lesbian women in relationships with women with AS
Also:
♦ Men with AS who are in relationships with women who do not have AS

Each group will hold 6 weekly sessions to provide mutual support and increased understanding about the effects of Asperger Syndrome on relationships, and to explore coping strategies, including ways to improve communication in the couple relationship. Groups are led by social workers with knowledge and experience with adults and couples affected by Asperger Syndrome. Group size will be between 5 and 8 participants. Meetings will take place in AANE’s Watertown office. For more information, please contact Grace Myhill, LICSW, at 617-504-3116 or gmyhill@gmail.com.

Asperger Syndrome and Employment

The Ultimate Test

with
 Nick Dubin

Saturday, December 13, 2008
9:15 am– 12:00 noon
Northeastern University
Room 434
Curry Student Center
Employed AANE Member: $50
Unemployed AANE Member: $25
AANE non-member (includes membership) $85
Register at www.aane.org or call 617-393-3824.
He’s finally trained! My husband of 26 years has scarcely completed a single one of my sentences all this year. Like most neurotypical people, Christopher has a tendency to want to finish someone’s sentence when there is a pause. That is not helpful for me!

I received my diagnosis of Asperger Syndrome (AS) in 1994, shortly after the birth of our fourth child. This was a wonderful event for me! Finally, there was an explanation for lost jobs, lost friends, and lost opportunities. My husband spied an article taped to the classroom door of a colleague about Temple Grandin, snatched it and photocopied it. He immediately recognized her pattern of thought and behaviors as similar to those of his wife. We went to a local specialist. Then I went to a regional expert. And after the birth of our fifth child, I spent two years with a psychologist friend sorting out my past and healing my wounded heart.

Until recently, very few women were diagnosed with autism conditions. I did not speak until I was almost 4 years old. My mother thought that being quiet was a gift. I was a very “easy” baby. I had numerous infections, particularly ear infections, and was subjected to many antibiotic treatments. Some of these resulted in life threatening reactions.

I was a loner, preferring the woodlands and lakes and streams to people. I was never read to, and I suspect my language developed as a result of the television—particularly soap operas—being on all day. In school I continued my aloneness, lurking near the trees at the edge of the playground, and watching the other children play games, screaming and laughing. I refused to participate in group discussions or reading time, preferring the other children play games, screaming and laughing. I refused to participate in group discussions or reading time, preferring the art table, and making painting after painting with my fingers. I also enjoyed sculpting with clay.

In third grade I was tested and my IQ was rated at 80, but the teachers thought I was bright. In fourth grade my teacher demanded that I learn to read. Apparently I was the class clown, “reading” the pictures in our books. I did learn, but reading was very difficult until sixth grade, when I learned to speed read. Finally the words on the page made pictures and my expressive skills, especially writing, caught up with my receptive skills! By tenth grade I tested with an IQ of 150. But I was always the odd one, shunned by the cool crowd. This shifted a little bit when I learned to play guitar and later became involved with the drama club.

I never wanted to get married or have children, and the fact that I have been married for 26 years and have 5 children amazes me. My eldest son is 22. He experienced what is now termed regressive autism just before his first birthday. I spent the next 18 months ignoring housework and playing with him on the floor, invading his space. What I did is similar to Dr. Stanley Greenspan’s Floortime®. My son has since pursued an associate’s degree in his special area of interest—cars.

My daughter, now 19, is much more typical in her behaviors. She is very social, outgoing, and intelligent. Our third child is 18 and struggled with ADHD. These two are both attending community college part time. Our fourth child is now 14 and is our child with AS. It is difficult, because even though I know so much about autism, he is very different from me. My heart hurts as I watch him struggle with the social rules. Our youngest son is almost 10 and 100% boy, running about, engaging in active play, chattering excitedly about whatever interests him at the moment.

I home educate all our children—and my husband, who is a special education teacher at the upper elementary level. Recently, when I went to a neurologist for follow up tests, the neurologist wryly suggested that I was my husband’s best student. I immediately retorted, “No, he is mine!” And this is true, as Christopher regularly requests my insight with his students on the spectrum!

For 12 years I did nothing about my diagnosis except further my own understanding and develop more sensory adaptations. If a crisis occurred in a relationship, I explained autism and its ramifications. Sadly the most frequent response to continued faux pas was along the lines of “I can’t deal with you anymore. I can’t believe that someone so smart can be so stupid.”

This brings me back to my family and life with AS. My children are well-trained. I often disappear into the bathroom when I need a sensory break, a quiet withdrawal from the constant noise of boys and chatter of girls. They know to not approach me unless someone is close to dying. In the car we have a code. “Mamie’s on overload” is the phrase for turning off the radio, turning down the air conditioner, and reducing interactions. When we enter a city, en route to visiting family, I state “We are all on silence until we are out of traffic.” I think that this might make them prone to entering a monastery, but they all understand that I have to completely focus on the numerous automobiles and dangerous drivers in high traffic. And they all know not to finish my sentences!

Last spring I proffered my usual apology for not bringing them up in a normal fashion. We were driving around town on errands and I was feeling sad about something. My middle son smiled calmly and replied “That’s okay, Mamie. We prefer to be lamron.” It didn’t take me long to realize this was normal—backward. So one positive result of living with a mother with sensory and cognitive difficulties is that my children have a great sense of humor!

My husband has been so supportive. He regularly illuminates my differences with excellent metaphors. He compares my mind to 30 Pentium II® processors. I am always running the permutations of a social circumstance. What do people intend? What does this person mean? What is the appropriate response? It explains how it appears that I am distracted, but I am actually running programs until I find the best one for an event or interaction.

Some of the relationship challenges are due to word usage. I used to read the dictionary and I use words literally. I have gotten better with metaphors, but I prefer to think of these as parallels, looking for events that mimic the pattern that I am seeing in daily life. Puns are not just “groaners” for me, they are outright incomprehensible! Jokes get the same response: “Um.” This is mostly a problem for that certain age when young boys discover joke and riddle books—so I have had nearly a decade of practice in understanding riddles such as...
“What’s invisible and smells like carrots?” “Bunny farts!” Oh yes, little boy humor is amazing!

When I was in my 20s I was attracted to organic gardening and natural foods. I was alert 30 years ago to gluten and dairy sensitivities. So I have been eating similar to the DAN! protocol for decades. This is how I meet so many parents who have recently diagnosed children. I am standing in the aisle with the natural, gluten-free foods at the supermarket and there is a mother (usually!) with a sheaf of papers and tears in her eyes. When she notices my confident acquisition of food products she asks, “Do you know about gluten-free diets?” My positive response encourages her, and we exchange phone numbers.

Now, in addition to my family activities, I have many speaking engagements across the region, and as far away as California and Tennessee (the national TASH disability rights conference). As I interacted with so many families I met at conferences, I realized that I have something important to offer: hope. Two years ago I went to a family support workshop called “Building Social Bridges” presented by Cathy Apfel. Two other mothers were supposed to attend with me but they bowed out at the last moment. I hate crowds but I chose to attend this meeting anyway. I got there later than when I prefer, so I could not sit down near the escape path and in front at the edge of the crowd—and it was crowded! As the workshop proceeded, I asked a lot of questions, and I had a lot of answers. It became almost a private conversation, I asked a lot of questions, and I when I prefer, so I could not sit down near the escape path and in front at the edge of the crowd—and it was crowded! As the workshop proceeded, I asked a lot of questions, and I had a lot of answers. It became almost a private conversation with Cathy, and we exchanged email addresses. I tried to escape, but I was cornered by a group of parents. This frightened me enormously, but I also had an epiphany. It was at that moment when I realized that what I had accomplished in my life and family could offer hope and courage to other families with children on the spectrum.

Cathy is now my closest friend. She is like my husband: calm, and good with explanations. She helps me interpret the social rules, and her encouragement keeps me going. I do presentations with her now through the Institute on Disability/UCE (UNH), as well as presentations to schools and support groups. My husband is supportive and radiantly tells everyone that his wife is a great presenter. My children think that my workshops are fun, even though they also miss me when I am away.

As for me, planet Earth finally feels like a safe place, almost like home. When the film ET came out, I cried through much of it, particularly when the little alien plaintively pointed to the stars and said “Home—phone home.” My earliest memories are of late nights, gazing out of my bedroom window at the constellations and wondering when I might go home. I knew I did not “fit in” at an early age. Now I know many adults and youth with AS who have the same longing for home and love of the stars—of all things sparkly or shiny.

I have begun giving myself little gifts. I eat my food the way I want to—in orderly patterns, one color at a time, and often with a spoon as I am still dyslexic. I wear clothing in unusual combinations. Recently a coworker inquired on a casual dress day if my cape and scarf were part of a costume. Of course they weren’t! Most especially I give myself permission to close my eyes, or direct my gaze when and where I want, controlling sensory overload and that sense of invasion that eye contact brings on. After five babies I am comfortable gently rocking and even occasionally spinning. I carry fidgets like smooth stones or Silly Putty® in my pockets, and I am unconcerned about taking them out when necessary. My best gift is my service dog, Shakespeare Aristotle, a dachshund mix trained to obey voice and hand signals. When I travel he is my best friend, keeping me calm and centered in busy airports and metropolitan centers.

I work at McDonald’s, which is not the best job for sensory issues with all the beeps and buzzers and machinery fans blowing. However, I worked at McDonald’s as a teenager, and it has good and fun memories. I took the risk of disclosing my diagnosis and explaining what I needed from management, and they are doing it! They use my name and explain fully what they need. I get little breaks after lunch rush. I love this job because all the policies are clearly explained and the routine—“Hi! Welcome to McDonald’s!”—is constant. I do not have to become anyone’s friend, so I am free to be a bit goofy. Best of all, I get to talk with parents and grandparents when they bring in children who—to me—are obviously on the autism spectrum. It is a little thing, but it is one more time where I can educate a little bit and encourage a whole lot.

This is the greatest gift of life with family: When I have a meltdown, they love me anyway. When I wear weird clothing, they love me anyway. When I do not get their jokes, they explain them and then actually repeat them so I get to laugh with them. When I cannot stand to be touched or hugged, they blow me kisses. When we argue because I so did not “get” their choice of words (and this happens A LOT in adolescence!), they are willing to talk it out, and we grow closer. This empowers me to keep going, to keep talking to others. My family is my “anchor.” I have examples of loving behavior that I can reflect back to others in my community. After 54 years on planet Earth, I have a mission, and I choose to accept it.

Pictured with CarolAnn is her dog Shakespeare Aristotle Redboots.

Liam Says “Hi”

Jessica Kingsley has published a series of five helpful, delightful books by AANE parent Jane Whelen Banks. Each volume uses a simple story, pictures, and humor to address a single issue that can be difficult for a child with Asperger Syndrome. By the end, Liam resolves his problem and experiences success.

Go to www.jkp.com, and search “Liam” to see all five titles.
Anxiety in children with Asperger Syndrome (AS) can easily go undetected and untreated. All too often the signs are hard to see, or they are misinterpreted. We all know that someone with Asperger’s processes social information in a way considered different from the norm, but have you considered how this neurological difference relates to feelings and emotions?

Emotional understanding is a key component to successful social relationships. Just think about your closest relationships and how you resolve personal conflicts. The simple (and sometimes not so simple) act of getting along with others is deeply entwined with emotions, so it only makes sense that children with Asperger’s are highly vulnerable in this area. Unfortunately, this leaves them at risk for anxiety and depression.

The following insights will help you see things from the child’s perspective. Whether a child is having a hard time coping with stress or has a diagnosed anxiety or depression disorder, they will benefit when those around them truly understand their world. Honestly, the more people who “get it”, the less stressful the world will be for children with AS.

**Insight #1: Children with AS desperately want to connect**

More people each day are realizing that children with AS long to connect with others, even when outer appearances indicate otherwise. I would take this one step further: children with AS need to connect. I may not be certain about much in this world, but I know that everyone needs to give and receive love.

I’ve had the privilege of helping many isolated children connect with others for the very first time. In each case I look to see: What took so long? What held them back? Usually the answer is fear. Perhaps a child had a bad experience on his or her first play date—say at age five. That child comes to me at age ten having never made a friend. Some parents may say, “Oh, he’s happier just playing video games.” Others have tried time and again to hold successful play dates, and it just hasn’t worked. In reality, the child is simply unable to cross the gulf on his own.

When you’ve finished reading this article, you’ll have an idea of just how wide that gulf is, and what you can do to bridge the gap. Begin by recognizing that children with AS “choose” isolation only because, without our help, they have no other option.

**Insight #2: There are continuous misunderstandings**

Recently, a school behavior specialist said this to me regarding children on the autism spectrum: “The more language a student has, the more opportunity for misunderstandings and confusion.” Sounds ironic, but in my own practice I have found this to be all too true. Sadly, the irony easily misleads parents and professionals alike, producing an even more confused child on a downward spiral toward anxiety and depression. The number of misunderstandings throughout the day cannot be underestimated.

What can you do? In any situation, assume there is an element of confusion until proven otherwise. Yes, this is the opposite of the “innocent until proven guilty” principle, but for children on the Autism spectrum confusion is always present, robbing them of happiness. This is true whether you see it or not, so you must be on constant alert for it. And make no mistake: the misunderstandings go both ways. Adults often fail to see the child’s point of view.

Get to know the child’s world. The more you see things through their eyes, the more you can expose this ever-present thief and break the downward spiral.

**Insight #3: You can’t always tell by looking**

A boy I was seeing in individual therapy had an unusual way of showing that he was nervous: A smile was his typical response to anxiety and confusing situations. His true feelings were not readily apparent. School personnel said to me, “He’s fine, don’t worry about it.” Then at school one day, with a smile on his face, the boy deliberately hit his head against the wall.

Professionals blamed the family and openly stated the parents must be abusive. In truth, school was simply too stressful, and the boy was doing everything he could to keep it together for as long as possible. This is a very serious situation. Being under this amount of stress on a daily basis is unacceptable. It can lead to serious mental health issues, including significant anxiety and depression. It is not okay to let it continue.

Don’t depend on typical signs of emotions. You can’t always tell by looking at someone with AS how s/he is feeling.

**Insight #4: You can’t always tell by asking**

A middle school student with AS invited everyone in her English class to her birthday party, but not one of them responded to her invitation. A sensitive teacher approached the student, who agreed to speak with the school psychologist. After telling the psychologist she was not upset, the girl left the office, took a pair of scissors from the secretary’s desk, and stabbed herself in the hand. She ended up as a client of mine.

Although she was academically exceptional, the student did not know what words like sad, nervous and upset meant. Oh, she knew the dictionary definitions. She simply didn’t relate them to feelings within herself. Strong verbal ability is not the same as emotional awareness. Children with Asperger’s tend to think in literal, concrete terms. Yet feelings are extremely abstract. Without the right tools, miscommunication is inevitable.

Fortunately, there is a way to use concrete language to identify feelings: associate something concrete with an emotion. For example, if a family once had a fun trip to Disneyland, you might ask, “Are you Disneyland happy?” Of course if Disneyland was over-stimulating and stressful, you could use it as an expression for that feeling.

The student and I did a great deal of work along these lines, in effect creating a personal dictionary of concrete terms, a sort of shorthand for feelings. “Do you feel disappointed like the time your video game broke?” became simply Do you feel broken-game? Such shorthand phrases are always based on past events where the child’s emotions have been accurately identified. New puppy excited, thunderstorm scared – you get the idea.

This student has come a long way. She has changed schools and now has a group of authentic friends.
Insight #5: Intelligence is not the same social awareness

Parents of newly diagnosed children with AS have often said to me, “But he’s so smart, how can he not get things?” It somehow seems obvious to them that social skills automatically come with a high IQ. The two are not correlated, and if you assume they are it will lead to complications.

You tread on dangerous ground when you wrongly identify the motivation behind a child’s behavior. Adults will claim, “He should know better,” or, “He’s just doing that for attention.” And in fifty other cases they might be right. But a child with AS is wired differently. How sad is it when a child is disciplined because an adult misunderstood? How much worse when that misunderstanding is due to the adult’s ignorance of the child’s neurological disorder? These situations are incredibly harmful. Frankly, I’ve found that some teachers are slow to catch on to this, forcing families to prove the extent of their child’s deficits to the school system, an awkward position for a parent if ever there was one.

On the plus side, you can raise a child’s social awareness using metaphors from topics that interest them. For example, you might explain feelings of liking and disliking others in terms of magnets that attract or repel. A child with knowledge of animals may relate to stories of animals that work together socially, versus those who hunt alone. Don’t be afraid to state the obvious. In some cases the gap between intelligence and social awareness is quite wide, but it can be bridged once you account for it.

Insight #6: Idioms are confusing

I recently skimmed though a book which described over 3,200 idioms in the English language, and this was just a partial list. “I’m itching to leave.” “Cut it out.” “I’d give my right arm….” We take idioms like these for granted. Even on hearing an expression for the first time, you can usually catch its meaning based on the context. But imagine you lacked this ability. If you’ve learned a foreign language – or tried to explain English idioms to a non-native speaker – you’ll have some idea of the difficulties faced by children with AS.

Be careful with idioms. Many children with AS can become extraordinarily frustrated with them, and have difficulty tolerating them emotionally. Even a simple phrase like “take a seat,” when interpreted literally, can lead to embarrassment. How would you feel if you risked such a misunderstanding in practically every interaction of your life? It’s not hard to understand why a child would withdraw from social interactions.

How can you help? Simplify language. Explain idioms when you use them, and avoid them in stressful situations. Some children I see have developed a good sense of idioms, but when in new situations, the meanings evade them. It’s wise to completely avoid idioms when talking to someone who is under stress.

You might be surprised how often you use idioms without being aware of it. Learning to spot them can be a fun family game. Turn on the TV and start counting, or observe two family members having a conversation. This can be quite enjoyable as you try to picture what phrases like it’s raining cats and dogs would really look like. Bring in the laughter, but be careful not to laugh at someone when an idiom is misunderstood, because this can be extremely humiliating. Provide a safe and fun environment to allow the child to learn that yes, language can indeed be confusing.

Insight #7: The physical environment is disorienting

Children with AS don’t know what to attend to or how to prioritize what they observe in their environment. It’s another source of stress in daily life, as the following story illustrates.

A mother sent her son into the fish market to pick up some fish she had ordered. He had done this with his mother on dozens of occasions, but this was the first time he went in alone. After ten minutes, he returned to the car empty-handed and explained that the store had been rebuilt. Naturally Mom went in to investigate. She found the place as it had always been, but very crowded, with people standing in front of the ticket dispenser, blocking it from view. Her son thought the store had been rebuilt because he did not see the familiar dispenser, and his mother could not convince him otherwise.

This type of experience leads to loss of confidence. The world appears to be a crazy and unstable place, disorienting and overwhelming. If situations like this are not handled sensitively, the child will be at risk for more serious emotional difficulties. I’ll repeat my earlier advice: Get to know the child’s world. It’s easier to understand their anxieties and unusual behaviors when you realize how differently they perceive the environment.

Conclusion

Today, there is so much written about helping children with AS that it’s difficult to know where to begin. In my opinion, it is important to implement just one new concept at a time, and then add more as you are comfortable. Above all, a child needs to feel safe and understood in order to thrive.

Therapeutic socialization groups, run by licensed mental health professionals, can do a great deal to help. Effective socialization requires the guidance of group leaders who have grasped the insights presented here, who know the difference between intellect and social awareness, and have the training to help children with AS navigate the tricky emotional landscapes. When you reduce their anxiety and help them to be happy, everything else begins to fall into place.

I’ve worked with children on the Autism spectrum for over twenty years, and have a tremendous appreciation for how their minds work. If at times it seems like a mystery, it’s a mystery that can be solved. The more you see life through the child’s eyes, the more support you can offer. Every heartfelt connection, no matter how small, can significantly improve the quality of life for the children we serve.

The Friendship Network for Children in Northborough, MA, provides over 25 weekly socialization groups for children ages 3-17 on the autism spectrum. Groups use the Social Accessibility Therapy™ model developed by Nancy Swanberg, MS, LMHC. In this model, clinicians see life from the child’s perspective, building an “access ramp” to friendships and an improved quality of life. Nancy Swanberg, MS, LMHC, is expecting a book to be released in 2009 and can be reached directly at 508.393.0030 or nancy@networkforchildren.org. For more information please see www.networkforchildren.org.
NO ES UN SECRETO: POR QUE LA DIVULGACION ES IMPORTANTE
por Lynne Mitchell, Maestria en Trabajo Social, Traducido por Diego Mansilla

En la cultura general de los Estados Unidos el significado oculto de la palabra secreto es vergonzante, algo malo que no debería discutirse. Cuando alguien quiere mantener confidencial “buena” información, es más probable que se lo llame sorpresa. El Síndrome de Asperger no es, y nunca debería ser algo vergonzante o embarazoso por sí mismo. Si alguien se comporta de modo vergonzoso, eso es totalmente diferente a etiquetar su forma total de experimentar el mundo como malo. Como padres de niños con Síndrome de Asperger, debemos asegurarnos que el mensaje que el niño recibe es que ellos no son vergonzantes o molestos sólo por ser quienes son. Luego, como adultos con Síndrome de Asperger, tendrán más probabilidades de aceptar sus tratamientos simplemente como una parte de quiénes son y no como algo a ser guardado como un “secreto.”

Hay una diferencia entre no guardar algo como un secreto y contratar el dirigible “Goodyear” para hacer un inmenso y conti nuo anuncio a todos aquellos que escuchan. Estoy propugnando que como padres de niños con SA tenemos ciertas obligaciones:

- Entender cómo nuestros niños experimentan el mundo.
- Compartir nuestro entendimiento con nuestro hijo.
- Encontrar las formas de compartir confortablemente la información sobre nuestro hijo con las demás personas claves en su vida.
- Ayudar a nuestro hijo a aprender cómo compartir información acerca de él según quiera y necesite.

En muchas formas, estas obligaciones no son diferentes de aquellas que todos los padres tienen con sus hijos que no tienen SA. La principal diferencia para muchos padres de niños con SA es que ellos mismos no tienen SA, y por lo tanto las experiencias de sus hijos les son más ajenas. Como padres, amamos a nuestros hijos. Es nuestra responsabilidad trabajar más duro para comprender el SA, y luego compartir esta comprensión con nuestros hijos y con los demás. Mientras los hijos aún son niños, los padres eligen quién necesita tener una mayor comprensión de lo que los motiva. Al crecer, esperamos que ellos sean capaces de tomar cómodamente aquellas decisiones en base a lo que han aprendido al mirar a sus padres que compartieron su entendimiento y orgullo por él con otros.

La divulgación no es algo para todos los momentos y situaciones. En realidad, es más probable que, en lo relativo al SA, se dé de forma diferente en cada instancia en particular. El punto de la divulgación es casi siempre dar a alguien una comprensión más completa y precisa de quién es un individuo con SA, cuáles son sus fortalezas y qué modificaciones puede necesitar para compensar sus áreas débiles. Éste es también el fundamento para la divulgación más importante, el momento en que los padres se sientan a hablar con su propio hijo. No habrá un momento para “la conversación.” Más bien habrá, mientras el niño se desarrolla, un millón de situaciones en que los padres tendrán la oportunidad de discutir lo que el SA es y cómo se relaciona con él (sin embargo habrá probablemente una primera oportunidad).

Para muchos padres esto es una tarea muy abrumadora. Generalmente están temerosos de la reacción que tendrá el niño. La preocupación por tener “todas las respuestas.” La preocupación de ser demasiado emocional o demasiado imposible o demasiado exacto o demasiado general… ¡Les tengo buenas noticias! Esta no es una conversación de una vez. Cada padre tendrá muchas oportunidades de “hacerlo bien”. La divulgación es un proceso de crecimiento y mayor entendimiento de quiénes somos como individuos. Nadie aprende esa clase de información en una sola conversación o leyendo un libro. Esto ocurre a lo largo de la vida para todos, incluyendo a aquellos que tenemos SA.

No hay una respuesta sola para la pregunta: “¿A qué edad le digo a mi hijo que tiene Síndrome de Asperger?” El criterio más importante es que los padres se sientan cómodos diciendo las palabras Síndrome de Asperger. A su vez deberían sentirse tranquilos con el nivel de conocimiento que tienen sobre el tema. Además, deben tener en claro sus ideas sobre cómo el SA constituye un aspecto positivo en lo que es su hijo. Es necesario conocer también cómo el SA es estimulante para su niño en particular. A la mayoría de nuestros hijos les resulta más entendible cuando hablamos de forma explícita. Por ejemplo, “¿Has visto como memorizas todas las películas de Disney sin esforzarte?” Bien, el Síndrome de Asperger te ayuda con ese talento,” es más efectivo que “Los niños con SA tienen habilidades de memorización mecánicas y fuertes.”

De forma similar, “Ya has visto que te resulta difícil aprender a andar en bicicleta. Bien, el Síndrome de Asperger te hace más difícil aprender eso que a otros niños, así que valoro mucho que no te des por vencido (o me imagino por qué estás tan frustrado que quieres abandonar).” Esto en oposición a decir: “El Síndrome de Asperger está usualmente asociado con retrasos en el desarrollo de habilidades motoras generales y finas.”

Otras preguntas comunes que los padres hacen son “¿Tengo que usar el término Síndrome de Asperger?” La respuesta es, no tienes que hacer nada. Sin embargo, he notado que la mayoría de los niños siente alivio al saber que hay un término real para su perfil de fortalezas y debilidades. Que pertenecen a un grupo. Que no están solos. Que hay un cuerpo de conocimientos sobre cómo compensar sus áreas difíciles. Que eso no es haraganería, o testarudez, o algún defecto de personalidad. Todos como seres humanos, tenemos una sensación de alivio cuando sabemos que no estamos solos. Al no usar el término Síndrome de Asperger, le niega a su hijo el sentido de pertenencia a algo más amplio.

Finalmente, una pregunta común es: “Mi hijo es un adolescente y obtuvimos el diagnóstico recientemente. ¿Cómo puedo decírselo a un adolescente?” Bueno, sin lugar a dudas es más delicado decirle algo a un adolescente, particularmente algo que tiene que ver con su sentido de identidad. Aunque los adolescentes son más propensos a negar inicialmente o a enojarse con el rótulo, con el tiempo, todas las razones para usar el rótulo con los niños más pequeños es aplicable a los adolescentes y a los adultos también. Aunque los adolescentes generalmente tienen una reacción visceral de que tener SA significa que algo está “malo”, hay también una sensación de alivio de que no está imaginando cosas. Durante años un joven no podía entender porqué las luces en clase le lastimaban tanto los ojos, y aún así nadie lo notaba. Si hablaba fuerte lo veían como un quejoso o un mentiroso o un buscapleitos. Así quienes lo rodeaban no le...
daban validez a su realidad y comenzaba a aislarse de los demás, o se enojaba con ellos de antemano por no ser entendido.

Una manera de encarar la cuestión de la divulgación al niño con SA es usar novelas de niños o de jóvenes adultos que tengan un personaje principal con SA (ver la lista más abajo). El argumento puede implicar tres deseos mágicos o un alienígena que aterrizara en los suburbios, pero las experiencias del personaje central están coloradas por su SA y de este modo le da al lector una forma amable y práctica de empezar a entender lo que el SA es y cómo afecta en lo cotidiano. Mientras el niño lo escucha leer el libro, usted puede amable y prácticamente, señalar similitudes y diferencias entre su hijo y el niño con SA en la historia. Su hijo puede no estar de acuerdo, y puede o no extender la conversación. Sin embargo, el diálogo ha comenzado. Algo llamado SA existe. Otros niños tienen el diagnóstico. Es simplemente parte de la vida. NO es un secreto.

Estas novelas, o una de las numerosas biografías de personas con SA, son también una gran manera de introducir el concepto de SA a los hermanos y compañeros de escuela. La discusión sobre “el personaje tiene SA y también nuestro compañero” no necesita ser manejado torpemente. Los niños verán las similitudes. Una discusión puede o no surgir espontáneamente. El punto que usted está tratando de mostrar es que el SA es una realidad y una forma de ser. Conocer el término brinda una forma de entender mejor a algunos individuos.

Otra forma de concentrarse en la divulgación para niños con SA es apelar a su tendencia a disfrutar enseñanzas de no ficción y hechos reales. Libros que explican conceptos como comunicación social, teoría de la mente, y gran memoria pueden ser útiles. Una vez que los conceptos son descriptos de modo general, los padres pueden ayudar a sus niños a aplicar estas ideas más específicamente a sí mismos. No hay dos personas iguales. Esto incluye a las personas con SA. Las características también cambiarán a medida que el niño madure y desarrolle. La primera vez que hable con su hijo, la conversación puede focalizarse en la torpeza en las habilidades motoras y sobre un impresionante volumen de conocimiento acerca de “Pokémon”. Unos años más tarde la conversación puede enfocarse en el increíble entendimiento de los conceptos matemáticos y en las dificultades en organizar las tareas escolares, la habitación, y el escritorio en la escuela. Aún más tarde, la conversación puede enfocarse en la hazaña de estar en el cuadro de honor de la secundaria combina-do con la increíble ansiedad por la deficiente forma de manejar las entrevistas laborales.

¿Qué es el SA y cómo me afecta? Esa es la pregunta. Las respuestas son sorprendentemente positivas y esperanzadoras tanto como inquietantes y lamentables. El mensaje importante aquí es que es esencial que su niño sea informado sobre todos los aspectos de quién es para que pueda hacerse a sí mismo esa pregunta. La única forma de que su hijo realmente entienda quién es, se acepte y se defienda en el mundo.

Sea valiente. Sea creativo. Conozca a su hijo. Siéntase cómodo con su propio conocimiento del SA. Recurra a su entusiasmo por las fortalezas de su hijo, y a la esperanza que da un mejor entendimiento de las diferencias de su hijo.

La siguiente lista de lecturas sugeridas pretende ser una guía a alguno de los libros que se pueden usar para introducir el concepto de SA y comenzar la discusión del diagnóstico de su hijo.
In the continuing expansion of services for individuals with Asperger Syndrome (AS), one group gets consistently overlooked: the general adult population. Due to the relative newness of the diagnosis, adults over age 26, especially, receive an AS diagnosis much less frequently than younger adults do. This doesn’t necessarily mean that AS occurs much less frequently among the general adult population than among younger adults; it is probably just diagnosed less frequently. The clinicians who work with these people are often undereducated about AS, and so they misdiagnose AS clients or, in some cases, give no diagnosis at all. This needs to change; clinicians who work with adults need to become more knowledgeable about AS.

The needs of the general adult AS population are often invisible or underestimated. Some people may think that because people with AS have already become adults, and in some cases earned college degrees, they don’t need any help. However, people who were never correctly diagnosed, and consequently did not receive appropriate interventions to begin with, certainly do need help. Others might say that adults can’t benefit from AS interventions because “it’s too late to rewire their brains.” However, that isn’t true. Given the opportunity (explicit teaching by AS-savvy professionals), many adults with AS really can learn social skills and compensatory strategies. To make an analogy: if illiterate adults can be taught to read, then adults with AS can learn social skills!

Adults with AS could benefit from classes or support groups addressing such issues as:

- General social skills to enable adults to better navigate their social worlds
- Employment
- Work readiness and career exploration
- Job placement
- Job coaching
- Social skills for the workplace; unwritten rules; communicating with bosses and coworkers
- Employer Sensitivity Training about the different pacing, social, and sensory needs of adults with AS
- Self-care; physical and mental health; healthy use of leisure time; personal finance; housekeeping
- Family life
  - Marriage or other long-term relationships
  - Child-rearing (Diagnosing adults helps children, too!)

Having lived for years undiagnosed and/or without support, adults with AS often experience a lot of failure or rejection, which can exact a real emotional toll. For others, anxiety and a tendency toward depression are just part of their AS. Therefore, in addition to getting practical help with social and life skills, many adults with AS may also need some kind of therapy to help them better understand and accept themselves—developing a more realistic picture of their own strengths and challenges—and repair their self-esteem and confidence. Psychotherapy tends to have the best outcome when it is fitted to the patient’s specific condition. Therefore, adults with AS need therapists knowledgeable about Asperger Syndrome and skilled in communicating with adults with AS.

While professionals who do not know about AS form one barrier to more effective services for older adults with AS, another major barrier is the lack of funding for supports or services adults with AS need. Although some adults are professionally successful, many are unemployed, intermittently employed, or underemployed. Younger adults may still have parents (or other family members) willing and able to pay for services, while older adults are less likely to have access to family financial support.

With a relatively small amounts of support, many older adults with AS have the potential to make large contributions to society. In many states, however, adults with AS are excluded from funding or services through the Department of Mental Health—on the grounds that AS is not a mental illness—and from the Department of Mental Retardation—since this population has IQs from 70 to well above 100. Vocational or Rehabilitation Commissions may attempt to serve this population, but may not be able or willing to help adults improve their underlying social and independent living skills—an essential prelude to employment. As state human services departments struggle along on already inadequate budgets, no one wants to volunteer to take on the AS population. It is as if there is a conspiracy of silence, a tacit agreement to keep the nature, size, and suffering of this population invisible. It is high time for society to stop passing the buck: to acknowledge the existence and needs of adults with AS, and to provide the necessary funding to help them. Our continuing failure to do so constitutes a gravely unjust form of discrimination against a very large group of people—and a waste of talents and potential that society desperately needs to put to work for the common good.

Elizabeth Avery is a adult diagnosed later in her life with AS. She has participated in AANE adult support groups, volunteered and spoken on our behalf at our annual gala, and in testimony at the State House on behalf of bills promoting support for increased services for adults with AS. She has also spoken to Newton public school students for the Understanding Our Differences unit on AS, and at trainings by AANE Executive Director Dania Jekel.

Nomi Kaim is a poet and writer who has also participated in AANE adult support groups and spoken at our annual gala. She has written valuable articles on AS and depression, and AS and hospitalization.
Thanks to all of you who responded to the Fundraising Event Survey. We will be researching lots of ideas and letting you know ways you can support AANE. This year’s annual Gala is scheduled for Saturday, May 9th at the Newton Marriott. Please let me know if you’d like to be a part of the planning committee. Also, we are currently recruiting members for the development committee, now chaired by board member Steve Garfinkle. And this fall, we have held Community Get-togethers for AANE supporters at three volunteers’ homes in Massachusetts. At each event, an adult with AS was the featured speaker. If you would like to become active on one of our committees, share ways you would like to support AANE, or refer us to other prospective donors, please contact me at kristen.white@aane.org.

Kristen’s children Cameron and Celia White took part in Sunkist’s Take A Stand program in September. At their lemonade stand on Wollaston Beach, in Quincy, MA, they distributed information and raised $46 for AANE!

Left: Laura Jekel entertains at AANE Volunteer Recognition Night. Right: Dania Jekel with Kathy and Bob Clark. We honored Kathy for her work on the Seeing with a Different Eye exhibit. Thanks to great hosts Marcy and David Stuart!

AANE Annual Appeal Card Concept by Bob MacWilliams Artwork by Jamie Maxfield

Left: Bekan Knox, Ann Holzman, and Marcy Stuart. Right: Susan Maxfield and Jamie Maxfield

...but without your help, we can’t budge-it!

Dear Friend,

Please make AANE your top priority for philanthropic giving—because only those who live or work with Asperger Syndrome truly understand the value of AANE. Please help sustain our shared mission of fostering awareness, respect, acceptance and support for individuals with AS and their families by making a gift to AANE. Your generosity will help ensure that help is just a phone call away—for you, and for thousands of families living with the challenges of Asperger Syndrome.

Hank Miller, Board President Dania Jekel, Executive Director

Thank you!

It's Annual Appeal time! Please make your gift before December 31st by mail or at www.aane.org. Please give as generously as you can. Your support is critical to sustaining and expanding AANE’s services, and all that we do in support of the Asperger’s community.
Congratulations to Our Artists for these Additional Exhibitions!

Sharlene Hurst, *Painting the Voices*, Robert Lincoln Levy Gallery in Portsmouth, NH, 8/27-9/21

John Williams, ArcWorks - *A Different Vision, Changling Lives and Perceptions* at the Gallery at Grosvenor Park in Salem, MA, 9/6-10/1

Left: Redline by Matt Broskie

Thank you to our advertisers! To advertize in a future issue, contact Carynn.Meyers@aane.org.
Cutting Edge technology and innovations combined with an expertise in child development, makes S&L Therapy exceptional in the field. Offering pediatric evaluations and treatment for a full range of childhood speech and language disorders, S&L provides family-centered services using interactive technology tools, which are both highly motivating and effective. All treatment is specifically tailored to meet the child’s individual interests and unique needs.

Evaluations, Therapy, and Consultations for pediatric speech & language disorders

- Receptive & Expressive Language Disorders
- Articulation Disorders
- Pre-Reading / Literacy Skills
- Social / Pragmatic Language Skills (Groups)
- Language-Based Learning Disabilities and many more

Early childhood through middle school.
Groups are enrolling now.
We accept Blue Cross & Blue Shield and Harvard Pilgrim.
Call for more information or to schedule an appointment.
Conveniently located, parking & public transportation available

68 Harvard Street, Brookline, MA 02445
p. 617-823-1366
sandltherapy.com - info@sandltherapy.com

Thank you to our advertisers!
Thank you to our advertisers!

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

www.campakeela.com

Camp Akeela is a coed, overnight summer camp in Vermont for children and teens with Asperger’s and NLD.
We focus on building a community in which campers feel great about themselves, make friends, try new things and have fun!
1-week and 3-week sessions available.

866-680-4744
info@campakeela.com

The Glenholme School
A Devereux Center
An exceptional boarding school for young people with special needs.

At Glenholme, we motivate, encourage and focus on the behaviors.

81 Sabbaday Lane, Washington, CT 06793
860.868.7377 www.theglenholmeschool.org

MILESTONES
460 Totten Pond Road, Waltham, MA 02451
781-895-3200

Speech Therapy | Occupational Therapy | Sensory Integration | Physical Therapy
Psychological Services | Educational Evaluations | Functional Behavioral Assessments

Advancing MILESTONES.com
The attorneys of

HILTON, SINDELAR & HAHN

proudly support AANE and the AS community.

90 Bridge Street, Newton, Mass. 02458
617-431-1201

SPECIAL EDUCATION
STUDENT DISCIPLINE
JUVENILE COURT
CRIMINAL
DCF/DMH/DMR APPEALS

WE SPECIALIZE IN EVALUATING CHILDREN
WITH ASPERGER SYNDROME
AUTISM SPECTRUM DISORDER

Lois Carra, Ph.D.
Natalie C. Goodman, Ed.D.
Lauren Weeks, Psy.D.
Lexington, MA

617-596-2270
loiscarra@comcast.net

ABA. Applied Behavioral Associates, LLC
We specialize in providing support for children with behavioral disorders and/or developmental disabilities.

ABA, LLC offers the following clinical services:

♦ Functional behavioral assessments
♦ Individual and family therapy
♦ Home-based services
♦ Behavioral consultation and training
♦ Inclusion support
♦ Professional development

Please contact us for more information:
661 Franklin Street, Framingham, MA 01702
(508)879-4161 www.aba4kids.org
An advertisement is not an endorsement of programs or services.

Thank you to our advertisers!

Harriet (Holly) Simons, Ph.D.
Licensed Independent Clinical Social Worker

Asperger’s Individual and Couple Relationship Support

Wellesley and MV Insurance Accepted
781-237-3317
HFSimons@aol.com

Networks
Supported Living & Employment Services

Employment Services
- Individually designed services to meet your needs
- Evaluation Services clarify interests, goals, & aptitude
- Job Placement Services placement, interviewing, job supports, resume development, & accommodations
- Post-placement support to ensure long-term success

Supported Living Services
- Provides individually developed services to support & promote independence
- Travel training, cueing, & resource development
- Organization, time management and planning support
- Budget management skill development & support
- Education supports available

For further information & service costs, please contact:
Sandy Biber, Program Director
781-821-1386, ext. 500 · sbiber@enableinc.org

community services supporting community independence
Barbara D. Jackins
Attorney at Law
Legal Planning for Special Needs

Phone: (617) 489-6140
Fax: (617) 484-0501
Suite 101
385 Concord Ave.
Belmont, MA 02478

Career Development Coaching
for adults with Asperger’s & NLD

Career exploration • Job readiness • Job support
Call for a Free Introductory Session. Offices in Wellesley & Wrentham, MA
Barbara Biasonnette, Certified Coach • 508-835-2482
ForwardMotion@charter.net • www.ForwardMotion.info

Chapel Haven

Transitional Independent Living Program
Asperger’s Syndrome Adult Transition Program
Chapel Haven West
near the University of Arizona

Providing an array of individualized support services for adults on the autism spectrum and those with cognitive disabilities, enabling them to lead independent and productive lives.

For Information: call Admissions at 203.397.1714 or visit www.chapelhaven.org

Chapel Haven, Inc. Teaching Independent Living Since 1972

Connecticut Campuses: New Haven, Connecticut
Arizona Campus: near the University of Arizona, Tucson, Arizona
Thank you to our advertisers!

**College Internship Program**

*National Centers of Excellence*

Massachusetts • Florida • Indiana • California

Comprehensive College and Careers
Aspergers and Learning Differences

1-877-Know-CIP • www.CollegeInternshipProgram.com

---

**Jewish Family & Children’s Service**

JF&CS Services for People with Disabilities provides an array of programs for adults and youth.

Contact us to learn more about our programs including: supported housing, life coaching, clinical services and Jewish life programming.

Ask about our new shared living opportunity for adults with Asperger’s Syndrome and NVLD!

For more information call 781-647-JFCS (5327) or visit our website at jfcsboston.org

---

**Side by Side**

Helping families to realize their dreams through innovative residential, vocational, and social supports

Side By Side Supported Living, Inc.
1470 Beacon Street, Brookline, MA 02446
617-277-6140
www.sidebysideinc.com
School Disclosure Sheet

A parent kindly shared with us a form she created one year to disclose her son’s Asperger Syndrome to his new teachers in the fall. (The boy’s name and many details have been changed, and the picture is from clip art.) Please feel free to adapt this format to fit your family’s specific needs. As children grow into teens, they may be able to develop their own, first person letters.

Joey Worth, 10th Grade, 2008-2009

Joey is a very kind, calm, and funny young man who has Asperger Syndrome. He has great enthusiasm and an excellent memory for facts about topics that interest him, such as Civil War history, Japanese popular culture, and computers. Joey has weak executive functioning skills; i.e., he struggles with short term memory and the ability to concentrate, plan, anticipate, and organize himself and his materials. He needs support and guidance in these areas, and occasional social coaching to understand what his peers are trying to tell him, or how he needs to respond.

Joey also has Type 1 Diabetes as a result of a virus. His blood sugar may get low in class (he’ll feel sick and wobbly) and will need to have a snack to raise it (he has some in his back pack).

Specific academic issues include:

1. Trouble remembering to take notes in class, unless specifically instructed.
   ➢ Please remind him through a motion or other sign to take detailed notes.

2. Will tune out and daydream during class.
   ➢ Please keep an eye out for this and redirect his attention when you see it happening.

3. Trouble keeping track of homework assignments and remembering to write them in his agenda planner.
   ➢ Check in with him during each class to make sure he has written down and understood the homework assignment.

4. Will not take notes on reading assignments at home unless specifically told to do so.
   ➢ Tell him to take notes when you think he should, and make sure he writes that in his agenda notebook. Then, he’ll do it.

5. Difficulty knowing how to prepare for tests and quizzes.
   ➢ Help him to develop a concrete study plan. What specific resources should he use (class notes, textbooks, worksheets, homework, etc…)? What will the focus of the test/quiz be? Is there a study guide? Please help him make a schedule to complete steps over the course of several days, so that he’s not cramming on the last night.

6. Difficulty planning how to complete long term projects and assignments.
   ➢ Please help him to develop a concrete plan for completing the project. Make sure he lays out all the steps required, with detail, in a reasonable timeframe, in order to complete the project on time.

7. Difficulty understanding symbolism, underlying meanings, analogies to real life, and overarching themes because he is a detail-oriented and factual person.
   ➢ Talk with him explicitly and plainly about these things. Once he hears the explanation, he can understand it.

8. If he doesn’t master a concept that will be built upon later, he will experience significant setbacks as the course continues. When this happens, he becomes lost and reduces his effort in the class.
   ➢ When you notice that he does not understand a concept, immediately work with him to develop a plan to master the information. This may include meeting with you, the teacher, doing extra work, etc…Stay on him.

9. He is a very literal person. He will not go the extra mile or do any extra work unless the teacher explicitly says he has to.
   ➢ We are trying to develop this initiative and sense of responsibility.
   ➢ Talk with him about specific ways he can take charge of his own work. Remind him that even if no one tells him to do a certain important thing, he should decide to do it himself. Recognizing what is important, however, can also be challenging. We’d be grateful for your guidance here.

10. He doesn’t tend to want to talk with teachers, but is missing out on a very significant set of relationships as a result.
    ➢ Please take the initiative in creating a relationships with him. Encourage him strongly to stop in at specific times (such as before or after school) to ask a question about homework or a new concept.

We are trying to teach him the skills that are outlined here over time, and greatly appreciate and value your involvement in his growth. Thank you for working with Joey. Please feel free to be in touch at any time, to share both your concerns and good news about Joey. You can reach me at JoysMom@abc.net or 617-123-4567.

Many thanks, Maria Worth
Replays: How to Turn Problem Behaviors into Opportunities for Fun
by Karen Levine, PhD, and Naomi Chedd, LMHC

Your son refuses to put on his shoes—sometimes several times a day. He whips them across the room, screams, and hurts himself on the floor in a fit of rage and frustration. You would like to do the same, but you’re the grown-up! Already you’ve lost several shoes at the mall, and once he threw a rubber boot out the car window. You’re at your wit’s end.

Or maybe… Your daughter is very motivated to succeed at school. That may not sound like a problem, but it is—because she can’t stand to make a mistake. In anything. Ever. If she gets a grade less than 100% she becomes angry and self-deprecating, announcing to everyone, “I’m dumb! I can never do anything right! I hate school!”

If these scenarios remind you of someone you know and love, you’re not alone. From toddlers to adolescents and beyond, many people with Asperger Syndrome (AS) display challenging, inappropriate, or disruptive behaviors—occasionally, several times a week, or so frequently that they prevent families from enjoying their time together, and each school day begins and ends on a sour note. As one mother put it, “Every bath is a battle; every trip to the grocery store is a voyage of dread and despair.”

Replays to the Rescue!
At least 50% of children with Autism Spectrum Disorders (ASDs) have substantial behavioral challenges surrounding many aspects of daily living, due to intense emotional responding. Professionals and parents everywhere have endless discussions about the most effective ways for dealing with such challenges, because there isn’t one foolproof approach that can turn a tantruming child or teen into a calm, rational human being, who is ready to listen and learn.

Replays is a new intervention: an innovative, interactive, play-based approach for decreasing distress and anxiety, and increasing compliance, in children with ASDs. It can be effective for minimizing or even extinguishing the negative feelings and dramatic behaviors that occur prior to, during, or as a result of routine activities of daily living or health care procedures (teeth cleaning, getting dressed, medical check-ups), as well as extreme reactions to sensory experiences (loud noises, slimy foods), and even for common fears, anxieties or obsessions. It can be used in concert with other approaches, such as Positive Behavioral Supports, Social Stories™, Picture Schedules, Sensory Integration, etc.

We are not suggesting that Replays will solve every problem, every time it occurs. However, it will give you a vehicle for approaching a problem, and a common language through which you and your child, student, or client can communicate, in a positive and mutually enjoyable way, about a dramatic or traumatic event.

How do you do Replays?
Replays involves engaging the child in an interactive, highly animated, and playful re-enactment of their own experience of regularly occurring and upsetting events. This should not occur in the heat of the moment when the child is totally out of control, and unable to access any coping skills, but at a calmer and more relaxed time.

First, the adult re-enacts the event in an exaggerated, usually silly fashion, using symbolic objects and toys, such as dolls, action figures, stuffed animals, props, etc. The dramatization incorporates the specific actions that took place as well as the child’s own maladaptive responses. For example, a doll may yell “NO!” and try to run away, as the adult tries to put a tongue depressor in the doll’s mouth. The adult figure, if the adult tells him it’s time for a bath, or another daily event that elicits a predictably negative response. Gradually the child becomes more interested and engaged in the performance, often participating, and taking on different roles, correcting reactions, or expanding the story line. Even children with little or no symbolic play appear to understand and participate in re-enactments if the playful actions and behaviors are part of their own behavioral repertoire.

We have found that many children, including some under age 2 who reportedly have previously engaged in no symbolic play, have learned some pretend play routines through watching and then participating in Replays. Children older than 12, who allegedly are “too old for pretend,” happily engage in fantasy play if Spiderman, Obi-Wan Kenobi, McQueen, or other popular characters are used.

Often children want to play the event over and over, as they begin to master the uncomfortable feelings they previously experienced. They enjoy the humor, and the interaction with a trusted adult in a safe setting, as they get the guidance and practice they need to overcome negative feelings. With repeated Replays, such as before a predictably dreaded event (going to the doctor for a shot; putting on an itchy hat, scarf and mittens) the event becomes less evocative, less toxic, and the child’s intense negative reactions diminish.

After replaying the event several times, it is often helpful to write and illustrate a brief story of the event. Keep it simple: use stick figures, cut-outs from magazines, digital photos, or pictures downloaded from the Internet. (We especially like Google Images, but there are dozens of others.) The child can carry the story around and “study” it, or read it aloud to others—or another family member or babysitter can read it to the child.

What are the Mechanisms for Change?
We’re not sure. (Several research projects involving Replays are currently underway.) However, there is a sound basis for a number of related interventions:

Traditional Play Therapy gives children the opportunity to re-enact traumatic experiences in a safe, loving context. The adult typically follows the child’s lead in playing out events, supporting the child who is attempting to master his or her intense emotions. This approach, however, is not always accessible to children with ASDs, due to limited social and, sometimes, symbolic skills.

Systematic Desensitization helps people overcome phobias and extreme emotional responses to commonly occurring events through gradually increasing exposure to the stimulus eliciting a negative response, while simultaneously pairing it with a neutral or pleasant event (favorite music, reassuring voice). The individual gradually learns to tolerate the stimulus. Replays is similar, but it also includes a playful incorporation of the child’s reactions, thereby desensitizing the child to the event and their own experience of being upset.
Social Stories™ teaches children and adolescents appropriate behaviors by using a simple story with pictures to learn and understand the rules and sequences of events. Unlike some Social Stories™, Replays includes and often emphasizes the child’s own emotional response and subsequent recovery.

Floortime, ^2 a variation of play therapy, is designed to access the child’s interests and emotions through the authentic expression of the adult’s emotions. The child typically takes the lead and the adult follows along, making suggestions, enhancing the story, and becoming more actively engaged. Replays has some similarities, but is more focused on problem behaviors and is more adult-directed.

The effectiveness of Replays may be a result, at least in part, of the activation of mirror neurons, a new area of neurologiological investigation. Sometimes called empathy neurons, mirror neurons fire both when an animal (possibly a human) acts and when it observed the same action performed by another member of its species. Think about how you feel when you see another person fall down, eat your favorite flavor of ice cream or greet a loved one at the airport. Your emotional responses may be a result of mirror neuron activation. ^6 Mirror neurons may also offer a partial explanation of why children “get” Replays. Or it may be the result of the child’s acquiring new emotional memories and behavior patterns through repeated Replays, or even a single session. Simply put, the child learns to associate fun and laughter with a previously traumatic event. In behavioral terms, the child pairs the stimulus with a reward in addition to, or in some cases such as “How mad were you (or was Spiderman)? A TRILLION GAZILLION mad?” or “You mean you really didn’t want to do your homework?” The advantage of the computer is that is uniquely designed to help the writer express and record feelings, immediately change or delete them if desired, and even add graphics. For example, if a child really dislikes homework, have the characteristic in the story say, “NO! NO! NO!!!! I’M NEVER EVER EVER GOING TO DO ANY HOMEWORK!! NOT THIS YEAR! NOT NEXT YEAR! NOT EVER!!!!!” Go ahead: use 30 pt type—in red—and fill the entire page! You may be surprised how much fun this is for the child—and for you. It is unlikely that the student has had an opportunity to fully express authentic, uncensored negative feelings to that degree—to truly blow off steam, and feel heard.

And finally…

One of the most appealing aspects of Replays, besides it being fun, is that the technique can be used in tandem with virtually every instructional approach. Whether the child is getting ABA/DDT therapy, Floortime, or RDI, or is in a classroom that uses the SCERTS Model (Social Communication, Emotional Regulation and Transactional Support) or another approach, Replays can augment those techniques and play a part. It is a technique that particularly lends itself to one-to-one therapy sessions (e.g. speech, social skills, or OT). However, it can also be used in small groups, especially if several students are experiencing similar difficulties, such as not knowing when to stop talking about a special interest, getting upset about how certain clothing feels, or having to sit next to the window in every class. And while doing Replays may not take every ounce of angst out of the next fire drill or surprise assembly, regular sessions may elicit a more relaxed, less intense or frantic response. And best of all, it is an enjoyable and creative way to play, have fun, and ease the emotional pain—at least a little and maybe a lot—of a troubled child.

Karen Levine, PhD, is the former Clinical Director of the Center for Autism and Developmental Disabilities, Center for Child and Adolescent Development, at the Cambridge Health Alliance, and an instructor at Harvard Medical School. She has recently opened a full-time practice in Lexington, MA, evaluating and treating children and consulting to schools and families. She and her family live in Bedford, MA. Naomi Chedd, LMHC, is a Licensed Mental Health Counselor and Educational Consultant in private practice. She consults to families and schools and conducts evaluations and in-service trainings. She lives with her family in Brookline, MA. Karen and Naomi share more than 12 years of professional collaboration and friendship. They are frequent invited speakers at local and national conferences and are coauthors of Replays: Using Play to Enhance Emotional and Behavioral Development for Children with Autism Spectrum Disorders. London: Jessica Kingsley, 2007. Among their current projects is a new book on the uses of humor in the classroom.

LifeMAP Program

AANE is piloting a new program, partially funded by DDS (the Department of Developmental Services, formerly the Department of Mental Retardation). The Life Management Assistance Program (LifeMAP) will provide practical assistance to adults diagnosed with Asperger Syndrome who are not eligible for services through DDS. This assistance will take the form of intensive, highly individualized coaching with a focus on identifying and overcoming specific barriers each client is facing. The goal of LifeMAP will ultimately be to empower adults with AS and increase their level of independence.

LifeMAP participants will receive up to 4 hours of personalized coaching per week. During those 4 hours clients and coaches will set concrete, obtainable goals to work on. This can take the form of, but will not be limited to, organizing one’s papers, cleaning one’s apartment, connecting to new social groups, support to make phone calls/pay bills, etc. Coaching will take place wherever the goals dictate, be it the AANE offices, the client’s home or in the community.

AANE’s hope is that LifeMAP coaching may help reduce the stress that goes hand in hand with living as an adult with Asperger’s Syndrome. By supporting participants to create and implement sustainable systems for trouble areas while focusing on individual strengths LifeMAP will provide new opportunities for personal growth.

Participation in the pilot LifeMAP program will be determined by an initial application and follow-up interview. All applications must be returned to AANE’s main offices for consideration.

Completed applications can be faxed to: 617-393-3827 Attention LifeMAP, or mailed to: AANE, LifeMAP, 85 Main Street, Suite 101, Watertown, MA 02472.

Please note: Recent state budget cuts reduced but did not eliminate funding for LifeMAP. We will have fewer subsidized slots, but can continue to add fee-for-service slots.

Max,  
Thanks so much for taking the time to meet with my son and me last night. I really appreciate your help in getting us started on a program for him, especially your advice on what you’ve seen work. My son has made some nice progress over time but has a long way to go, and it’s great to have you and the AANE organization there to help him. I’m glad to hear that he is participating in a positive way with the other folks.

As I mentioned last night, you are doing a great job with the programs - it really makes a difference! Thanks again for your time.

A Father

Max Sederer, M.A.T.
Coordinator of Adult Services  
617 393-3824 x 302  
Max.Sederer@aane.org

AANE’s adult social services have continued to grow to meet the demands of you in our community. We are currently offering six Pizza and Game Nights a month, including regional nights in Canton, Framingham, Acton and Danvers, MA! Our Speaker Series continues to attract knowledgeable experts and good crowds to listen, observe, learn and engage. Our Film Series is excited to present Unstrung Heroes on Sunday, December 14th at 12:30 pm in our Watertown office. Hikes and strolls this fall have been a great opportunities to enjoy nature while exercising. Our Book Club and Anime Club are both actively recruiting new members. For those interested in the arts, we have continuing art sessions and visits to museums and galleries. Also, we hope all of you in our Adult Community will join us for our annual Halloween celebration on October 30th at 6:30 pm, and our Holiday party on December 17th at 6:30 pm. You can find a complete listing and calendar of social events at http://www.aane.org/upcoming_events/events_adult_social.html.

Please contact me if you interested in a new online support group for adult siblings of people with AS.

Jamie Freed, Debby Geheran, and I are always available to answer your questions over the phone, through email, or in person. You can meet some new staff members on the opposite page. Do not hesitate to stop in at one of our many regional Open Support Groups. You will find listings and contact information at: www.aane.org/aane_servicessupport_social_groups_adults.html.

Left: Max’s new dog, Margot

Jack Heavey, M.Ed., M.S.
Life MAP Coach  
Jack.Heavey@aane.org

Jack Heavey retired recently from his job at Newton North High School, after 35 years of teaching—and has now found a great new home at AANE! 2008 was his third summer enjoying Cape Cod. He has been volunteering in AANE’s adult programs since spring, and doing social coaching for teens and adults with AS and related conditions. He also continues to coach a hockey team.
Deborah Geheran, Coordinator of Adult Services
(617) 393-3824 x 317
Deborah.Geheran@aane.org

AANE has been “home” to me for many years, as I attended conferences and support groups, called in with questions, volunteered, and met some incredibly talented, unique, and good people. AANE provided me with support and guidance over the years, just as it has for so many parents. It also provided me with many unique opportunities to participate in the AS community. I have had the privilege of working on the first AANE Gala and watching the event grow with each year. I have served on the Autism and Law Enforcement Coalition, and helped AANE honor those in law enforcement who have worked to foster an understanding of diverse populations. One year, AANE gave me the opportunity to hear my teen daughter speak passionately and eloquently at Autism Awareness Day at the State House! Now I have been given the opportunity to work at AANE, joining Jamie Freed and Max Sederer on the Adult Services Team. How AANE has grown, and what an incredibly creative and dedicated group of professionals work here! It’s very exciting to be part of such a dynamic and unique organization.

I would like to describe something of my background. While my training was in Clinical Psychology, and I have worked in the past as a psychologist and teacher, I have traveled far afield. While working part-time now at AANE, I also continue my work as a real estate agent. For more than 20 years I have been involved on many levels with Girl Scouts and Boy Scouts, and have especially enjoyed training adult leaders. Of course, I also found myself backpacking, canoeing, kayaking and even one night of winter camping! My fascination with different cultures was enhanced by hosting foreign students for a number of years. I loved teaching English informally and did spend some time formally teaching GED classes in an English as a Second Language program. (I also loved traveling to Japan to attend the wedding of a student.) Now, I mostly travel via books and am “hiking” with my dog, Lucy, around Natick.

Karly David
Graduate Social Work Intern
Adult Services Team
Karly.David@aane.org

I have a BA in neuroscience and behavior and have spent the past three years working in the neuro-oncology department at the Dana-Farber Cancer Institute. I am currently in my second year at the Boston University School of Social Work. Here at AANE I facilitate an adult support group, and host the “Friday stroll” group. In my free time I enjoy playing the guitar and reading.

Dan Croft
LifeMAP Administrator
(617) 393-3824, ext. 321
Dan.Croft@aane.org

Dan Croft grew up in Saugus, Massachusetts, and attended college at UMass Amherst. Before joining AANE, he was the operations and training manager for More Than Words, a non-profit job training program that empowered DSS-involved youth with marketable job skills. There he had the exciting opportunity to lead a team of young people to turn a start-up used bookstore into an inviting and professional community gathering-place. At AANE, Dan’s first task will be developing the new LifeMAP program, which will provide practical life assistance and coaching to adults with AS. He currently lives in Jamaica Plain with his husband and two cats, and enjoys camping, gardening, cooking, and crafts.

Do you need information, support, or referrals to meet the challenges of living with AS? Help is just one phone call away!
617-393-3824

Ask for an age-appropriate information packet—Child, Teen, or Adult.
Request a brochure of workshops for parents of teens or parents of younger children, or adult activities.
Find out about online and face-to-face support groups.
Alexandra Graham, Coordinator of Teen Services

(617) 393-3824 x 314
Alexandra.Graham@aane.org

Before becoming AANE’s Coordinator of Teen Services, I was an Assistant Professor at Smith College School for Social Work, where I served as an advisor for Social Work graduate students completing their research theses. I am also a LICSW with over 10 years of experience as a therapist, working primarily with children and families. I found AANE through a dear friend, who has been involved with AANE for many years and who enlisted me to assist with the annual Gala committee. Through increasing contact with AANE, I came to better understand how AS has affected several members of my family and me, personally. My respect and interest in the mission of AANE deepened. Somehow my friend understood that I needed this connection to AANE, and it is through her reaching out that I now find myself part of this wonderful organization.

My husband and I moved to Massachusetts from New Mexico six years ago with our two young boys. Moving to New England was a dramatic challenge and brought many new opportunities for us, as well as a beautiful new daughter to our family. I am a former marathon runner and mountain cyclist, but find myself spending more time in the gym than on the road these days. However, I can often be found hiking in the local woods with my Standard Poodle puppy, Caesar, and sometimes even one of my children, usually with a pail containing something exciting like frogs or tadpoles in hand.

Caesar is a wonderful companion. When he turns one year old, he and I will take a Canine Good Citizen class and work toward his certification as a Therapy Dog.

Catherine Mayes
Plymouth County Program Coordinator

(617) 393-3824 x 320
Cell: (617) 999-7639
catherine.mayes@aane.org

Catherine Mayes joined the AANE staff this summer as Plymouth County Program Coordinator through the generosity of a grant from the Edwin Phillips Foundation. As Plymouth County Coordinator, Catherine will facilitate the development of AANE programs in the region. She is interested in developing partnerships with Plymouth County organizations and in hearing directly from families about what kinds of programs they would like. Catherine also works at Massachusetts Advocates for Children as the Autism Project Advocate. She lives in Marshfield Mass with her husband Stephen, their 18 year old son Mike, two dogs and two cats. Before coming to AANE Catherine worked for over 25 years as a museum curator and arts administrator.

Chapter Update
Robin Lurie-Meyerkopf
AANE Associate Director
617 393-3824 x 316
robin.lurie-meyerkopf@aane.org.

It is part of my job to help develop and communicate with AANE’s chapters in Western Massachusetts, New Hampshire, Maine, Vermont, Rhode Island, and Connecticut. Some of the chapters already have vigorous Advisory Boards, and others are at the beginning stages of developing their boards. I am available for helping the Chapter Directors expand their boards to include parents, professionals, and adults with AS. There have been some Chapter activities this fall which included workshops in Maine and Western MA. It is very exciting to grow our Chapters in all the New England states and I am looking forward to supporting the Chapter Directors and Boards as they develop. If you would like to get involved with one of the chapters, please contact me. We expect to have a lot more to report in the spring issue of the Journal!

Save the Date!
Roy Richard Grinker, Ph.D.
author of
Unstrange Minds: Remapping the World of Autism
A Father, a Daughter, and the Search for New Answers

Museum of Our National Heritage
33 Marrett Road, Lexington, Massachusetts
Friday, January 16, 2009, 8:30am-12:30pm

Save the Date!
The 3rd Annual
Matthew Dandurand Memorial Fund Lecture & Award Ceremony

SELF-ADVOCACY AND DISCLOSURE
FOR TEENS AND YOUNG ADULTS WITH AS
Presenter: Stephen M. Shore, Ph.D.

Saturday, March 28, 2009 from 1-4 PM
at the Holiday Inn, Holyoke, MA

Please see nomination forms for the
Matthew Dandurand Award for Exceptional Effort
www.aane.org/make_difference/dandurand_award_nomination_form.html

Catherine Mayes
Plymouth County Program Coordinator
(617) 393-3824 x 320
Cell: (617) 999-7639
catherine.mayes@aane.org

Catherine Mayes joined the AANE staff this summer as Plymouth County Program Coordinator through the generosity of a grant from the Edwin Phillips Foundation. As Plymouth County Coordinator, Catherine will facilitate the development of AANE programs in the region. She is interested in developing partnerships with Plymouth County organizations and in hearing directly from families about what kinds of programs they would like. Catherine also works at Massachusetts Advocates for Children as the Autism Project Advocate. She lives in Marshfield Mass with her husband Stephen, their 18 year old son Mike, two dogs and two cats. Before coming to AANE Catherine worked for over 25 years as a museum curator and arts administrator.
My name is Jennifer, I’m 42 years old, and I have Asperger Syndrome (AS). Lately I’ve been frequently asked to talk or write about dating, friendship, and relationships. This may be partly because I’ve been happily married for 14 years (to a man who also has AS), and socialize reasonably well with the “neurotypical” (NT) population. I have learned over the years that it is absolutely possible for people with AS to develop friendships and relationships with each other, and with NTs. The ways we learn to socialize, and the degree and type of social activities may well differ, but we can socialize more than enough for our own health and well-being.

Why Socialize?
In trying to help people with AS develop social skills and friendships, parents and family members forget to address one vital question: why socialize? Socializing is often stressful for people with AS. There must be motivation to develop social ties; something a little more compelling than “It’s on your IEP,” or “Because I said so!” The reality is that humans are social animals, and whether those of us who have AS like it or not, we are, in fact, human beings.

However, the social wants and needs of humans vary widely. There are folks who just loooove to socialize incessantly, and who seem to consider their week a dead loss of more than a few hours alone. Typically, those of us with AS have much smaller need to socialize, and a much greater need for solitude. Nonetheless, being human means interacting with other humans to reach goals, meet needs—and to practice the skills necessary for reaching our goals and meeting our needs.

For example: many of my fellow Aspergians or Aspies have told me that they don’t want to participate in social activities, but they do want to have a boyfriend, girlfriend, or spouse. The reality is that it’s almost impossible to connect to potential mates, without practical experience in the social world. If you want relationship skills, you need friendship skills. Social isolation is not conducive to developing long term relationships—or even short term ones.

Similarly, if you want to be self-supporting, you need to develop social skills for networking, which is another word for being friendly. Getting jobs requires connecting to other humans, and having Mom do it for you is problematic at best. Employers are leery of someone whose Mom is too involved!

The way humans build social skills is through trial and error, as well as through getting feedback from other people. To build the repertoire of skills needed for survival in the dating process or in job hunts, it is vital for us, as humans, to spend time in a non-hostile social environment so that we can get used to actual social interactions. Not only that, but we need to develop connections to the “social Internet” of humanity that will help us make connections beyond those we reach through our families and professionals.

School Daze
Some of the places that typical folks meet people are just not healthy for Aspies in general. In my experience, high school and junior high are largely not the best places for Aspies to be at all, and are certainly not good places to learn social skills. Every time I discuss the perils of high-school-based socializing in a presentation, at least one parent writes a note on the feedback form decrying my “anti-teenager” attitude, and saying there are many nice kids in high schools, and that if I say that high school is bad for people with AS it could become a self-fulfilling prophecy. And every time I discuss high school and point out that it is a terrible place for Aspies to learn social skills, multiple people with AS from the audience write me notes thanking me for “telling it like it is.”

The reality is that the standard school experiences of the teen years have a huge tendency to be rough on people with AS, and a positive attitude towards school cannot compete with the reality of the social pecking order of the adolescent world. I wish it was otherwise, but I’m trying to provide real-world advice that will benefit real people with AS. The skills people need to excel socially in the world of high school (and the world of K-12 generally!) are not the skills that help people survive and thrive as adults.

For example, being able to bully people without getting caught has very limited value in the adult world; however, in the world of high school, bullies can thrive. In fact, “mean girls” and cruel guys usually thrive in high school, but in the real world, they falter. They have a statistically significant tendency to develop broken relationships and to have difficulty holding jobs. But in high school, they rule and often are considered “good kids” by the adults around them. And the nice kids who do exist have very high standards for admitting people into their circles. Trying to get “in” with them is like trying to crack a safe during a full-scale tank attack.

So school is not necessarily a good place to learn to be social. Nonetheless, there are some specific times and places in high school where one can start learning to build friendships. Any place in the school that is filled with geeks, wonks, and nerds is a good place to engage in the slow but steady process of developing friendships and social skills. AV Club, Chess Club, Drama Club, Band Front, and the Cubing Club are all possibilities. Another really great thing to encourage teens with AS to try is volunteering to help in the resource room or library. These last two are particular helpful as they can provide safety zones for bullied kids. The back room of the school’s library is likely to be monitored by adults and not easily accessed by bullies.

The Outside World
The school scene should not be the full measure of social opportunities for any human, much less one with AS. The non-academic world has a great variety of groups related to a wide variety of special interests. Model rocket clubs, book discussion groups, and cycling clubs are great places to get social. And while meeting and talking to people online is NOT ever equivalent to social activities in the real world, online searches are a great way to find such groups. It is often easier, more fun, and more fruitful for a seventeen-year-old with an interest in model trains to hang out with model train club members where the average age is fifty than to hang out with other teens. This

Connecting to Humans: Some Ideas for Parents, Family, and Professionals
by Jennifer McIlwee Myers

AANE Journal Issue 3 Fall 2008
(Article continues on next page.)
is a great way to develop the connections that can lead to successful dating and relationships. Yes, the local Jane Austen book club may be a little short on available guys, but the members will have brothers, cousins, sons or male friends. Connecting to any one social circle paves the way for connecting to the larger social world. Statistically speaking, the most successful relationships are those in which the couple were introduced by mutual friends.

Volunteering

“Opportunity is missed by most people because it is dressed in overalls and looks like work.” —Thomas Alva Edison

One great social opportunity that I wish every lonely person with AS could take advantage of is volunteer work. When I was a teenager, my mom got pretty sick of having me mope around the house every summer, so she found a local nursing home that had a summer teen volunteer program. My special interests—old radio shows and Fred Astaire movies—were much more interesting to the nursing home residents than they’d ever been to typical peers. My politeness and tidiness were valued instead of mocked. I worked hard, got valuable job experiences, built up some potential employment references, and actually got to hang out with people who were glad to see me. It was the opposite of high school, and I thrived on being valued.

There are tons of opportunities for volunteer work in most communities. Animal rescues, Habitat for Humanity, and children’s shelters are often hungry for help. Match the work to the person: a super-cleanly aspie might well be welcome to help at a local hospital, while those Aspergians who like to get their hands dirty might be great at cleaning out animals’ pens at the local science museum or zoo. One volunteer opportunity that non-geeks may overlook is local science fiction or comic book conventions. These groups run on volunteer manpower, which can mean a free membership to the convention and opportunities to meet dozens of people who are part of the “geek world” of engineers, scientists, programmers, and librarians! Trust me, the average person with AS is going to be much less “different” when among people who like to discuss topics like maximizing bandwidth and time travel paradoxes!

The Life Lab

These various opportunities to develop friendships and relationships are not just chances to meet people. They are living labs, and should be clearly identified as such. Learning to develop interactions with human beings over time is an ongoing process. No one every interacts perfectly at all times, and no one ever has such great social skills that they never say or do things that cause embarrassment or difficulty.

My way of coping with this reality and turning it to my advantage is to view life as a laboratory where I experiment. Every interaction I have with others is not just an interaction, but also an experiment in relating to humans. Some experiments go as I had hoped; some do not. Some experiments go completely awry and result in outcomes I would never have predicted and definitely did not want! However:

“In the spirit of science, there is really no such thing as a ‘failed experiment.’ Any test that yields valid data is a valid test.” —Adam Savage, Mythbusters

Adam is absolutely right. When an experiment fails, or mistakes happen, those failures and mistakes generate data. The thing to do is to analyze why it failed, and then adjust the procedure for the next experiment accordingly. Sometimes it can take many, many tries to get an experiment to produce a desirable outcome; sometimes it is necessary to abandon one technique completely and begin over.

If I were experimenting in chemistry and had an experiment go wrong, I might seek out an expert in the field of chemistry for advice on what went wrong, or I might consult chemistry reference books. If a social experiment goes wrong, I seek out reliable experts and reference books. The shelf next to my desk has a set of books that I reference often for this purpose. They include the following, which I fervently believe should be in every home in the country (if not the world):

How to Win Friends and Influence People by Dale Carnegie
Social Psychology by David Myers (no relation)
Reading People by Jo-Ellan Dimitrius and Wendy Patrick Mazzarella
If I’m So Wonderful, Why Am I Still Single? by Susan Page

Yes, although I’m happily married, I keep one or two of the very few reliable dating books that exist handy for general information on the interactions involved in romantic relationships.

Seeking out reliable books, and people who have social expertise, is its own experiment. As a parent, teacher, or other person involved in an Aspie’s life, the reliability and accuracy of the social information you give can (and should) be an indicator of whether you should be used as an “expert advisor.” If you base the advice and information you give on how you wish things were, how you think things should be, or how you remember them being at one time, you may not be in an advisory position for very long.

In other words, do your best to be pragmatic and accurate when providing social advice. If you tell your son who has AS, “I’m sure you’ll find a girlfriend at school this year!” when in fact that outcome is by no means guaranteed, you aren’t helping. If you use words like “always,” “must,” or “definitely” when they are not warranted, you may find that you are no longer trusted.

Those last two paragraphs are truly vital. One of the most important things any parent, teacher, or other advisor can contribute is honesty, and the ability to admit when he or she cannot be sure about an outcome. If you model and express the reality that the social world is not based on a finite set of surefire rules, if you admit it when you are unsure or make a mistake, you are providing a great service and very real support. I suspect this is also true when helping out non-Asperger’s children, friends, relatives, and students. Don’t be afraid to be truthful and “get real” when it counts.

Jennifer McIlwee Myers delivered AANE’s 2008 Matthew Dandurand Memorial Fund lecture. She was (finally!) diagnosed with Asperger Syndrome at the age of 36. Nowadays she travels throughout the U.S.A., speaking on many issues related to the autism spectrum, and loves to gather and share as much information on ASDs as she possibly can. She has contributed articles and sections to a number of books and magazines about ASDs, including a chapter on dating and relationships in the Future Horizons book Asperger’s and Girls.
A HEARTFELT THANK YOU to ALL OUR GENEROUS DONORS!

More donors are listed on next page.
A HEARTFELT THANK YOU TO ALL OUR GENEROUS DONORS!

In honor of Ruth Levine Arnold, SLP
Toby & Barry Farman, Jon & Ruth Tepper
Beth & Brad Kramer,
for all your hard work with Maisie.

In honor of Mr. Tim Delgado, Art Teacher
at Morrison Elementary School
Robin Adams
Natasha & David Chomas
Kelly Croke
Nina Egan
Nancy Flynn

In memory of Marguerite Persky
Louis K. Adler
Tina & Stan Kraus
Marilyn & Ted Tompkins
Sue & Jed Diehl

In memory of Ruth Sager
Sandy Bornstein & Alan Sager

In memory of Aaron Carey
Walter Carey II & Winifred Carey

In memory of Vincent N. MacIlvain
Francis & Marlene MacIlvain

AANE Board of Directors
Hank Miller, President
Phil Schwarz, Vice President
Elizabeth McLaughlin, Esq., Secretary
Jan Saglio, Treasurer
Elisa Abele, SLP/CCC
Bonnie Betters-Reed, Ph.D.
Steven Garfinkle
Ann Marie Gross
Judy Gooen, MS, OTR/L
Dave Harmon
Dorothy Lucci, C.A.G.S.
Scott McLeod, Ph.D.
David Pauls, Ph.D.
Grace Peng
Barbara Rosenn, Psy.D.
Daniel Rosenn, M.D.
Nancy Schwartz, M.S.W.
Stephen Shore, Ph.D.,
President Emeritus
Shelley Viles
Michael Wilcox

AANE Staff
Dania Jekel, Executive Director
Robin Lurie-Meyerkopf,
Associate Director
Kristen White,
Director of Development
Jean Stern,
Director of Children’s Services
Brenda Dater,
Coordinator of Children’s Services
Yolanda Kolinski,
Directora de Programas para
la Comunidad Latina
Stephanie Loo, Editor,
Director of Teen Services, Grantwriter
Alexandra Graham,
Coordinator of Teen Services
Catherine Mayes, Coordinator
Plymouth County Teen Services
Jamie Freed,
Director of Adult Services
Max Sederer & Deborah Geheran
Coordinators of Adult Services
Gail Kastorf
Vocational Trainer
Dan Croft
LifeMAP Administrator
Marci Shaffer
LifeMAP Job Placement Specialist
Nataliya Poto, Graduate Intern
Lisa Graffeo, Administrator
Carynn Meyers,
Administrative Assistant
Timothy McDaid, Business Manager
Mary Ann Medlar, Database Manager
Matt Conrad, Web Master
Bekan Knox, Packet Coordinator, with
Ann Holzman and Nancy Bieringer
Karly David, Graduate Social Work Intern
Lynn Flaherty, Family Grants, and
Volunteer Coordinator
Kathryn Jantz, Schweitzer Fellow;
Teen Facilitator
Stephanie Geheran, Teen Event Assistant.

AANE THANKS THE FOLLOWING FOR THEIR SUPPORT

ADK Charities
Adler Foundation
Agnes M. Lindsay Trust
An Anonymous Foundation
Edwin Phillips Foundation
J.E. & Z. B. Butler Foundation
Catalogue for Philanthropy
Combined Federated Campaign
Community Foundation of
Western Massachusetts
Danny Foundation
Doug Flutie Jr. Foundation for Autism
John Hancock Giving
Gerald R. Jordan Foundation
Grantham, Mayo, Van Otterloo & Co.
Nancy Lurie Marks Family Foundation
Massachusetts Autism Spectrum Division
Massachusetts DDC
Massachusetts Rehabilitation Commission
National Semiconductor Corporation
Rebecca Pomroy Foundation, Inc.
Pzena Investment Management, LLC
Rolling for Autism
TXJ Foundation
Tudor Foundation
Verizon Foundation
Vermont DDC

Special thanks to
Susan & Bradley Michals of Michals
Insurance Agency Inc.
for sponsoring the beautiful blue tote
bags for our fall conference.
& also to
Yolanda Kolinski for initiating
this project,
& to
Dan and Neil Tatar of ADK
Promos
who made the bags for us.

Special Projects
Jo-Louise Allen, Elizabeth Avery,
Edith Burns, Sue DeAmario, Erin
Flaherty, Nomi Kain, Lynne Mitchell,
Mary Ann Monheimer, Grace Myhill,
Murray Ostrov,
Eric Shamus, Nancy Schwartz, Isabel
Shields, Sara Willig,
Ann Woodbury
Gene Kennedy Receives Award at Autism Awareness Day

I am a current employee thanks to Gene Kennedy over at Pioneer Valley Rebuilders. I decided that after three and a half years that I needed a better paying job that would let me ply my trade on a computer. Gene saw that I had great potential with my computer skills and hired me back in early February of 2008. I can’t thank Gene enough for giving me a chance to start a new career. Which is why you should honor him in Boston.

Sincerely, Alex Zimakas

Educator Ann Oakes and her students had school-wide displays for Autism Awareness month last April. Ann is also winner of a 2008 AANE Award for Excellence in Teaching Students with AS. AANE artist Jamie Maxfield contributed his sketches of famous suspected “Aspies.”

Left: AANE Zoo New England Day
August 3, 2008


Three families used AANE’s online support group to meet up to pick apples. Above: Trevor Larson, with John and Donna Ber-

Murray Ostrov (third from left) and AANE Adult Services Coordinator Deborah Geheran (fourth from left) co-leading a great fall hike at Land’s End in Hingham, MA.

Jack Fidler, Jo-Louise Allen, their son Daniel, and his prom date. Daniel is currently a freshman at Emerson College.
The Asperger’s Association of New England: Changing Perspectives, Changing Lives

May 9, 2009

AANE presents

Laugh OUT LOUD

2009 Gala Benefit

featuring Paula Poundstone

Join us for an evening of laughs

The Marriott Hotel, Newton

Gala and live auction to benefit the Asperger’s Association of New England

Sponsorship opportunities available.

For information please contact Kristen White at 617-393-5824 extension 319 or email KristenWhite@AANE.org