Before and After LifeMAP for Our Son
by an AANE parent

<table>
<thead>
<tr>
<th>Before LifeMAP</th>
<th>LifeMAP Coaching</th>
<th>After LifeMAP</th>
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<tbody>
<tr>
<td>Had employer/managers who did not understand or appreciate his strengths and mocked his challenges</td>
<td>EMPLOYMENT The LifeMAP coach helped him apply for jobs, develop resumes, helped him write a disclosure letter to inform his current employer of his strengths, challenges, and willingness to work at improvements, with requests for information about areas of need before they hinder employment.</td>
<td>Has employer/owner who knows strengths and challenges and willing to work with both.</td>
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<td>Did not have supportive coworkers because manager was not supportive</td>
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<tr>
<td>Was in constant stress due to work</td>
<td>Financial The LifeMAP coach helped him work on a budget and prioritize. The coach helped make contact with free legal assistance on an issue that brought in the $13,000 that is now in savings.</td>
<td>Has a regular fulltime paycheck</td>
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<tr>
<td>Lost job in humiliation due to Asperger type issues</td>
<td>HOME The LifeMAP coach meets at our son’s apartment, so he has that to encourage him to get the place ready.</td>
<td>Has own apartment and pays own bills with sister’s oversight</td>
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<td>After job loss, had no income at all</td>
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<td>Was being supported totally by parents</td>
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<tr>
<td>Was thousands of dollars in debt</td>
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<td>Was not able to prioritize with money</td>
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<tr>
<td>Would have been homeless if not for parents and his sister</td>
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<td>Could not keep an area clean or clear</td>
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<td>Unable to take care of himself, he was unable to care of a pet</td>
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<td>Had not had a medical exam in about 20 years due to no health insurance</td>
<td>MEDICAL The LifeMAP coach helped him apply for health insurances and encouraged him to get long overdue checkups. Due to this, he was found with a life threatening heart issue that he never would have had diagnosed. He also has an official Asperger’s diagnosis.</td>
<td>Has regular checkups and is being treated for a serious heart issue that he never would have known he had or been able to treat before</td>
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<tr>
<td>Had no dental care in about 20 years due to no dental insurance</td>
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<tr>
<td>Was never officially diagnosed with Asperger’s Syndrome</td>
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<tr>
<td>Was unhappy, bitter, angry</td>
<td>Self The LifeMAP coach studied with him to help him understand and appreciate him self. They work on self-esteem and personal issues. He is involved in AANE activities, groups, and conferences. He is glad to share that he has Asperger’s Syndrome and all that means in strengths and limitations. He works on hygiene and social skills and stands up for himself when he feels wronged.</td>
<td>Is happy and forgiving to those who treated him poorly</td>
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<td>Was deeply depressed (at times on family suicide watches) and was often extremely reclusive</td>
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<td>Did not understand himself, was down on self, and embarrassed by self</td>
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<td>Did not show personal hygiene care or take care of himself well</td>
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I truly believe he would not be alive without parents, sister, and LifeMAP. Now he has a life!

See another LifeMAP story on page 18.
Message from Executive Director Dania Jekel, MSW

Dear Friends of AANE,

Can you believe that AANE is approaching sixteen years old? Clearly, this is a good time for reflection and goal-setting. Accordingly, over the past year, AANE board and staff members have focused a lot of energy on a strategic planning process. One result which I would like to share with you right now is our revised mission statement:

The Asperger’s Association of New England (AANE) works with individuals, families, and professionals to help people with Asperger Syndrome and similar autism spectrum profiles build meaningful, connected lives.

To learn more about the fruits of the strategic planning process, and the main objectives we have set for the three meaningful, connected lives.

• We will continue to advocate for beneficial legislation and for changes in state agencies guidelines in Massachusetts.

• We will continue to monitor and respond to the proposed changes in the DSM-5 (fifth edition of the Diagnostic and Statistical Manual). No matter what new nomenclature results, please rest assured that AANE is determined to continue delivering our current programs, and to keep developing new ways to serve our community’s many and varied needs.

On behalf of AANE’s board, staff, and membership, I want to extend my warmest thanks to Nancy Schwartz for her outstanding leadership as Board President, as her term comes to a close. Fortunately, she will continue to share her wisdom and caring as a board member.

I would also like to thank four other board members: Barbara Rosen, Judy Gooen, and Melinda Miller, who are rotating off the board for now, and Ryan Lewis, who is moving. We will miss Ryan, and wish him every success in his new life in Texas. Barbara and Judy have used their professional expertise to guide AANE’s development since our very early days. Melinda joined the board following her participation in the early days of the Gala, where her artistry helped transform it into the polished and delightful event we know today.

Thank you for being part of our community during 2011-12, and for supporting AANE’s mission. I look forward to seeing you at many of our events, workshops, and conferences in the months to come.

Sincerely,
Dania Jekel, MSW
Asperger Syndrome and Employment: Research and Reflections
by Charlie Remy, MLS
Assistant Professor/Electronic Resources and Serials Librarian, University of Tennessee at Chattanooga

Introduction
In recent years popular culture has brought about an increase in awareness of the higher functioning end of the autism spectrum, particularly when it comes to children. Unfortunately, there is less understanding of the realities faced by adults on the spectrum and even less regarding their employment or lack thereof. Far too many adults with Asperger Syndrome (AS) are either underemployed or completely unemployed. Hendricks (2010, p. 127) estimates that between 50 to 75 percent of adults with AS are unemployed. The purpose of this article is to combine insights gained from my personal experience in the world of work with literature on the topic, in order to empower adults with AS to lead more fulfilling lives through gainful employment.

First, a little background about myself. I am 27 years old and have Asperger Syndrome. I completed a master’s degree in library and information science in 2009, and started my career as the Electronic Resources and Serials Librarian at Western State College of Colorado. After discovering that life in a small, isolated town in the Rocky Mountains was not a good fit for me, I decided to take a position as the Electronic Resources and Serials Librarian at the University of Tennessee at Chattanooga. I am extremely fortunate to have part-time, stable work in my chosen field, and feel an obligation to do what I can to encourage adults with AS to maximize their potential and overcome their employment challenges.

The Power of Our Special Interests
One significant asset that those of us with AS have is our special interests. We have invested incredible amounts of time, energy, and resources in the subjects for which we have a passion. Because of an intense focus that overpowers our lives, we likely know a great deal more about these areas than the average neurotypical (non-autistic person). We tend to find solace in our special interests, which leads us to develop them even more. What might be considered random and mundane topics to some neurotypicals never cease to captivate our attention. My interests include broadcast journalism, the Spanish language, higher education, and information in general. There is no doubt that society can benefit from our deep and highly specialized areas of expertise. One of the main factors that can contribute to successful lifelong employment for those with AS is making the connection between our special interests and employment. We need to find careers that can make use of and value our unique contributions. Too many in our society see AS as disabling, when, in reality, it can be the source of innovation, competence, and dedication, among other positive by-products.

Postsecondary Education
College is an ideal time for us to get to know our strengths and weaknesses, fine-tune our special interests through relevant coursework, and develop a better sense of our career path. Many students with AS thrive in higher education settings because of the structure, intellectual stimulation, sheltered environment, and the sense of accomplishment that we feel when we do well in our courses (Emmett, Steffan & Fast, 2004, p. 165). For me, college was a refreshing change after a difficult high school experience. Most important, the environment felt safe to me since I was no longer a target of those unable to accept my differences. I could begin to pursue coursework that was more aligned with my special interests, and not be forced to take courses in areas in which I struggled (particularly math and science) beyond a few core requirements.

Depending on our organizational skills and executive functioning, some of us with AS can easily lose focus and get lost in the details, particularly when it comes to our special interests. It is important to maintain a strong sense of direction so that we can more easily achieve our life goals. At the same time, we must be flexible enough to accommodate any surprises that life may bring us. Colleges offer several tools to assist in maintaining our focus, including an assigned academic advisor, extracurricular activities in our areas of interest, and job placement centers to guide us in the transition from school to work. These components of a college education are as important as the time we spend in the classroom.

The Importance of Mentors
Grandin and Duffy (2004) suggest that we establish relationships with mentors who can assist in our development of social and job skills (p. 2-3). Mentors were one of the most important aspects of my undergraduate experience. I went to a small comprehensive university in North Carolina called Elon. The institution encourages its faculty and staff to mentor students both formally and informally.

I had three primary mentors while at Elon: a librarian, an English professor, and a philosophy professor. The librarian helped me grasp how satisfying librarianship can be as a career. The English professor was an important role model and helped spark an interest in gender studies. The philosophy professor served as the advisor for my independent major in gender studies, and imparted strong feminist values that are key to my belief system. I quickly bonded with these mentor over our common interests and saw them as role models, both personally and professionally. Some of us with AS are good at emulation, and this can be a great skill when it comes to embodying positive characteristics that we admire in others. In addition to my parents (who were far away back at home in Maine), these mentors helped me become the person I am today. They taught me important values, helped improve my social skills, listened to me and gave me advice when I was upset or nervous and, of course, shared valuable knowledge from their subject areas with me.

I am thankful that Elon’s administration understands the value of mentor/mentee relationships and invests in them through initiatives such as the “take a student to lunch” program, faculty living in residence halls, small classes, an academic advising system, study abroad, and undergraduate research. Mentors are not just limited to the undergraduate environment: I was assigned to one when I started my current job at the University of Tennessee at Chattanooga.

Experience Counts a Lot!
Another important component to career preparation is getting practical experience in your area of interest. This can come in the form of summer or part-time work, tutoring, volunteering or participation in extracurricular clubs (Emmett, Steffan & Fast,
In the library world, experience is extremely valuable—in some cases more so than classroom education. My original plan after graduating from college was to work as a paraprofessional in a library for a few years before moving on to get my master’s degree in library and information science. After applying to over one hundred jobs, and getting nowhere, I realized that I lacked the work experience required in the library field. Even though I had a bachelor’s degree, I had not worked in a library except for a semester as a student worker. Many of the jobs for which I applied only required a high school diploma, yet I was quickly rejected because of my lack of hands-on experience.

While in library school, I worked as a substitute library assistant at the Falmouth (Maine) Memorial Library. I obtained this position in an interesting way. While home after my first semester of graduate school, I sent a message to those individuals on a statewide library email list asking if anyone needed extra help during the summer to fill in for employees who were going on vacation. I quickly received a reply from the Falmouth Library and ended up working there for two years during summers and breaks from classes. I obtained public service experience by working at the circulation desk, helping patrons find what they needed, and shelving materials. This was the first significant library job on my resume. The experience was a splendid one where I could apply what I was learning in my graduate study to the “real world.” As a result, I received solid recommendations from the staff there, which helped me to secure my first professional job after graduating with my master’s degree.

**Why Libraries?**

Librarianship can be an ideal career for those of us on the spectrum. Libraries are relatively quiet places to work. (I say relatively because academic libraries can get quite loud these days with students frequently working together and socializing.) Those who work in libraries are constantly surrounded by information, which can be like living in paradise for someone with AS.

Librarians work in a wide range of positions depending on their strengths and personalities. For example, if you are an extrovert who enjoys helping people directly, a reference or instruction position would be a good fit. Reference and instruction librarians teach patrons how to most effectively use library resources while promoting all that the library has to offer. If you are more reserved and tire easily from frequent social interaction, a position in technical services might be more appropriate. Technical services is the backbone of any library operation: this is where library materials are selected, acquired, cataloged, and maintained. Libraries have increasingly become dependent on technology and perhaps working in information technology or systems would be suitable if you are adept in this area. Most library work requires that the employee be detail-oriented—something at which people with AS tend to excel. I am fortunate that I love my career. I feel a sense of accomplishment when I leave work for the day, knowing that I have helped people obtain the information that they need in their lives.

**Our Unique Contributions**

As adults with AS, we already know our weaknesses all too well; society is constantly reminding us of how we do not fit in. It is, therefore, important to highlight our unique strengths—assets that employers may struggle to find in most neurotypicals. People with AS tend to have above average intelligence, and amazing capabilities when it comes to remembering details, particularly when our special interests are involved. We can hyper-focus on tasks without being distracted by social situations, which can greatly increase our productivity. Technology and writing frequently come easy to us (Coulter, 2009). In addition, we are trustworthy, reliable employees who are rarely absent from work (Hendricks, p. 126). Taken together, these combined attributes are valuable assets which organizations can and should leverage for their benefit.

**Important Preparations to Consider**

It is no doubt very challenging to obtain work in this slumping economy, particularly due to the large numbers of people graduating with degrees, creating intense competition for a shrinking pool of jobs. However, you can take concrete steps to maximize your visibility, highlight your strengths and skills, and help convince potential employers that you are the proper fit for their opening. Start by having your resume reviewed by several people in your particular field. If you can find someone who has recently served on a hiring committee, even better! Getting others’ feedback can help you greatly improve your documents, from content to style. Some professional organizations such as the American Library Association offer this service at their conferences. The more people who review your work, the greater the number of perspectives you will receive, and this will result in a top-notch final product.

Grandin and Duffy mention how word of mouth can also lead to employment opportunities (p. 41). “Networking” is certainly a buzzword in contemporary corporate culture and this can be a difficult task for us due to its inherent social nature. It can, however, be easier to meet people with whom we share common interests, particularly when all parties are passionate about them. Venues for networking with people can include websites such as Meetup.com, email lists, professional organizations, internships, volunteer work, sororities and fraternities, and honor societies. You can also network by shadowing someone on the job for a day. Always be prepared for a random opportunity to meet someone, perhaps on an airplane or at a restaurant. Consider having business cards made, even if you do not currently have a job. This allows you to easily and quickly pass on your contact information.

Almost every job opening is advertised online these days and many also require that you apply electronically. There are different types of job-related sites to look for: general, local/regional, and professional. General sites such as Monster.com include listings for all types of jobs regardless of their geographic location. Local and regional sites such as newspapers only include listings in a particular city or region. Professional sites such as the ALA’s JobLine contain openings limited to a given field. Aggregators such as Indeed.com can save time because you can retain specific searches and have updated results regularly sent to your e-mail. Some employers are better at advertising their openings than others, so it might be useful to look directly at the websites of some individual organizations. (Turn page.)
Upon reflection, much of my success at landing jobs is a result of flexibility, especially when it comes to geographic location. Some regions could be hiring more than others due to a variety of reasons. I am single and easily mobile since there is nothing that requires me to live in a certain area. I recognize that this can be easier for some of us who are less dependent on our families and home environments, but it is an important consideration to keep in mind while looking for work. I can say, with almost one hundred percent certainty, that I would not have full time professional work if I had remained at home in Maine. Other potential areas of flexibility include a willingness to learn new skills and technologies, adaptability to different organizational cultures, and openness to change. It may not be your dream position but it could help you to obtain the needed experience to get there someday.

The (Somewhat Dreaded?) Interview

The interview process for a professional position in higher education is much different than in other sectors. It usually starts with a phone interview, the purpose of which is to narrow down the applicant pool. If you make a good impression on the phone you will likely be invited for an on-campus interview. Most institutions pay for travel, food, and lodging expenses involved with an on-campus interview. The in-person interview can range from a half a day to three days depending on the type of position. You are expected to be “on” at all times which can be very tiring. You meet with several different groups of people, take tours of the campus and surrounding area, share meals with the search committee, and frequently are required to give a presentation on your area of expertise. Many search committees will assign a topic relevant to the position. Just as I suggested that you show your resume to as many people as possible to obtain their feedback, it is important that you practice your presentation with several people so that you can be confident that you are projecting yourself in the best light possible.

Phone interviews can be difficult for some of us because of our discomfort with communicating via this medium. It can be hard to understand what those on the other end of the line are thinking because we cannot see any of their non-verbal cues. My parents encouraged me to talk on the phone at an early age so I am accustomed and at ease with this medium. Phone interviews can really sway a hiring committee. For example, I later found out that the search committee for my first position was highly captivated by my presence on the phone. On paper I had little work experience but my phone interview convinced them that I was a strong candidate with a vibrant personality and genuine passion for helping people.

Blim (2004) believes that the interview is an opportunity for the employer and potential employee to get to know one another (p. 187). Your visit can help you determine if the fit (organization, position, management, etc.) would be suitable. Always do research about the organization before the interview. Read its mission statement, strategic plans, organizational charts, history, and other pertinent information and write down questions about things you do not understand or are interested in. Mentioning information that you learned prior to the interview and asking challenging questions make you seem prepared and engaged.

There are many simple, yet important, things you can do to increase the chances of conveying a positive and professional image of yourself during the interview. Make sure you are dressed formally (jacket and tie for men and skirt, dress, or pant-suit for women) and are carefully groomed. Although the world of work has become more casual in recent years, interviews still require this level of formality. When answering questions, use good eye contact, provide concise yet open-ended answers, pause regularly, and, of course, smile (Blim, p. 188-189).

I have noticed that search committees tend to pose a standard set of questions to the interviewee. These include telling them about yourself, predicting where you would like to be in five to ten years, how you handle difficult situations or colleagues, how your experience relates to the job, your ideal work environment or supervisor, how you work both with others and by yourself, and why you would like to work for their organization. They will often ask you to share your strengths and weaknesses. I always try to frame my weaknesses as strengths. For example, I am detail-oriented and can get so lost in the details that I lose my understanding of the big picture. This is actually an asset in the library world since many of the tasks require lots of focus.

After an interview I always send the search committee and library director thank you notes by postal mail. I want them to know that I had a positive experience and appreciate the invitation to campus. This can help you make one final positive impression, especially when the search committee members are in the process of making a hiring decision. Although the uncertainty caused by waiting for the news of a decision can be painful, it is important to be patient and give the process time to complete itself. Timing often depends on the number of candidates selected to interview and their order. Before leaving an interview I ask the chair of the search committee approximately when I should expect to hear back from him or her. If I did not receive a call or letter within that timeframe I wait a few weeks and then follow up. In academia, decisions can take awhile to become final. Although I have never done it before, some suggest that it can be helpful to ask the search committee for constructive criticism if you did not receive the job offer. This could help you to avoid the same mistakes in the future.

Disclosure

The process of disclosure “involves telling another person potentially damaging information about oneself in order to build better mutual understanding and fulfillment” (Shore, 2006, p. 173). Disclosing intimate details about oneself is risky and there are no hard and fast rules that will work in every situation. Perhaps the most difficult part of this is that you cannot control how the other person will react, which is why it is important to think carefully about when, how, and to whom to disclose. Shore believes that disclosure can be necessary “when the effects of autism significantly impact a relationship with another person and there is a need for greater mutual understanding” (p. 180). Shore suggests disclosing only as needed and then revealing a minimum of information. You could begin with a discussion of your strengths, needs, challenges, likes and dislikes (Shore, p. 181-182). In some situations it may be more appropriate to state the characteristics and how they impact your work without mentioning the label autism or Asperger Syndrome.

Disclosure can be an educational opportunity for the neurotypical person receiving the information. As more of us are open
about our autism in the workplace, we might begin to see a more tolerant environment emerge, embracing our strengths and helping us to minimize the impact of our shortcomings. Meyering (2006) expresses hope that “the cumulative effect of all the separate disclosures will add up to enough societal awareness of autism that ‘coming out’ will not be so risky for anyone” (p. 254). A positive result of increased media exposure relative to autism (having a main character with Asperger’s on the popular NBC show “Parenthood,” for example) is that more people know what autism is and how its characteristics can manifest themselves. Unfortunately, this can also lead to the trivialization of our legitimate struggles: some individuals who are not truly autistic will start to identify similar traits in themselves and, in trying to appear empathetic, tell us that they know our reality. This phenomenon was common with obsessive-compulsive disorder in the 1990’s. It is frustrating for those of us with autism to frequently feel the need to prove our disability so that we can receive accommodations (Meyering, p. 253).

Personally, I believe that AS is only a part of my complex identity as a person and therefore do not let it define me. When I meet people for the first time, I never say “I’m Charlie Remy and I have Asperger Syndrome.” I prefer to wait until I get to know the person better and feel comfortable with sharing more personal or sensitive information. I need to know that the other people are mature enough to handle this information and not let it influence their opinion of me. If I am going to have a long-term professional or personal relationship with an individual, sooner or later he or she will likely find out, whether I tell the person directly, or the person is perceptive enough to notice it as a result of my social awkwardness.

When I was offered my current job at the University of Tennessee at Chattanooga, I requested a few accommodations that I would need to be successful. One of those was a compressed work schedule. When I was at Western State I discovered that working four ten-hour days was highly beneficial. This schedule allows me to have three consecutive days every weekend so that I have plenty of time to both rest and enjoy my life outside of work. As you likely know, social stimulation, anxiety, and the need to constantly emulate neurotypical behavior are exhausting. If I were to work a regular five-day week, I would spend the vast majority of my weekend sleeping and would therefore have little time to enjoy hobbies and cultivate a social life outside of work. The three-day weekend allows me to spend most of Friday recharging my batteries so that I can enjoy myself on Saturday and Sunday.

The time to make requests for special accommodations is during negotiations after having received an offer. Discussing this during an interview could prejudice the search committee against you. I disclosed much earlier to the Dean than I usually would have but I knew it was the appropriate time to share this information with her. I also used this as an opportunity to ask if my having Asperger Syndrome would change the dynamic in any way. In other words, I wanted to be sure that she was comfortable hiring someone like me because, if not, I would not want to work there. This probably did not come as a shock to her as I had already partially disclosed on my resume by listing my involvement with the Asperger’s Association of New England.

Disclosure is liberating for me because I am a transparent person who does not like to hide much from others. I no longer have to worry as much about how others will perceive my actions or differences (Fast, 2004, p. 250). If I do something that is odd or inappropriate, the neurotypical person has a context from which to understand what is happening. Asperger’s should not and cannot be used as an excuse for inappropriate behavior, but it certainly can help others to understand why the behavior is occurring in the first place. Disclosure can be a step toward educating others about our neurological differences. I explain that I am completely open to their constructive criticism about my behavior. If they are concerned about something that I am doing, my hope is that they will tell me about it so I can correct my behavior before it causes a larger problem.

**Ongoing Challenges**

Unfortunately, hurdles can continue after you receive a job offer. There are many ongoing challenges that I face on a daily basis, including anxiety, social awkwardness and boundary issues, obsession, impatience, and stimulus overload. The good news is there are ways of proactively working around these issues so that they do not get in the way of my success.

Like many people with AS, I experience constant anxiety in my life. It could be genetic. I come from a line of worriers; my mother is a very anxious person and so was my grandfather. I become overwhelmed easily, particularly when it comes to completing large tasks. For some reason, I start to make the project into something much larger than it is, and then doubt that I am capable of completing it by the deadline. Additional things that can provoke anxiety are uncertainty, distrust of others, the unknown, hypothetical situations that may not even actually happen, and others’ perceptions of me and my behavior. Grandin and Duffy suggest treatments such as medication to manage anxiety, depression, or other problems that can go along with our autism (p. 2-3). I have been taking an antidepressant for over fifteen years and believe that it is helpful in my ability to cope.

Unfortunately, medication does not completely take away my anxiety, it simply mitigates it. Therefore with the help of a therapist I saw several years ago (before I was even diagnosed with AS), I developed several strategies that help prevent anxiety from getting the best of me. Making to-do lists has always reduced my stress level. I find it a relief to put everything I have to do on a sheet of paper so that I do not have to worry about remembering it all in my head. I then feel a sense of accomplishment (and relief!) when I can cross out a completed task and move on to the next one. When I am upset about something it helps me to talk about it with someone I trust, such as my parents, mentors, supervisors, or colleagues. They can help me calm down, put things into perspective, and set priorities. They can also offer me suggestions on how to handle a difficult situation more effectively. Asking a supervisor for clear instructions in writing can help me understand better what is being asked of me. If I am still confused, I ask the person to talk me through it so that I know I am on the right track. Recently I have also discovered that listening to classical music puts me at ease.

Those of us with autism tend to commit social gaffes more often than we would like. I have the unfortunate tendency of saying things without thinking about how they will be interpreted by others. An example of this was when I tried to compliment a co-worker but ended up saying something that came... (Turn page.)
across as insulting. I must consciously think about what I would like to say and determine if it is appropriate in that particular situation. Essentially, it comes down to impulse control: think before I act. I must also consider social boundaries when I am interacting with those whom I do not know well. I tend to be a naturally curious person and like to ask others questions about their lives. This can be interpreted by some as being overly intrusive and, quite frankly, creepy. I must limit the number of personal questions that I ask others so that they do not feel as if they are being interrogated.

I have a highly obsessive personality, which can be good and bad. Obsession has helped me when it comes to my special interests, because it drives me to learn a lot about certain topics. It has also made me an organized person who never misses a deadline. The downside is that I cannot easily clear things from my mind. Unlike most people who can easily forget things and move on, I frequently have thoughts that circulate endlessly in my mind. It could be something that is causing me a great deal of discomfort due to anxiety, or another person’s quirk that I find eccentric. I can then start to annoy others by verbalizing this obsession over and over again. It simply keeps ruminating around in my head and, as you can imagine, is exhausting. Medication, as well discussing them with others, has helped me reduce my obsessions. Another important thing that my previous boss helped me to understand is the importance of “letting go,” especially when the situation is out of one’s control. It is simply a waste of time and energy to obsess about something that is in others’ hands.

A principal characteristic of my work style is to accomplish a task within a reasonable amount of time and rarely procrastinate. Unfortunately, others work on different timelines, which can become a source of frustration when you are depending on them for something that you need in order to complete your project. When I get nervous as a result of not getting a response from someone, I start to become persistent and this can annoy them. A former supervisor taught me helpful strategy: to mark my calendar when an appropriate amount of time has passed so that I can know when to contact them for a follow-up if I have not yet received a response. I like this idea because it eases my anxiety. I establish a concrete date to follow up while the other person has a reasonable amount of time to complete the task. This also requires that I do some perspective-taking—trying to imagine what the other person’s life might be like—which can then help me develop more reasonable expectations of the other person.

I am fortunate not to have as many problems related to sensory stimulation as some people with AS. One thing that does bother me is ambient noise, especially when I am trying to concentrate on something. This is ironic because I am a loud person. I can also be easily startled by sudden, unexpected noises or touch, such as a pat on the back. I think I am becoming more tolerant of noise than I used to be. Throughout college and graduate school I would need to wear earplugs whenever I did homework or anything else requiring extended concentration. It is surprising that I do not have to do this more these days, since I work in an office where walls do not reach the ceiling, thus allowing me to hear almost everything happening around me. Perhaps I have adapted to noise without even knowing it!

The most important resource that I use to be successful at work, as well as in my personal life, is getting a more than sufficient amount of rest each night. I know that I simply cannot function properly when I am over-tired; I cannot think clearly, become overly emotional, struggle to concentrate on tasks, and am more prone to lose my patience with others. I try to get at least 9 hours of sleep per night and then spend most of my Fridays resting. I can then come to work on Mondays refreshed and energized to do what I need to do. Another benefit of obtaining a generous amount of rest is that I rarely get sick. Too many people underestimate the power of this “downtime” and how much it can benefit everyone, autistic or neurotypical.

Conclusion

Employment is an important part of most neurotypicals’ identities and should also be for those of us on the autism spectrum. It helps individuals achieve economic independence and feel a sense of accomplishment every day (Grandin & Duffy, p. 1). This is true in my life, because income from my job allows me to live independently, have reliable transportation, obtain health insurance, and purchase the goods that I need.

The reality is that people with Asperger’s must focus more and work harder than the average person to obtain and maintain employment. Most jobs entail a certain amount of socialization, unpredictability, and stress, which can be difficult. These issues, however, should not serve as barriers that prevent adults with AS from entering the labor market. Dependability, integrity, focus, attention to detail, passion, and specialized knowledge are among the many virtues that we offer our employers. Progressive workplaces can easily recognize and appreciate these traits in all employees. We Aspies have unconventional strengths, skills, and a work ethic that the larger neurotypical world would be foolish to marginalize or ignore. Together, neurotypicals and people on the autism spectrum can create a much richer, more inclusive workplace.

Works Cited


Early diagnosis and services beginning in grade school mean that college is a possibility for more and more individuals with Asperger Syndrome (AS). However, many face significant difficulty translating academic achievement into gainful employment.

Adam, for example, graduated near the top of his class with a degree in computer science. After sending out more than 40 resumes, he received an invitation for a telephone interview. Confident about his technical ability, Adam anticipated no problems answering the interviewer’s questions. “Anyone would know that having a degree in computer science means that I know how to write code,” he explained.

The interview did not go as planned. Adam hadn’t kept a copy of the job he applied for, and had a hard time answering specific queries about his qualifications. Since he hadn’t done any research on the company, he wasn’t prepared to explain why he wanted to work there. The call lasted 10 minutes, and Adam never heard from the company again.

Adam continued visiting job boards twice a week. He read articles on the Internet about how to find a job, and found much of the advice confusing. Uncomfortable meeting new people, he refused to even consider networking. Eight months after earning a degree, Adam wondered if he would ever find work.

Within days of graduation, Steven began searching for a job in government, figuring that his major in political science, interest in research, and 3.8 GPA would result in multiple offers to choose from. Instead, he discovered a highly competitive field where employers expected job applicants to have internships or related volunteer experience under their belts. Most opportunities were in the Washington, D.C. area, and Steven did not want to move. Eleven months later, Steven wasn’t thinking about a job shaping public policy. His priority (and that of his parents) was any job that would provide steady income.

The experiences of Adam and Steven are not unique. In my coaching practice, I see more and more young people who cannot find work, despite having college degrees. While the weak economy is a factor, the greater challenge is navigating the complexities of the job search. According to the U.S. Bureau of Labor Statistics, only 5% of people find jobs by responding to posted openings; nearly 25% find work by making direct contact with a company. Staffing firms and recruiters are the conduit for another 25%. The biggest percentage—almost half—find their job through networking.

Job seeking is not usually thought of as a major social event; yet simply introducing oneself to an interviewer requires a smile, eye contact, a firm handshake, and a greeting that sounds friendly and confident. There is small talk to make on the way to the interviewer’s office. Once there, a decision must be made about where to sit. The interview involves deciphering the meaning of ambiguous questions. Does “Where do you want to be in five years” refer to geography? Body language and tone of voice must communicate enthusiasm. Lying about a degree or dates of employment is not acceptable; yet you are expected to say that you want the job, even if you are not sure.

Good executive functioning is necessary as well. There are job boards to visit, online groups to join, company research to complete, customized letters to write, and follow-up inquiries to make. Timing is of the essence. Waiting three weeks to respond to an opening virtually guarantees a lost opportunity. Figuring out which jobs you are qualified for involves big picture thinking and the ability to differentiate required from negotiable skills. Motivation must be sustained for a prolonged period of time, during which one will often hear “no” and seldom hear “yes.”

Making the Job Search Work

Assisting individuals with AS who are seeking employment requires a pragmatic approach. Personal interests must be balanced with the realities of the job market. Knowledge of a subject cannot be confused with having the capabilities to succeed in a field. Job search strategies must be explicitly explained.

People with general liberal arts degrees, in particular, may not know how to sort through career options to find a good match for their abilities. It was only after Scott earned a Master’s Degree in Anthropology that he realized how very few job openings there were in the field, and that most teaching positions require a doctorate. The entry-level jobs that he did get lasted only a few months. Scott was easily overwhelmed, and needed explicit directions for every assignment. When stressed, he either became mentally paralyzed or made impulsive, poorly thought out decisions.

When we first met, he was working as a data entry clerk, frustrated at not being able to use his intellect. We explored Scott’s other interests, which included writing and technology. After several months, he decided to pursue technical writing. The content was highly structured, and he would be able to work alone for extended periods of time.

When matching personal interests to possible careers, it is important to find out what the person envisions doing once he is employed. When I ask this question, most individuals say that they don’t know. Some have inaccurate ideas about job qualifications and their own abilities. Interest in a subject area does not mean that a person will be
able to make a living in the field. While this is also true of neurotypicals, the specialized abilities of Aspergians (people with AS) limit the number of possible career paths. Additionally, for them, working conditions often play a bigger role in employment success. Many entry level jobs require speed and sophisticated levels of interpersonal interaction. Young people may discover, after making a big investment in education, that they are not suited to jobs in their field of study.

An up-to-date neuropsychological evaluation can be a useful tool for understanding how cognitive difficulties in areas such as attention, memory, and visual-spatial processing will impact employment. Some limitations can be mitigated by learning new skills or utilizing assistive technology. Other limitations make certain jobs frustrating or impossible. For example, Suzanne lost a customer service job because she could not simultaneously listen to customers and type their comments into a database.

Joe assumed that because he had a degree in communications, he was qualified for jobs in broadcasting, multimedia, social media, marketing, and editorial. He read job titles, not job descriptions, and applied to many positions for which he lacked basic qualifications. Our first order of business was to identify the skills that are needed to perform job tasks.

Due to literal thinking, people with AS may not understand that multi-tasking and “good people skills” are relative, not absolute, terms and therefore disqualify themselves from good jobs. One young man believed that he wasn’t qualified for a position that required 2 years of experience because he had been working for 19 months.

People with AS frequently equate the idea of marketing themselves to employers with being dishonest or arrogant. A number of my clients have expressed concern that in order to get hired, they must pretend to be someone they are not. It can be helpful to explain that job seekers are expected to edit information about their education and experience, and select what is relevant to the employer’s needs. Stress that it is desirable to discuss accomplishments. Dan summarized two years of writing experience in one brief sentence on his resume. “Employers know what writers do,” he said. I explained, “They don’t know that you researched topics, found experts to interview, and wrote feature articles, or that you won a writing award, unless you tell them.”

Many individuals with AS think that they are incapable of networking. However, there are several ways to network that do not involve walking into a room full of strangers, for example: informational interviews, one-on-one job networking, and participating in online professional groups. All three provide a controlled environment and advance preparation.

Finding a job must be treated like work. Two or three hours a week checking job boards and sending out resumes is not enough. A detailed plan with weekly goals and daily tasks can keep things on track. It is also important to maintain a regular workload schedule. Indulging hobbies into the wee hours, and rising at noon, is not conducive to a serious job search! Volunteering is one way to add structure to the week, and has the added benefit of providing current work experience that can go right onto a resume.

Applying job search advice to one’s particular situation is often a difficult task. When it comes to information, more is often less. Bill was paralyzed by the volume of material he received at an employment workshop. One document contained four pages of web site addresses. “Am I supposed to check all of these every day?” he asked. Differing opinions about what to include in a resume, or how to answer interview questions, can cause considerable consternation.

In certain cases, early disclosure should be part of an individual’s search strategy. When a person has challenges that are very noticeable or hard to control, offering a brief explanation during the first interview will allay an employer’s concerns, and focus attention on the job-seeker’s abilities. Disclosure should be planned in advance. Reciting diagnostic criteria from the DSM-IV, or volunteering irrelevant details (“I’m not good at making small talk”), will confuse rather than reassure the interviewer.

Academic achievement does not necessarily mean that a person is prepared for employment. For anyone seeking to help a person with AS carry out a successful job search:

- Be sure that the individual has thoroughly researched occupations, and understands what skills are required on the job.
- Make a realistic assessment of strengths and limitations. Help the individual to understand how AS may impact him in the workplace.
- Encourage thorough preparation and frequent practice of interviewing skills. A person who cannot communicate his abilities to potential employers will not be offered a job.
- Create a detailed job search plan that includes several different activities. Provide explicit instruction on how to execute each activity.
- Realize that full-time work may be too stressful for someone just out of college. Part-time positions offer the chance to ease into employment (and provide a pay check).
- Explain that the individual will not “waste” his degree by working outside his field of study. Emphasize the importance of finding a job that is manageable and minimizes stress.

While it is important to demystify the job search process for individuals, there is another piece to the employment puzzle. Employers must be educated about how to utilize the talents of individuals with AS. When I speak to organizations, or to a particular client’s supervisor, nearly all express a genuine interest in learning how to assist these individuals to be successful.

Additionally, more and more enterprises are being created to train and employ individuals for skilled jobs that utilize their intellect. Aspiritech in Illinois is one example. Often the catalyst for establishing these enterprises is a child or other family member of the founder who has Asperger’s Syndrome.

Barbara Bissonnette is the Principal of Forward Motion Coaching (www.ForwardMotion.info) and author of the Asperger’s Syndrome Workplace Survival Guide. The “College to Career: Asperger’s Syndrome Employment Intensive” is an 8-week program she developed to guide individuals through every step of the job search process.
In 2001, my husband Thomas and I were living in Philadelphia with Luke, our two-year-old prodigy. The three of us had moved from London a year earlier: a smart career move for my husband, who worked for a finance company based in the U.S.

One hot summer’s morning, I was summoned to my son’s nursery school, where his principal and teacher told me Luke wasn’t “normal.” His expressive language was unusual, and not in a good way: his speech was repetitive, consisting of overheard conversations or television scripts repeated verbatim. He played alongside other children, not joining in. He was low on eye contact and recognizable empathy. He would seem oblivious to something said directly to him, yet responded to barely audible exchanges across the room. He ran awkwardly. I, too, had noticed these traits, and vaguely expected his teachers to step in and reassure me. Instead, they were more concerned than I was.

That night I told Thomas about the school meeting, expecting him to share my agony. But his reaction surprised me. What did they know—trendy preschool educators, progressive nonsense! Luke was fine, he said. Anyone could see how smart he was. (The teacher had, in fact, said, “He’s really, really, really smart!”). Thomas insisted that Luke was misunderstood at this so-called preschool where they blathered on about feelings, regarded toys as educational tools, and didn’t actually teach (teach what? I wondered: calculus?).

Reluctantly, Thomas agreed to Luke seeing an educational psychologist. At the consultation, I filled out questionnaires while Luke answered questions and drew shapes. But this testing was inconclusive, and a more comprehensive evaluation was recommended. Thomas, however, was opposed. In his view, he’d indulged my neurosis quite enough: Luke should not be put through any more unnecessary assessment.

I felt torn. In the evening, watching Thomas and Luke play happily together, I wanted to believe that Thomas was right. Yet I was increasingly uneasy. Every day I saw evidence of Luke’s developmental quirks, especially in playgroups and playgrounds—places where Thomas never went. His insistence that Luke was normal started to seem to me like denial. I realized I had to prioritize Luke’s needs even if that led to conflict with Thomas.

Typically, after Thomas left for work, I’d start my frantic internet clicking. When I typed in “expressive language delay” and “eye contact” it brought up “autism” and “autism” and—oh!—“autism.” I did research in bookshops, while Luke dozed in his stroller. (Was this a normal doze or an autistic doze?) Against Thomas’s wishes I sneaked in a visit to another psychologist, who watched Luke drawing—all his pictures were variations of the same train—and told me casually that my son was probably on the autism spectrum.

We were already into the so-called autism epidemic, an apparent surge in the disorder (probably due, at least in part, to increased detection). Currently, in the US, autism is believed to affect one child in 88, according to new figures from the Centers for Disease Control and Prevention. The figures were lower ten years ago, but startling nonetheless. I presented the statistics to Thomas, but he remained unmoved. No more testing! His exasperation with me turned to anger. The real problem, he insisted, was me: I was pregnant with our second child at the time, therefore “emotional.”

I had read about the importance of early intervention for developmental eccentricities, and fretted about the lack of it in our case. Thomas saw my research as a loss of faith in our child, so I pursued it in secret. He said relentlessly and cruelly, “You need to love Luke for who he is.” We moved Luke to another preschool, which Thomas expected would “cure” him. Once when I drew Thomas’s attention to Luke’s social withdrawal, he shouted, “I’ll divorce you if you continue with this bull****!” He became extremely critical of me and impossible to please, sometimes smashing glasses, grabbing me, and screaming in my face. Advocating for a child with special needs is a series of battles—with the education system, the health system, society, oneself—but the future looked most hopeless when the battles were with my child’s other parent.

Parents of children with special needs, in their anxiety, are prone to arguing over what’s best for their children. In our case there was more to it than that. Thomas had always been a bewildering husband. He’d left behind a deprived background, driven himself to academic excellence, and forged a stellar career in finance. He could be charming, funny and generous, but also dogmatic and hostile. I’d glimpsed his moodiness early on, but in the excitement of new romance, alarm bells hadn’t rung.

Our relationship had moved quickly, and with each new stage—living together, having a child, moving abroad—his manner became harsher. He had a fear of change and a need for control. He decided, for example, that we’d take very few possessions to the US, not understanding the loss this meant to me. He also had a fear of new or unstructured social situations, which became much starker after we emigrated and I tried to make new friends. Any social plans invoked excuses—reasons why he couldn’t attend—and agitation. On the rare nights we did try to go out, he always picked a fight before we left. It would start with accusations: I was overspending, I’d cooked something he didn’t like. He yelled so loudly that once a neighbor called the police. Occasionally we had to cancel our arrangements; perhaps, on some level, this was his intention all along. He had told me that, in earlier periods of his life, at stressful times, he’d compulsively self-medicated with alcohol or drugs.

So it wasn’t just our son who presented a list of symptoms. Now, after all my research into neurological and psychological conditions, I had such a list for Thomas, too: anxiety; pathological difficulty with change; inability to control his emotions; lack of obvious empathy; intense social discomfort; rigidity in thought and manner; extreme pickiness with foods. The more I read about my child—Luke seemed a likely candidate for Asperger Syndrome—the more insight I gained into my husband. Perhaps his personality, too, which at its best was charmingly idiosyncratic, but at its worst was making our marriage intolerable, reflected shades of Asperger’s, if not the full syndrome.

(Please turn the page.)
For the time being I kept this new insight to myself. It didn’t fix the marriage and it didn’t help Luke. I wondered about going to court to have a judge override Thomas’s wishes. Then I could get Luke a full neuropsychological evaluation and find out what kind of support he needed. Realistically, going to court would mean separating from Thomas—perhaps not an entirely bad thing, but a huge step, a new set of battles—and so poorly timed. I learned the new baby we were expecting was another boy. What if she, too, had autistic traits? I imagined myself divorced, with two autistic children and an obstructive former husband, on the other side of the world from my family. At my pre-natal appointments I wept to my midwife.

In the end, I didn’t need to take legal action. After Luke had attended his new preschool for three months, the principal (whom Thomas respected) told us a developmental evaluation was required. Thomas could not find it in himself to tell her what he would have said to me (“Go to hell!”), so he consented. Luke was assessed by a psychologist who worked for the school district, who decided he had a sensory integration disorder (a not-quite-official diagnosis that sometimes precedes or accompanies one of autism). Soon after the birth of our second son, William, help was put in place for Luke: speech and language sessions, occupational therapy (everything from using pencils and scissors to rolling and climbing), and a classroom assistant to teach Luke how to play with other children. Thomas was nominally on board, though he refused contact with Luke’s teachers and therapists.

We’d made progress, but the year of tension and isolation, the delay in getting Luke treatment, had left me wrung out. I’d known my marriage was fragile; now it felt hopeless. I could not do justice to Luke’s needs or to our new baby while so much of my emotional strength was being sucked into the mysterious sinkhole of Thomas’s psyche. I could not make my husband milder, sympathetic, flexible, or supportive. We struggled on for three more years, but then, inevitably, Thomas and I divorced.

In a more cheerful twist (isn’t it time for one?) both our sons are thriving. Our younger boy has developed typically. Luke, re-assessed and diagnosed with Asperger’s when he was six; this made him eligible for enough special education services that he was able to make good progress. My grief about autism has passed. I understand it now, and respect and value the autistic mind. Both my boys delight and inspire me. They spend time with their father, who loves them and provides for them, although he takes no role in the demanding process of addressing Luke’s special needs. Perhaps he fears that in the sometimes stressful dealings with teachers and consultants—more strangers!—he would expose his own emotional volatility.

As I’ve gotten to know other families in the autism community I’ve learned that it is not unusual for a quirky child to have a quirky child to have a quirky personality. Still, I don’t think Asperger’s neatly explains away Thomas’s personality. There is nothing intrinsically autistic about his irrationality or aggression. But I’d bet autism is involved somewhere and, these days, Thomas himself agrees. With the help of a therapist, his anxiety and moodiness have lessened.

There are times when Luke’s intelligence, confusion and frustration remind me of his father. In all the interventions he receives—from social skills sessions and psychiatric appointments to family discussions about understanding others and ourselves—I try to help Luke embody the best of his Dad. Luke will always be on the autistic spectrum and, yes, his future relationships are likely to be more limited and challenging than the norm. Still, based on who he is now, I’m confident that he will bring to them an unusual humility and forgiveness, a readiness to take responsibility and try again—skills that too few of us even aim to acquire.

**Throw Away the Yardstick or The Blessing of the Diagnosis**

by Erika Drezner, MSW, AANE Coordinator of Child and Teen Services

Many of us started this journey through the now famous metaphor of visiting Holland. If you haven’t read Emily Perl Kingsley’s brilliant essay on having a child with special needs, Google “Welcome to Holland” and read it. In it, she compares getting ready to have a baby to planning a trip to Italy. (Only expectant parents could think of parenting as a trip to one of the most beautiful places on the planet--how naïve we were!) But having a child with special needs, according to Kingsley, is like landing in Holland. You start off with grief for the dream you lost, but you end up appreciating “the very special, the very lovely things ... about Holland.”

Kingsley is smart; she reminds us that we shouldn’t spend our lives mourning the loss of our “Italian Dream” and, while she doesn’t say it exactly this way, she makes one thing clear—you can see Italy from Holland, even on foggy days. What I mean is that even once we get past that initial stage of mourning and come to accept, to normalize Asperger Syndrome (AS), the rest of the world doesn’t go away. What I want to talk about here is how we live in the world and help our children do the same.

I don’t mean to breeze right past that initial mourning stage. Many parents come to AANE in the throes of sadness and sometimes panic. Receiving a diagnosis can feel devastating. Most parents admit that they were aware that there was “something wrong” or “different” about their child, but believed that he was a temporary thing, a developmental hiccup. Diagnosis takes that belief away. Parents are faced with the prospect of a lifelong condition, and what follows is a mountain of uncertainty. What will my child’s life look like? Will he be able to go to college? to support herself? As parents we want prognoses, we want certainty. But folks, I am here to tell you that nobody has certainty when it comes to children. Other people may think they know what to expect, but they don’t really—they just don’t know it yet.

This is the benefit of diagnosis. As parents of kids with AS, we know things that other parents won’t figure out for years—and that some parents—much to the detriment of their kids—will never figure out. We learn early that we don’t own our kids’ lives, we don’t write their stories. They may not turn out like us and they very likely won’t turn out anything like the fantasy child that lives in our head. And that is a good thing.
It is not difficult to see that most contemporary parents exist in a state of anxiety about outcomes. If the documentary “Race to Nowhere” plays in your community, I recommend that you go and see it. It calls into question the excessive pressure society places on children and teens. Today’s kids receive more homework, participate in more extracurricular activities, than kids of any previous generation—and many are collapsing under the stress created by these ramped up expectations. (The film provides a number of reasons for this, one of which is competitive college admissions.)

It’s not hard to see that parental anxiety about the future is fueling a lot of these unhealthy trends. Parents push their kids relentlessly to guarantee a vision of the future. Many kids are miserable and stressed out. The present is sacrificed to the future. And as a consequence, no one is enjoying the present. What kind of lesson is that? It seems that what is left out of the equation is personal happiness. Children are not taught to make decisions that will suit them or make them happy, they are taught to follow a path that—as the movie’s title suggests—leads nowhere.

Enter the kid with Asperger’s into this equation. We know our kids are different and that their needs are different. But how do we remain mindful of this as we guide them? It can be so easy to get caught up in the race, to wish that you were in Italy—to want a moment of slurping up pasta in the shadow of the Roman Coliseum. The temptation to compare your child unfavorably to his/her peers can rise up when you least expect it. People love to want a moment of slurping up pasta in the shadow of the Roman Coliseum to get caught up in the race, to wish that you were in Italy—to get sucked into the assumptions that govern so much of life. Everyone launches in his own time and in her own way. There are lots of paths to travel toward adulthood.

- **Slow and Steady wins the race.** Letting our kids do things on their own timeline is actually better for them. This approach allows them to break things into smaller, more manageable parts. As one adult with AS said of his teen and young adult years, “I gradually took on more and more responsibility for my own welfare. Because it was gradual, I never felt overwhelmed.”

- **Development does not stop at 18, 21—or 40!** Anyone who has taken Psychology 101 has been taught about adult development, and yet it is easy to forget that it exists. For most of us, it seems that development slows considerably in adulthood, but that doesn’t seem to be the case for our adults with AS. Working at AANE, I have gotten to know many adults on the spectrum who are continuing to grapple with issues that are typically considered developmental tasks of adolescence. I have seen them make progress, grow and change. They are some of the most interesting and engaging people I know. I admire them greatly. They continue to work hard to make sense of a world that is innately confusing to them.

The fact is that we live with these expectations, this invisible yardstick that measures everyone’s progress. Picture a yardstick; it is a straight line, and the numbers all go up in the same direction. So linear, so straight—so boring! If we are not careful, it can be a stick we use to metaphorically beat up on ourselves and our kids.

When you feel yourself falling into this mindset, picture a yardstick and imagine yourself breaking it over your knee and throwing the pieces away. And if that’s not enough to make you feel better, pick up the phone and call AANE.

**Puzzled? Discouraged? Questions?**

Call AANE at 617-393-3824
Disclosure in College

Speech by Scott Finkelstein

Scott was one of two student panelists at AANE’s spring 2012 “Perspectives on College Life” program.

You can view all speakers from the 2011 panel online in the video gallery on the AANE member page.

My name is Scott Finkelstein and I just graduated from Brandeis University. I actually finished a semester early and am currently looking for a job (in case any of you are hiring…), but I will walk with the class of 2012 in the spring.

One of the topics that people are really interested in is disclosure so I thought I would talk about that today. There are four places where disclosure comes up when thinking about college: the essay, with professors, with friends, and with significant others.

Should you talk about Asperger Syndrome in your college essay, or not?

Your main goal is to produce an essay that convinces the admissions directors that you should go to that school. To do that you need to produce a strong narrative that shows you in a good light and shows good writing skills. Guidance counselors advise that your essay should demonstrate personal growth or overcoming adversity. AS can be good for that if you can show how you overcame a challenge or turned your disability into an asset. At the same time, unless it is the focus of your essay or is an important part of the narrative, I think you should leave it out as you would other superfluous information. Basically, you want to produce the strongest, best-written, and most compelling essay you can.

I thought it was important to show that I thought of Asperger’s as an opportunity, not a disability, so I chose to write about it in my college essay. I also felt I had a compelling story to attach to it. My essay was about Temple Grandin. After the part where I disclose my AS, I wrote:

“Temple Grandin has autism too. She writes about how she thinks in pictures, not in words like other people. This has been a huge asset to her career. I also tend to think differently from other people. Sometimes, my thought process has surprised my classmates with some clever insights and unorthodox solutions that had not occurred to them.

As a consequence of her unique abilities, Temple Grandin is a world famous expert on animal behavior and an authority in livestock handling and animal management. She overcame the limits of her autism and was able to use her differences to her advantage. I see myself as similarly advantaged. The fact that she has autism and has succeeded in my field of choice shows not only that my field is viable as a career, but that it is viable for me.”

How did I talk about my AS with my professors and TA’s?

I did disclose to my professors at the beginning of each semester. Because I was approved for accommodations at Brandeis, the college’s disability services office would issue letters to each professor stating that I had a disability and needed extra time for tests since I am a slow writer. Although the letter did not specifically list my other challenges (like my tendency to talk too much if I think I have something important to say) the letter signaled them that I had AS and I think they supported me in many other ways.

I did not talk specifically with my TAs (teaching assistants) about my disability, but I think my professors did. Sometimes I had trouble with my TAs. I was a biology major and many of the TA’s were from another country and had strong accents. I often have trouble understanding accents and found this challenging. Most of the time, the TAs were willing to put something in writing so I could read it instead of hear it. I got them to do this by self-advocating. Sometimes, I would ask them to repeat it and after the third or fourth time they would write it down. Other times, I would write them an email asking a specific question.

In general, I do not ask for special treatment I think of the Asperger’s label as an explanation, not an excuse, and I strongly prefer to do things just like everyone else. At one point, I nearly got into serious trouble with one of my classes. I was having a terrible time with organic chemistry. My parents finally convinced me that even regular students struggle with orgo and hired me a tutor. This made all the difference and I ended up doing fine, but I suffered needlessly because I was so stubborn about asking for extra help.

Did I disclose to my classmates and friends?

In general, I do not tell anyone about my AS unless there is a compelling need for them to know. I don’t want to be known as the guy with Asperger Syndrome. However, I think roommates or suitemates should know if your Asperger’s tends to express itself in a way that could be grating or annoying. Since the lack of ability to discern what others are thinking or feeling when you have Asperger’s often looks like what non-aspies are like when they just don’t care, you want them to know you are not inconsiderate.

Most of my friends I made in my clubs. I joined clubs like the BORG club, which is a geek club for science fiction and fantasy readers and most of the kids were pretty accepting. I did not disclose in any of my clubs. However, I think a lot of those friends know.

Did I disclose to my girlfriend?

I have been dating my girlfriend since my sophomore year. I met her at Hillel services. I went there because I had noticed that reform Hillel had mostly girls and I figured that we would have some common interests. I told her pretty early in our relationship. This was probably smart, since she has noted in retrospect that a lot of the stuff I did when we were first dating were things that she otherwise would have dumped a guy over. She told me that she didn’t know that I had AS by the time I told her, but that she immediately knew she should have. She remembers that at lunch one day I continued talking about a subject she was not interested in for a really long time. I am much more aware of her reactions now, and don’t do that anymore. She has been very tolerant and supportive. She tells me directly if I am doing anything weird or annoying. Also, she has taught me some very useful social skills, so that I am much more comfortable in social situations and can get along with her friends. I made a lot of friends by parasitizing her social circle!

(See author photo on facing page.)
Bird Haiku
by Kayla Kimball

1.
Owl spots his prey
and glides down from his tree branch—
The silver moon glows.

2.
A mother eagle—
She has returned from hunting;
Her chicks will be fed

3.
I spread out my wings,
I fly away with the birds
High above the clouds.

Kayla Kimball comes from the small town of Danville, NH. She is a part-time college student at Northern Essex Community College, majoring in Liberal Arts: Writing, and is currently working on short fiction.
Call for Artists for 2012 Art Exhibit

On Saturday, October 13, 2012, the Asperger’s Association of New England will hold its annual fall conference at Boston University. The conference will feature a juried exhibit of work by artists and poets 18 years of age and older, who have Asperger Syndrome and are residents of New England. This year the exhibit will be managed by the AANE Artist Collaborative, a group of adult artists who meet monthly to exchange ideas and promote their artwork.


Congratulations also to Al Clark and his mother Kathy Clark. Both artists exhibited pieces in the 2D Small Works juried show at the Chandler Gallery in Cambridge, MA during April and May.

AANE congratulates artist John M. Williams, whose exhibit, “A New Perspective on the Civil War” appeared in the Winchester Public Library throughout the month of January.

Above, John Williams’ “Sacajawea.”
As a young man with Asperger Syndrome my son has overcome many challenges to achieve success in a meaningful and enjoyable way. David has always enjoyed the great outdoors—whether being tooted on my husband’s back over mountains, wearing a child-sized backpack down the Grand Canyon at age ten or fulfilling the requirements to earn an Eagle Scout rank. Years of family trips with the Appalachian Mountain Club and participation in Boy Scouts provided the ideal mix of structured socializing and exercise that didn’t depend on athleticism or winning.

David learned of a high school classmate’s post graduation trek up the 2,000 mile Appalachian Trail. David wanted to join him but was scheduled to attend a special program for academically gifted students with learning disabilities at Westfield state College. Five years later—after changing schools and college major—my son’s dream became reality when we dropped him off at the Delaware Water Gap a couple of days after Salem State College’s May finals. By early August David reached the Maine hundred mile wilderness area, but headed back to New Hampshire when we considered the lack of cell phone service, stores and relative isolation.

As a mom—my greatest concerns were for safety and my son being lonely. I thought that David had inherited my poor sense of direction and would get lost. But once motivated he quickly paid attention to signs, used his compass, charged the cell phone regularly and sought information from strangers. My husband played long distance captain—studying maps, weather conditions and suggesting detours for food and shelter.

There is nothing like experience for learning that a backpack won’t keep a down sleeping bag dry, winter hiking boots are too heavy and that cabbage keeps pretty well in the heat. When asked what was most challenging about the experience—David said dealing with boredom and achy knees—that is until buying walking sticks. And what was the best part? Meeting so many unusual people—like “Country Gold”—a reformed alcoholic who traveled up and down the trail for years while spending the winter earning money at ski resorts.

A hand’s on person by nature—David learned from a Youtube video how to make an ultra-light weight alcohol stove out of aluminum beer bottles. He designed and fabricated equipment to make the process more efficient and now sells stoves, marketed to long distance hikers. Visit to learn more at: BottleStoves.com and See the video I made about this incredible experience at: http://www.youtube.com/watch?v=_BoIlCnMzIM (titled: David doing AT summer 2011) Recently, author and autism advocate Temple Grandin presented David with the Temple Grandin Award for outstanding accomplishment and contribution. I was told that she enjoyed the video I made of his backpacking adventures!
Before LifeMAP, I was a lost 24-year-old, fighting to become successful with Executive Functioning Disorder. I flunked out of community college, lost job after job. Nothing I did seem to ever work out. I lost eleven jobs in total. My last boss like the rest of them said I just wasn’t getting it, something just wasn’t working out. I was always late even when going out on dates.

Before LifeMAP, I had given up. I was devastated and hopeless. I had finally hit my biggest low point in my life. My parents tried everything to help me. They have always been there when I needed them the most. On our last leg of hope, my mother found the program LifeMAP.

I have now been in the program for about seven months. I have a wonderful coach who works with me every week. Her name is Judy Cloherty. We work on strategies to help me manage my time. After years of not wearing a watch, I finally bought my first watch a month ago, and have been wearing it religiously. Although time is still an issue, it is not consuming my life any more. I am hopeful again that I can reach my goals and become more independent.

Judy is a great coach, and after a few months I was seeing improvements in my life. I even bought my own car and with the help of Judy I have managed to pay things on time. I have gotten great reviews in my new job. Things are going so well, my boss put me in charge of an art show.

LifeMAP and Judy have given me hope again, and helped me become the independent woman I now know I can be.
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Hello. My name is Kirsten Root and I have two sons with Asperger Syndrome. My 4 y.o. was diagnosed about a year ago and my 3 y.o. was diagnosed four days ago. I am very new to the world of Asperger Syndrome, so today I wanted to talk about how I am making sense of it all. The first thing I have learned is that I can’t use figures of speech or symbolism of any kind at home. If I say “it’s raining cats and dogs” my literal-minded sons look up into the sky for falling animals. So, since my sons are not here today, I am going to go all out with the symbolism. Here we go. We’re headed to Oz.

We are all Dorothy. We always assumed we’d be living in Kansas, but then the tornado—the diagnosis—struck and we landed in Oz. We brought Toto with us. Toto symbolizes the healthy habits, hobbies, or friends we cultivated back in Kansas. Before the diagnosis, what kept you balanced? Was it yoga? hiking? getting enough sleep? Was it the women in your book club? your spouse? Now that we’re in Oz, and more stressed out than ever, we cannot short-change the things that keep us strong: when we take time to replenish ourselves, we are not being selfish!

Next we meet the Scarecrow. The Scarecrow symbolizes our brain trust. We need answers, advice, and ideas. I won’t dwell on this point because you are here at this conference, so you already get it. I do want to offer props to the cult of the waiting room. Has this happened to you? Your child is in a therapy session, and you are planning to catch up on e-mails or just close your eyes. But then it happens. You strike up a conversation with the mother or father sitting across from you and by the time your child comes out of her session, you’ve given and received great advice and information. I have learned that Scarecrows are everywhere, and I’ve learned to listen to them!

Next on our journey we meet the Tin Man: someone who can see into our hearts and knows what we’re going through. Let’s talk about The Public Meltdown that happens in the last aisle of the grocery store. People stare—some with kindness, and some like the woman who once said to me, “There’s nothing wrong with that child that a good spanking couldn’t resolve!”

If only all the strangers staring at you and your suffering, out-of-control child knew what you have already done to prevent or minimize this moment! That morning you checked to make sure all the tags were cut out of her clothing. You served strawberries for breakfast, of course, because Tuesday is strawberry day. You drove the same route to the grocery store, etc. etc. etc. But I have learned that what strangers believe doesn’t matter. I have learned that it is far more important to find some Tin Men who know exactly what we did that morning in an attempt to forestall the meltdown, and what we do each and every day. How we contour our lives in order to smooth a path for our children. How we bend so our children won’t break. I am lucky to have met some Tin Men. I have met Page, who took me to coffee after each tornado—each diagnosis—hit. And Gloria, another mom who is here today. I hope you all have some Tin Men supporting you.

Now it’s time to add the final companion, the Cowardly Lion. And who does the sweet, misunderstood Cowardly Lion symbolize? Our sons and our daughters, of course! Because it does look like cowardice, doesn’t it, when they refuse to go to school or ride the bus? When a birthday party is too much to handle. When a flushing toilet or broccoli on a dinner plate sends triggers terror. But we have learned how courageous our children actually are. Every day, we send them into a world fundamentally unsuited for them, full of sensory overload and incomprehensible social rituals. Every day we ask them to master the academic curriculum, the hidden social curriculum, and to do this under constant sensory siege.

Every time I fight for insurance coverage, or attend an IEP meeting, I remember what the world requires of my sons. I keep a quote by artist and author Mary Anne Radmacher in my wallet: “Courage does not always roar. Sometimes courage is the quiet voice at the end of the day saying ‘I will try again tomorrow.’” This kind of courage lives in all of us and in our children.

We have met all of our traveling companions and we’re on a journey through Oz, but how do we know when our journey is at an end? Unlike the real Dorothy, we know we can never go back to Kansas. I have learned to dream big, so for me, the end goes something like this:

I close my eyes and see my two boys about 15 years hence, in college, on the first day of the semester. They are dressed in relatively clean clothes, and although they both need haircuts, their faces and nails and teeth are clean. They have found their class, and have arrived a few minutes early, and they are talking to their new professor. “Hello,” they say, “I’m in your seminar this semester, and I have Asperger Syndrome. Some people need glasses to help them see, or a hearing aid to help them hear. Like them, I need a few small things to help me succeed in your class. I’d like to discuss this with you; when might be a good time?” Can you see how obsolete I have become? In my dream, when my journey has ended, I have stripped away every role I currently play in their lives and, one by one, my sons have taken over these roles for themselves: chauffeur, housekeeper, laundress, chief cook and bottle washer, social secretary, accountant and advocate. I will know that my journey has ended when the only job left to me is to love them. And here’s the strangest thing: Remember all of those other mothers, the ones we left behind in Kansas? They have the same goal! Just like us, they want to launch happy, independent children into the world. The journey’s endpoint is the same for the Kansas moms as it is for the Oz moms!

This journey will not be an easy one for us—or for the Kansas moms, either. But there is a very important distinction. During all the years that we, the Dorothies, will work to build our children’s independence, WE WILL GET TO LIVE IN OZ! We have this tremendous honor, the honor of raising our sons and our daughters, and we get to do it in a world full of quirky, beautiful, impossible things like talking trees, Munchkins, and cities made of emerald. And finally, everything I have learned makes sense. Of course our children expect to see falling animals when we say, “It’s raining cats and dogs.” A After all, we live together in Oz, where monkeys can fly. How lucky, how fortunate, are we?

“Zendala” made in AANE Plymouth County Teen Program with artist Sally Dean. Also see page 18.
Autistic people have a very different way of thinking about the world. That different way is just that: a difference, not a deficiency. Autism is not a “spectrum” condition. There is a clear dichotomy between being autistic and non-autistic (neurotypical). In fact, autism itself is a word that describes a variety of heterogeneous neurological conditions. It might be more accurate to say there are many different kinds of autism. Perhaps a better metaphor might be the “autism constellation.”

Major Findings

1. Pharmacotherapy: There are medications that can be effective in addressing some of the negative symptoms sometimes associated with autism, including anxiety, irritability, and hyperactivity. There are no drugs, however, that can treat the core symptoms of autism, which have to do with social interaction and communication.

2. Multimodal Neuro-imaging: Insights gained from combining different brain-imaging techniques tell neurologists that, from a neurological point of view, autism overlaps with bipolar and schizophrenia. It is also evident that what we call autism is quite heterogeneous. That is to say, there are different types of autism, and it is not a condition that one can have more or less of (autism does not exist along a continuum, or a spectrum). Cognitive control is a key subject under investigation, and one thing has become clear: behaviors that appear the same to a casual observer may look very different neurologically. This is worrisome since autism is diagnosed primarily by observing behavior.

3. Social Engagement at School: On-site observations have called into question the value of the one-on-one aide model, at least as currently implemented. One underutilized technique for addressing socialization challenges is to engage children in suggesting solutions, instead of having teaching being guided entirely by adults. Also, the artificial environment in which most social thinking training is done makes it less relevant than it could be.

4. Different Preferences for Attention: At least a couple of the stereotypes that have grown up around autism seem to have no scientific support. Studies designed to measure central coherence (seeing the big picture) and “sticky attention” (the relative inability to shift focus) have revealed no essential difference between autistic and neurotypical subjects. What is clear is that autistic people have different preferences: they prefer, for example, to dwell on detail. That doesn’t mean they can’t see the big picture; it’s just not as interesting.

5. Adaptive Behavior Deficits: It used to be thought that 70% to 80% of autistic people also suffered from intellectual impairment. Recent studies show the number to be the other way around. (As an aside, I’m not aware of any connection between autism and intelligence, so I wonder why the percentage of people who are categorized as intellectually impaired (5%) would be any different from the general population. One caveat here is that there could be developmental delays associated with autism so that age-adjusted testing could be skewed.) The concept of “high-functioning” as it relates to autism is generally only related to IQ, and so is not really addressing the ability to function in a pragmatic sense. A study of a large group of autistic people found no correlation between scores on a scale of adaptive skills (the Vineland scale) and a measure of “severity” of autism (the ADOS test). This calls into question the relevance of labels such as “mild” and “severe,” since they seem to have no practical significance.

6. Physiological Features of Anxiety: As with brain imaging, measurement of physiological signs of anxiety (such as higher heart rate and perspiration) found that outward behavior is not necessarily an accurate indication of what is going on inside. This suggests that even careful observation by staff may not give an adequate (or even accurate) warning of when a person is experiencing distress. Better techniques are needed.
José María tiene una voz peculiar, creo que el tono de su voz asusta a algunos niños, sobre todo si son pequeños. A otros, mayores que él y a ciertos adultos les resulta molesta, por lo que le hacen bromas al respecto, comparándolo con algún personaje de la televisión, por lo general con el pato Donald. José María no se enfade, no comprende porqué no entiende las bromas, está lejos de conocer o interpretar la verdadera intención que tenemos las personas con nuestras palabras. Carece de entonación, su voz no flucúa, es alta y chillona. Cuando copia y repite con exactitud las palabras de otro, reproduce también exactamente el tono de la voz.

Cuando está nervioso, su voz se convierte en un gemido alargado, que acompaña haciendo muecas con la boca, como si las palabras se quedaran atrapadas en ella, dentro de una mueca constante que no puede evitar.

Durante mucho tiempo me vi asediada por el continuo reproche de distintas personas, incluidos algunos maestros, que atribuían el extraño tono de voz de José María a un exceso de enojo, o a una falta de autonomía calificándolo de “Noño”.

A los ocho años, cuando por fin obtuve un diagnóstico acertado, se me confirmó que el tono de su voz es una alteración de la melodía o prosodia, característica típica de los niños con síndrome de Asperger. El diagnóstico resolvió algunos de mis constantes conflictos con ciertos maestros, en especial con los que fueron tutores de José María durante los dos últimos años de preescolar, pero confirmó mi ignorancia y me hizo sentir totalmente estúpida y culpable, pues debido a sus constantes reproches, que me acusaban de consentirlo demasiado y de ser éste el motivo de que él empleara esta noñería al hablar, le había regañado continuamente, creyendo que así dejaría de hacerlo, sin que él pudiera entender lo que pasaba o porqué le reñía.

Aún ahora continuo enfadada conmigo misma, pues me dejé llevar por quienes ni conocían ni estaban informados respecto a su problema. He intentado perdonarme infinidad de veces utilizando las mismas razones que ellos: que no lo sabía, que no conocía su problema. Pero si sabía que había algo en él que era diferente. Y aun así, no he conseguido justificar mi ignorancia culpando a los otros.

En todo caso, fuimos culpables todos, ellos por hacer juicios precipitados sobre mi hijo y yo por habermelo dejado guiar por sus desinformadas y desacertadas instrucciones. Todavía hoy el inicio de cada curso escolar me se presenta como una incógnita y me produce angustia, pues sé que nuevamente tendré que poner en marcha todo tipo de explicaciones que puedan ayudar a los profesores a conocer las dificultades por las que cada día atraviesa José María y lo difícil que le resulta adaptarse al cambio; como quien dice, volver a empezar: cada año un nuevo maestro, cada año una nueva incógnita.

Hace poco recibí una nota de un maestro en la cual me indicaba textualmente: “José María es un niño inteligente, aunque la mayor parte del tiempo no tiene la mente preparada para aprender, cuando la abre asimila los conceptos correctamente”. Efectivamente, hay días en los que el niño se muestra dispuesto a aprender, participa y hasta muestra alguna de sus habilidades; sin embargo, hay otros en los que permanece absoluto y confuso, negándose a colaborar.

Su vida es como la mar, a veces está en calma y a veces con tempestad. Demasiados ruidos o instrucciones le confunden, como si no pudiera escuchar parte de lo que dices y se quedara solo con algún concepto. Los días de calma me resulta más fácil obtener cosas de él a través de pequeñas notas, que acepta de buen agrado si le interesan; de no ser así, rompe el papel y vuelve a su rutina.

En muchas ocasiones, creo que no logro hacer las cosas bien del todo, o por lo menos no consigo que otros capten lo que le sucede; sin tener el Síndrome de Asperger, actúan igual que él, quedándose únicamente con una pequeña parte.

Recuerdo nuestra visitas semanales a una conocida hamburguesería a la que a mi marido le encantaba llevarnos y en la que había un espacio especial para jugar. Luis hacía amigos de inmediato, mientras José María permanecía observando, negándose a participar y sonriente. Todo transcurría con normalidad. Algunos niños se le acercaban y eso le hacía sentir feliz.

De pronto oía sus voces haciendo una y otra vez la misma pregunta: “ ¿Cuántos años tienes?” El tono extraño y chillón de la respuesta, demasiado pomposo y alto, provocaba el rechazo como única reacción. Los niños se apartaban de él mirándole con desconcierto, en tanto que comentaban algún secretillo con su padre. En aquellos momentos, el dolor me embargaba y le pedía a Dios que me pusiera en el lugar de mi hijo.

El tiempo me ha demostrado que el único milagro posible es dominar tu propio dolor. Nunca he creído que dios me castigara con el problema de José María, no creo en el dios inquisidor que te castiga por no acudir a misa. Me obligué a ser valiente. Debia ayudar a mi hijo y para hacerlo hacía falta una madre fuerte. Mi dolor no es más intenso que el de otros. Me hice valiente cuando me sentí egoísta y desagradecida.

Tengo dos hijos estupendos, un marido maravilloso y la experiencia única de conocer un mundo que con el paso de los años me ha hecho más humana, más humilde y más agradecida.

La mayoría de los padres vemos crecer a nuestros hijos con la única idea de que se conviertan en hombres o mujeres importantes; deseamos que sean grandes médicos, abogados, directores de multinacionales...... Mientras más importantes logren ser, más los amaremos. Yo he aprendido a amarlo solo por el mero hecho de amar, sin condiciones y sin prejuicios, por una mirada, por una sonrisa, por una palabra, y eso me reconforta.

No deseo que mis hijos se sientan obligados a ser importantes ni que desprecien a otros por serlo. José María no suele diferenciar adultos de pequeños, blancos de negros, pobres de ricos, feos de guapos. La apariencia no es importante para él, está al margen de los cánones de belleza, no los comprens. Ni siquiera comprende porqué la gente normal se pasa media vida intentando ser guapa o preocupándose en exceso por su imagen. Desconoce que es por agradarse a sí mismos y agradar a los demás. Para él, la vanidad es sólo una palabra, una más de las que están en el diccionario.

(Continúa en la página siguiente.)
José María casi nunca agrada a los demás, su lenguaje remilgado y pedante le hace parecer antipático, su ausencia hace que crean que los ignora intencionadamente. Adquirió el lenguaje utilizando la memoria; aprendió a memorizar inmensas cantidades de palabras cuyo significado muchas veces ignora: frases, oraciones, diálogos enteros. No lo hace por vanidad, sino porque es la única forma que ha hallado para, de algún modo, comunicarse.

Igualmente, nadie le enseñó a leer las mismas palabras que fue memorizando de forma mecánica le sirvieron como código para descifrar la lectura. No me di cuenta de ello hasta poco después, cuando descubrí que le era imposible explicar aquello que había leído. Las palabras eran sólo palabras, no estaban unidas a ningún significado. Entonces buscamos la ayuda de un logopeda, e incluso así sigue siendo difícil que preste atención o se centre en algo que no sea de su agrado.

Recuerdo que durante algún tiempo, la edad se convirtió en una encrucijada para José María. Estaba obsesionado con preguntarle la edad a todos cuantos se le cruzaban de camino a la escuela. Cuando alguien respondía, si sobrepasaba los 58, la siguiente pregunta era: “¿Va a morir?” Esto lograba intimidar a unos cuantos, por lo general a quienes desconocían las dificultades de José María y, sobre todo, sus obsesiones. Otros, casi siempre los más ancianos, se lo tomaban con filosofía.

Me llevó un tiempo considerable explicarle que no es correcto preguntar la edad, sino más bien decir “Hola.” Últimamente ha dejado de hacer aquello, pues está más interesado en la vida de los insectos.

A medida que el tiempo pasa, la mayoría de personas tendemos a quitarnos años, algo que en mi caso está descartado, no por mi agrado, sino por la rigidez de José María; tampoco puedo ocultarla ya que si lo intento, él de inmediato me recuerda que naci en 1964. Sin duda, hacemos estas cosas porque deseamos permanecer siempre jóvenes.

Aún no entiendo muy bien porqué José María relaciona constantemente la edad con la muerte. Me dice: “No quiero que sea vieja, no quiero que te mueras,” o “Tienes 39 años, eres un poco vieja, vas a morir.” Intuyo que esto tiene que ver con la muerte de mi cuñado a los 58 años. En aquel entonces José María sólo tenía cinco años, pero todavía me pregunta por él de vez en cuando.

Pocas veces José María logra conectar con otros niños de su edad. Desea tener amigos, pero los amigos no son fáciles de hacer para un niño como él. Conforme se va haciendo mayor va siendo cada vez más consciente de su creciente soledad. Su lenguaje es y sigue siendo limitado, limita su mundo encerrándolo en el silencio con el que lo castigan aquéllos que no lo conocen, aquéllos que sienten temor de quienes son diferentes.

Being a Father to a Someone with Asperger Syndrome by Gina Mitchell

At AANE’s conferences and workshops, and in our online and face-to-face support groups, the dominant presence of mothers is impossible to ignore. While mothers appear to be in the majority as primary caretakers and advocates for children with Asperger Syndrome (AS), I interviewed four fathers who have taken a very active role—or even the lead—in raising and educating their children with AS. These dads spoke readily about their own experiences; they expressed a desire to connect with other fathers of children, teens, or adults with AS, to seek advice and to offer support. Their stories offer important insights into what it means to be a father to someone with AS.

Before the annual AANE fall conference in 2010, AANE approached Steven Snitzer, the father of a young adult with AS, and asked him to moderate a panel and discussion group about fathers of children with AS. At this time, there were already support groups in place to address the unique experiences and needs of mothers, siblings, and grandparents, but so far, none designated solely for fathers. At the conference, the panel of fathers confirmed the demand for this type of discussion; the workshop drew an audience of fathers “who seemed to really need this—this forum and this particular way to connect with other fathers.” The workshop was repeated at a later conference. The fathers interviewed for this article participated in these AANE panels, and in the informal discussion groups held in preparation for the conferences.

These dads come from very different families and circumstances. Some remain married to the mothers of their children with AS, while others have separated, divorced, or remarried. One father has only one child; the others have two or more. Together, they attest to the experiences of biological fathers, stepfathers, and fathers of adopted children. The diversity of their situations gives rise to interesting divergences as well as striking similarities.

When asked to describe the time that followed their children’s diagnoses, the fathers offered similar accounts. With the news came a sense of loss and an initial phase of grieving. As one dad explained, “No one goes into parenting with any intent other than that the kid’s going to be perfect. That’s everyone’s expectation.” But as each father started to pursue resources and information about the diagnosis, their feelings of grief and helplessness began to subside. They recalled feeling empowered when they learned more about the complexities of AS, and reassured after talking to other parents in similar situations. “There’s so much information out there. Just getting to know other parents who can say ‘Yeah, I know what it feels like when your son is having a meltdown and doesn’t want to eat breakfast and doesn’t want to go to school, and here’s how I deal with that,’ is really helpful.”

Of course, seeking advice and support from other parents can’t remedy all of the many of the challenges fathers of children with AS confront. Despite the overarching messages of optimism and resilience that emerged in our interviews, the fathers also addressed loaded issues and shared painful memories. Many of their children suffer from multiple mental health issues, and some have struggled with depression and drug use. They attested to the strain that having a child with AS can put on marriages and family dynamics, describing tension and disagreements, divorce,
and in one case, a heartbreaking custody battle. Reflecting on his work facilitating the support group, Steve explained, “Some people have very, very difficult situations... So a moderator has to be prepared for that, to acknowledge the difficulties that people are expressing. Sometimes there isn’t anything positive to say—but sometimes people have come up with wonderful solutions.”

From talking to the fathers, it’s easy to see how this would be true. One dad recounted raising a child who evolved from a deeply disturbed teen—“spinning out of control” as he grappled with the news of his Asperger’s diagnosis, additional emotional and behavioral disorders, and the more ubiquitous pressures of adolescence—to a “very respectful, well-mannered” adult. That life story could be invaluable to another man I had spoken to days earlier, the father of an angry and confused eighth grade boy. And for all his current anxiety about the social difficulties his son will continue to confront in the years to come, this father had outstanding advice for other fathers of children with AS: “I think dads tend to feel like they kind of have to take a backseat on their involvement in this area, because they feel like it kind of gets relegated to moms... But in my case it was exactly the opposite. I was really, really aggressive about getting services for my son, getting more information, and being very assertive with the school... I was the one who really drove the involvement in the special-ed process for our son.”

All of the fathers responded articulately and thoughtfully to my questions about their children’s diagnoses, about which resources they had found most helpful, about their expectations of fatherhood and how they dealt with those expectations changing. But the most moving and instructive responses often came when I asked them to tell me more about the children themselves, and about the kinds of connections they shared. With a marked shift in tone and expression, the dads turned from stories of difficulty, confusion, and patient learning to recount moments of gratification and joy. AS diagnoses have by no means prevented them from discovering activities to enjoy with their children, including paintball, skiing, fishing, and cooking. It was a pleasure to hear their voices brim with pride as they discussed their children’s accomplishments. One father delineated his son’s successful transition into his freshman year at a college several hours from home. Another described the birthday card, filled with signatures and kind words from his coworkers, that his son received earlier that week.

So while the news of an AS diagnosis can provoke painful emotions, and though fathering a child with AS yields unanticipated and distressing obstacles, the men I spoke with were far from pessimistic about their situations. Their distinct yet overlapping stories, endlessly textured and complex, illuminate the unexpected lessons and rewards born from fathering a child with AS. As one father remarked, “I’ve often wondered: if I had a chance to wave a wand and make my son neurotypical would I do that? I think to some extent I might, because I know it’s been hard on him; I know he’s struggled with depression, he’s been angry, he’s been confused, it’s been a painful thing for him. But there are a lot of things that I’ve learned about my son and about myself that I never would have known if he hadn’t had this challenge. I think it’s made me a better dad because it’s made me a better listener. It’s made me ask different kinds of questions. It’s made me a better communicator with my kids; it’s made me not take things for granted.”

We hope that more dads will reach out and join the fathers group, enabling it to continue and expand. We also hope that fathers (as well as mothers, grandparents, etc.) will feel free to call AANE Child & Teen Services or Adult Services for information and support. To find out about future support group meetings for fathers, please email steve.aane@gmail.com.

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our auctioneer, speakers, and entertainer.

Please enjoy the photos here and at www.aane.org.

We hope to see you all again next spring!

AANE board member Ken Shulman and Yolanda Kolinski, AANE Director of Programs for the Latino Community

AANE board member Lucy Berrington, AANE Journal: Spring 2012 Issue 10

AANE presents the 2012 LAUGH OUT LOUD GALA APRIL 28, 2012

Gala Co-Chair Deb Allaire, AANE Executive Director Dania Jekel, MSW, comedian Gary Gulman, and Gala Co-Chair Jill Purpura

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AANE board member Lucy Berrington, looks over one of the decked-out silent auction tables.
Register today at www.aane.org!

4th Annual Cape Cod Summer Conference with Stephen Shore, Ed.D.

Date: Thursday August 9, 2012
Time: 8:30 AM-4:00 PM
Location: Cape Codder Resort and Spa
Iyannough Rd & Bearses Way, Hyannis, MA 02601

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Asperger Syndrome Connections 2012 with Tony Attwood, Ph.D.

Date: Saturday, Oct 13, 2012
Time: 8:30 AM to 4:30 PM
Location: George Sherman Union Ballroom, Boston University
775 Commonwealth Avenue, Boston, MA 02215