AANE member John Williams, whose paintings appeared in AANE's 2007 and 2009 “Seeing with a Different Eye” exhibits, also has some of his work included in a forthcoming book, *Drawing Autism* by Jill Mullin (Mark Batty Publisher, November 25, 2009) celebrates the artistry and self-expression found in drawings, paintings and collages created by people diagnosed with autism. You will be able to purchase this book through the AANE online store. Soon the AANE website will also launch a special store to connect our artists to art lovers who wish to purchase or commission work.

www.aane.org
MESSAGE FROM AANE BOARD PRESIDENT NANCY SCHWARTZ, MSW

Dear Friends,

In July, I assumed the role of Chair of AANE’s Board of Directors. It is an honor and a privilege to work with the many people who make up the AANE community—the talented staff, dedicated volunteers, and the remarkable parents, professionals and adults with AS who reach out to AANE on a daily basis. I am extraordinarily pleased to be joined in my work on the Board this year by six new directors: Dr. Sangeeta Dey, Melinda Miller, Janet Price, Susan Shamus, Atty. Ken Shulman and Shannah Varon. Please help me welcome them.

Please also take a moment to find out what’s new at AANE. Our fall season has been busy and our winter programs offer some unique opportunities for connection and education. Pulitzer Prize winning journalist and music critic Tim Page spoke about his new book, Parallel Play: Growing Up with Undiagnosed Asperger’s, to an audience of more than 150 people in mid-September. World-renowned psychologist Dr. Tony Attwood, and author and educator Kari Dunn Buron, shared some of the latest thinking about Asperger Syndrome with more than 600 people at our Asperger Connections conference on October 2st and 3rd. Francisco Stark, author of Marcelo in the Real World, a popular young adult novel about a teenager with AS, conducted a book reading on October 21. In March, AANE, in partnership with YouthCare MGH, will host a groundbreaking conference on anxiety and its implications for those affected by AS. And that’s just the beginning! Please check our website, www.aane.org. I hope you’ll take advantage of what you see!

As a final note, remember that AANE is only here because of your support. Please consider a gift to the annual appeal when you receive our donation card in November. Every gift is important and greatly appreciated.

Thank you for being part of the AANE family. I hope to see you at an AANE event soon.

Sincerely, Nancy Schwartz

MESSAGE FROM AANE’S EXECUTIVE DIRECTOR DANIA JEKEL, MSW

Dear Friends of AANE,

Hunter, the young man whose photo adorns the cover of this issue of the Journal, is someone who has grown up along with AANE. I believe I first met his mother ten years ago, when he was only seven years old. Last spring, Hunter not only graduated from high school, he also persuaded his band to hold a fundraiser for AANE. (See his speech on page 33.) Now he’s attending college.

It’s wonderful to see or hear about the development and achievements of the children, teens, and adults with AS in our AANE community. Chris Robbins recently had an article published in the magazine section of the Boston Globe, about his experiences as an adult with AS. It’s also wonderful to connect to new people in the national AS community, as we did this summer with activist Ari Ne’eman, and this fall with music critic Tim Page (see page 34).

Of course, people in our community also have their struggles and losses. Our hearts go out to Sharon and Darren McCann who lost their husband and father Thomas McQuoid. (Several other families who are mourning lost family members or friends are mentioned on pages 38 and 39.)

We are also deeply concerned about the negative impact of the recession on our families and our schools. We hope that two current legislative campaigns will help our families: one to expand insurance coverage for autism spectrum disorders, and one to make sure IEPs address our children’s need to be safe from bullying.

In times of joy and in difficult times as well, I hope that participating in the AANE community will enrich your life and strengthen your spirit. May you find insight and inspiration, comfort and support here.

Dania Jekel

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To most parents hearing it for the first time, the term “neuropsych eval” is mysterious, a phrase that never comes up in toddler music classes, playground chat, or the mainstream parenting manuals. Parents facing the possibility that their child has developmental problems, however, must quickly become accustomed to it, because the neuropsychological evaluation is integral to parenting and educating a child with special needs. If a child is experiencing difficulties, and parents or educators suspect that a neurological condition such as Asperger Syndrome (AS) is the root cause, a neuropsych evaluation can confirm or rule out that hypothesis.

Ideally, however, the neuropsychologist’s written report does more. It should communicate clear information about the child’s needs—and how best to meet those needs—to parents, educators, and sometimes advocates, lawyers, hearing officers, or judges—not just to other neuropsychologists or members of the medical community. To write the most user-friendly and effective report, the neuropsychologist needs to speak not just medical-ese, but also parent-ese, educator-ese, and legal-ese. This article examines the needs and perspectives of three of these sub-cultures—neuropsychological/medical, educational, and legal.

The Neuropsychological Perspective

The most comprehensive assessment available, the neuropsych, provides an overview of a child’s functioning, drawing on the child’s history, the clinician’s observations, and test scores in various cognitive domains, including language, memory, visual-spatial skills and so on. “We look at each specific skill and integrate them all into a holistic picture of the child’s functioning,” says Ann Helmus, Ph.D., founder of Neuropsychology and Education Services for Children and Adolescents (NESCA), a pediatric neuropsychology practice in Newton, Massachusetts. The neuropsych evaluation can serve many purposes. Among them, it determines whether developmental problems are present, establishes a diagnosis, guides treatment and educational planning, measures progress, and demonstrates eligibility for special education services.

Ideally, the process starts with seeking a skilled neuropsychologist who has a thorough understanding not only of the clinical aspects of the process, but also its educational and legal implications. However, identifying who to work with can be challenging. Currently there is no specific licensing for a neuropsychologist. “Almost anybody can call themselves a neuropsychologist whether they have training or not,” says Dr. Helmus. Parents should make sure the evaluator is a licensed psychologist who has undergone two years of formal post-doctoral training in neuropsychology, primarily with children. In private practice, similarly, the evaluator should specialize in children and adolescents. “The developmental and educational needs of children are very different from those of adults,” says Sangeeta Dey, Psy.D., a clinical neuropsychologist who practices privately in Lexington, Massachusetts and is a member of the AANE Board of Directors. “If your child needs medical help, you would like them to be seen by a physician who specializes in children.”

Traditionally, neuropsychologists’ training has had a clinical focus (evaluating seizure disorders or brain injuries, for example) rather than a focus on the educational goals that have come to dominate private pediatric practice. “When we’re learning how to do the job, we’re taught to write for the professor and supervisor. In the real world, though, we are rarely writing for other psychologists. The burden on the neuropsychologist is to translate recommendations into the language of the special education system,” says Joseph Moldover, Psy.D., a developmental neuropsychologist who practices independently in Wellesley, Massachusetts and frequently works with children who have AS. Neuropsychologists acquire insight into the education system—to varying degrees—through practice and exposure. Before commissioning an evaluation, parents should clarify what the psychologist usually will or will not do. Will the neuropsychologist write educational recommendations? Is the person familiar with school districts and programming? Can the person meet any relevant deadlines (for example, completing the report in advance of a team meeting)? Is the person willing to make classroom observations and attend team meetings at the child’s school? Should mediation or litigation with the school district become necessary, will the evaluator collaborate with an educational advocate or attorney?

To begin the evaluation process, the child’s parents and teachers fill out questionnaires and supply other information (including medical and school records) to the neuropsychologist. At the intake meeting between the parents and the clinician, parents can further articulate their concerns and goals. (At this stage, a conscientious evaluator might decide a neuropsych evaluation is not merited and the child can be better served by more prosaic means. “Sometimes I say to parents, ‘Spend the money on tutoring’,,” says Dr. Helmus.)

The intake meeting is followed by four to eight hours of testing the child. Because some children require frequent breaks and other accommodations, testing may be spread over two to five appointments. By arrangement (and perhaps at an additional charge), some neuropsychologists will observe the child at school or in another environment more typical than their own office. While many evaluators consider this essential for a complete picture of the child’s functioning, others won’t (or can’t) provide the service at all. “Neuropsychologists work with the brain/behavior relationship,” says Dr. Dey. “But if they work with children they should go to school to look at the program, and if they can’t do this they should disclose it before they start.” The evaluation process concludes with a parent feedback session.

The evaluator’s attention can be more carefully targeted if he or she comes to the testing with a clear sense of the issues. “If parents go into the process with a clearly formulated question, they will end up with a better answer,” says Dr. Moldover. “‘The child has a hard time with writing,’ is a general concern.
If you say, ‘His homework and vocabulary are good but he can’t get started when he’s asked to write a composition,’ that is much more specific. Similarly, ‘He has poor social skills and doesn’t have many friends,’ is a general concern, versus the more specific, ‘He seems to be socially motivated but can’t interpret facial expressions or sarcasm.’” Asking for educational recommendations is less specific than asking whether an inclusion program is appropriate. However, parents who are new to the process shouldn’t worry if their initial concerns are more general.

In making an assessment, the evaluator draws on three categories of information. First, the child’s history includes relevant psychiatric or neurological disorders within the family; a narrative covering pregnancy, birth, and development from infancy on; the problem that prompted referral—including the emotional impact on the child and family—and the educational history, including what special supports or interventions have already been tried. The second category is observations of the child’s behavior and functioning, which incorporate input from the parents and teachers, in addition to the neuropsychologist’s own observations. The third component is testing. When an AS diagnosis may be indicated, areas of testing include verbal and nonverbal reasoning, organization and executive functioning, language pragmatics, social processing and visual-motor skills.

Ideally, the neuropsychologist should review the written information they receive from both parents and educators prior to the face-to-face intake meeting with the parents, and prior to the testing. “One goal of the neuropsychologist is to ferret out specifics,” says Lynne Mitchell, MSW, an AANE trainer and private educational consultant who works for school districts in Eastern Massachusetts. “If neuropsychologists don’t review the parents’ responses until they put the report together later, they’re wasting a huge opportunity to use the parent sessions more effectively.”

Test scores are interpreted in the context of the other information. “Two children might show exactly the same score on a test, but that could mean entirely different things based on the history of the child and the observations,” says Dr. Helmus. “Just showing me a score tells me very little if I don’t know how it was achieved.” In a geometric design test involving blocks, for example, a child who gets even one block wrong would score zero (suggesting an impulsivity or attention problem). A child who simply throws the blocks also scores zero (suggesting a serious cognitive or behavioral issue).

Some deficits cannot be quantified. Social skills and executive functioning, for example, are assessed to a large extent through observation. “My office desk is near the window and often my evaluation starts when I see the parent park the car and try to get their child out,” says Dr. Dey. “If the child stamps her foot and there are difficulties in the transition, and she arrives in the office and won’t initiate conversation, or has absolutely no regard for my perspective, that could be an important clinical indicator of the child’s functioning in unfamiliar settings. All these observations are documented.”

Confusion around diagnosis is not uncommon. AS is a relatively new label (added to the Diagnostic and Statistical Manual IV in 1994) and shares traits with conditions including ADHD and Non-verbal Learning Disorder. “What a neuropsychologist calls Asperger Syndrome, a neurologist or speech and language therapist might call something different,” says Dr. Moldover. The background of evaluators can incline them more toward one diagnosis than another. A psychologist particularly knowledgeable in ADHD, for example, might over-diagnose it. “Sixty to seventy percent of all kids I see with Asperger’s have been misdiagnosed with ADHD. If you know how to use a hammer everything looks like a nail,” says Dr. Dey. “But there are other signs—social interactions and play are unusual, or the child is overly fixated with certain themes, like dinosaurs—that can’t be explained by ADHD.”

Conversely, some psychologists may assume a child with social difficulties has AS, when the real issue might be ADHD or social anxiety disorder. If a child is given different diagnoses by two different professionals, parents can ask the evaluators to explain their criteria or reasons. Says Dr. Moldover: “You’re trying to understand whether it’s an issue of language—two different professionals or disciplines using different terms for the same thing—or a substantive disagreement about what’s being observed in your child.”

A skilled evaluator, says Dr. Helmus, “integrates all the data available from the developmental history, testing, and behavioral observations into a diagnostic formulation that explains why a child can do well in one situation but not in another.” (As an example of a report that failed to integrate all the evidence, she cites a child with visual-spatial-perceptual problems who was inappropriately given the Rorschach inkblot test and misdiagnosed as psychotic.)

Educational recommendations are arguably the most important part of the report—so it is all the more problematic that some evaluators don’t provide them. “Many neuropsychologists tell parents it isn’t their job to write educational recommendations, that’s the job of an educational consultant,” says Dr. Dey. “Parents should clarify this at the outset. It’s important that a neuropsychologist who works with children is capable of writing educational recommendations or performing program evaluations if needed.”

The recommendations are most persuasive when closely related to an individual child’s performance and circumstances. “The recommendations are usually not a direct extension of the test results, but are a product of the child’s interaction with his or her environment,” says Dr. Moldover. “A particular school or program may work well for one child with a given disability, and not for another.” The recommendations should be accompanied by an assessment of the risk to the student if his or her needs are not met.

A detailed description of appropriate services adds weight to the report. “The consumer must demand very specific recommendations which are operational,” says Dr. Moldover. “If the report recommends extra help with social skills, the child can wind up in a lunch bunch, which may not be helpful. It is
more useful to say, ‘The student needs pull-out social pragmatics instruction at least three times a week using a formal social skills curriculum, delivered by a graduate level special education teacher with experience in Asperger’s, in a group of no more than three children, with peers who are well matched in IQ and behavior.’”

Independent neuropsychological evaluations are costly. In Massachusetts, the average fee for private evaluations is often $3,000-$3,500 (covered in full or in part by some insurance plans, and perhaps lower for preschoolers). However, families do not necessarily have to pay out of pocket for comprehensive testing. By law, school districts are required to provide testing in all areas of suspected need to determine the eligibility of a student for special education support, and to re-evaluate students on Individualized Education Plans (IEPs) every three years (and more frequently in some circumstances). However, in most cases it will be the school’s choice who conducts the evaluation. If parents are not satisfied with the findings of the neuropsychologist chosen by the school, they can request that the school pay for a second opinion: an independent educational evaluation by a neuropsychologist of the parents’ choice. Because the funding for this is limited, and payment rates are set by the state, the pool of available professionals is small. (Many of the large Boston hospitals will make these evaluations, but their waiting lists can be long.) In some cases a school district may decline to fund an independent evaluation, arguing that their own testing was comprehensive and complete. Disagreements in such cases can be settled in a hearing of special education appeals.

By whatever route the parents make their way to an independent neuropsychologist, they can help ensure their expectations are met by considering, first, their own questions, and second, the type of professional who can best answer them. “All neuropsychologists are not the same,” says Dr. Helmus: “It’s not like going to get a manicure.” Parents should feel free to call AANE to get a referral to a trusted provider.

The Educational Perspective

As the primary source of information guiding the education of a child with AS, neuropsychological evaluations serve several functions: establishing eligibility for special services, providing insight into the way a child learns, describing how to address the child’s needs, and informing decisions about school accommodations and placement.

“A neuropsych report is so much more than the diagnosis,” says Jean Stern, M.Ed., AANE Director of Children’s Services, who has over 30 years’ experience in teaching and educational consultation. “It helps the educational team formulate the best educational and treatment plan for the child. The specific recommendations can translate directly into the services, accommodations, and modifications in the IEP.”

By law, schools are required to review independent neuropsych reports. The reports should be used to guide educational planning and substantially inform students’ IEPs. (Testing provided by public schools also serves this purpose.) “I take the recommendations in a neuropsych and transfer them into a new user-friendly document, the IEP,” says Natalie Labouchere, Lead Teacher at the EDCO Manville Partners Program (based at Brookline High School) for students with AS, Nonverbal Learning Disorder and similar profiles. “I use the neuropsych report to guide goal development and to summarize the student’s current performance. The teachers are more likely to receive the IEP, not the student’s whole file.”

Schools are not required to accept the recommendations, only to consider them at a meeting within ten school days of receiving the report. If possible, having the neuropsychologist participate in the meeting can help the team understand and accept his or her recommendations. If differences arise and cannot be resolved, parents can revoke their consent to any part of a current IEP, or reject a new IEP. In Massachusetts, they will then receive information from the Department of Education about applying for mediation or a hearing at the Bureau for Special Education Appeals.

Even if a school accepts the recommendations, however, the process by which neuropsych reports are translated into action in schools can be “extremely variable district to district, and sometimes within a district,” says Lori Hodgins Brazell, M.S. Ed., an independent special education consultant who works for schools and families. The reasons for this vary. Most neuropsychologists have been trained to write reports for other medical professionals, not for educators. Their reports—typically 8-20 pages crammed with scores, statistics and technical language—can be confusing to those not well versed in psychology, including parents and most mainstream teachers. Even some special educators, with their broad responsibilities for many different types of students, may not have expertise in autism spectrum disorders, and might misconstrue references the neuropsychologist takes for granted. “After parents or educators receive these reports, there can be misunderstandings,” says Jean Stern.

In some cases the process begins with tension around the role of the neuropsychologist in diagnosing the student and advising the teachers—tasks that school administrators may feel their district is equipped to handle in house. Providing services to a child with AS may place additional burdens on schools that are already strapped for resources. (Federal and state laws mandate that eligible students receive services, but do not fully fund them.) In addition, educators are preoccupied with high stakes testing (such as MCAS in Massachusetts) that holds them accountable for students’ progress in math and literacy, but not for some skills that are critical to children on the spectrum, such as social pragmatics or emotional self-regulation. As a result, parents and educators sometimes come to the team meeting with frustratingly different perspectives. “You’re thinking of one child, the people across the table are thinking of them all,” says Terri McLaughlin of the Federation for Children with Special Needs, a leading Massachusetts support and advocacy organization. “Parents need to understand the process and what the school is responsible for, what the parent is responsible for, and how can they all work together? Ultimately a working partnership has to be the goal.” In this somewhat challenging context, the responsibility belongs to parents and neuropsychologists, not just to educators, to ensure that recommendations in a report are effectively implemented.

Once the child’s testing is completed, a competent neuropsychologist schedules a meeting with the parents to
discuss the test results and observations, and explain the recommendations. This conversation should equip parents to help interpret the neuropsych report for the child’s educational team, which is particularly important if the educators are relatively new to AS. The completed report should be available to parents and educators with time to spare before the IEP meeting (“Sometimes the parents wait for months, and the IEP meeting comes and they don’t have the document,” says Jean Stern.) This time frame allows for the report to be reviewed by special education staff, who should be prepared to interpret the report for general education teachers. “Even if the school department accepts the report, it’s not going to be put into practice if the teacher doesn’t understand what the recommendations mean. I’m not blaming the teacher—it’s just that sometimes someone has to translate,” says Lynne Mitchell. In some situations, for example if parents anticipate resistance to the report and its recommendations, the neuropsychologist may need to attend the team meeting. (This usually entails an additional fee. Not all neuropsychologists provide this service, a point that should be clarified up front.)

A neuropsych report goes far beyond traditional academic assessment. Usually it is the other areas of need—social and motor skills, emotional and behavioral issues, and executive function problems—that may entitle a child to services. “Sometimes a child is refused eligibility because he’s not failing academically,” says Jean Stern. “The neuropsych report should make the statement that even with a child who gets straight As, it’s the deficit neurological areas around which you build an IEP, not the strengths.”

With AS, social issues are central. The report is likely to recommend direct instruction in social skills, and tracking the frequency and quality of peer interactions. “The report should cover how a child may interpret social situations and perspective-taking challenges in the classroom,” says Lori Hodgins Brazell. “It needs to make the point that for these students the social is academic. You don’t just expect reading to happen—you teach it directly. You give kids examples and practice and feedback, and then you go onto the next level. With AS, the same thing has to happen for social development.” The neuropsychologist, and then the educational team, should also consider how a child’s social naivete makes him or her vulnerable to teasing and bullying, and the necessity of including in the IEP protective measures, and teaching the child skills and strategies to keep him or herself safe.

A strong report should also address a student’s emotional needs, which may not be obvious, especially if the child doesn’t exhibit behavioral problems at school. “A good neuropsychologist should identify not only how much anxiety is there, but the impact it has on this particular child,” says Joan Toussaint, an educational consultant and advocate based in Maynard, MA. “There’s almost no greater challenge than being able to get the team to understand that, whether teachers see it or not.” Author and educator Kari Dunn Buron recommends that an IEP also include a goal for relaxation and self-calming.

The neuropsych report should also address the need to teach independent living skills, a deficit that tends to be highlighted when students with AS undertake major transitions (for example, to high school or college). There is increasing awareness that the foundations for success in that transition need to be laid when the child is much younger. “We need to be proactive, not reactive,” says Robin Lurie-Meyerkopf, M Ed, AANE Associate Director and a classroom educator for more than twenty years. “Services must be put in place even though some difficulties might not be obvious, because without support they will become more obvious. A good neuropsych report, especially for a young child, contains information about the need to teach independent skills at every age.” Promoting independence requires addressing executive function difficulties. “Some neuropsychologists could do a better job explaining that executive function isn’t just about your materials. It’s about how you approach and organize anything, including your thoughts,” says Lori Hodgins Brazell. Evaluations for an older teen should assess whether the person’s executive functioning is sufficient to enable him or her to transition to an independent life after high school.

For educators, the crux of a neuropsych report is its recommendations. Evaluators need to funnel the student’s testing scores and history, and their own impressions, into a meaningful approach to the child’s education. Sometimes, however, recommendations are not clearly spelled out. They may be scattered throughout the report, buried in psychological jargon. They can be too numerous—overwhelming and paralyzing educators—or too generic. And sometimes parents find themselves with a report from which recommendations are absent altogether, a situation comparable to “leaving the doctor’s office without a script,” according to Terri McLaughlin. “According to the law, recommendations should be part of the report. Parents need to make sure the recommendations are in place, and if they do not understand the test results they should call the evaluator.”

The strongest neuropsych reports use structure and language, as well as professional expertise, to make their case. It’s helpful to assemble the recommendations in one location, focus on the highest priorities for that child, and express them in language geared towards teachers. Natalie Labouchere says, “A neuropsych whose report I liked picked five strong goals, the most salient ones, and explained them. She didn’t overwhelm us with twenty.”

Recommendations are more powerful when delivered in straightforward language rather than medical-ese. “I want the language to be so clear there is no equivocating about what is recommended for services,” says Joan Toussaint. “If it’s too clinical—or too vague or generic—it’s very difficult for the school to implement. How can this translate into functional terms? A good neuropsych report makes the evaluator’s findings applicable to daily life at school and at home—what it means for that particular student.”

Evaluators can accomplish this by backing up their points with realistic classroom examples. These help clarify terms such as “chunking” (breaking down an assignment into smaller ones with separate due dates) and concepts such as sensory integration, an issue often poorly understood by mainstream teachers. “A report might talk about ‘diminished auditory comprehension due to filtering difficulties’, which is not necessarily helpful to a teacher without translation,” says Lynne Mitchell. “Not being able to filter background noise has huge implications in the classroom. Teachers need to understand that this recommendation actually means not seating this particular student with Asperger’s by an open window when Kindergarten is at recess.”

Recommendations should be specific, both to guide
educators and to help hold schools accountable. Recommending a “small class” is less useful than specifying, for example, a class of six to ten students with a similar learning profile, taught by a certified special education teacher with expertise in AS. Specificity also reduces the chance of common misinterpretations. “Schools may think that if they throw an extra body in there that’s the same thing as a smaller class size,” says Lynne Mitchell. “But a better teacher: student ratio is different from smaller class size. Sometimes for students with AS the problem is the sheer number of people in the room; more adults can make it worse, not better.” Some neuropsychologists include attachments providing detailed strategies, explanations, and further resources.

Parents can follow up with special educators to help ensure that the IEP is implemented. Even a basic reference—such as “clear explicit language”—might require supervision to be effectively realized, says Lori Hodgins Brazell: “Regular ed teachers may think they’re being clear and explicit, but actually they’re not being clear and explicit enough, because a child is not understanding complex or figurative language and the teachers are not fully aware of the metaphors they use.”

Neuropsychologists should specify the attributes of the school that best meets the child’s needs. For students with AS, that list might include social pragmatics embedded throughout the day, staff skilled at handling anxiety, and a language-based approach to programming. The recommendations should be justified in terms of the particular child’s needs, and the risk to that child if they are not implemented. The neuropsychologist should avoid statements such as “This child requires and out-of-district placement,” or even “This child is eligible for special education services,” as these are judgments that are up to the child’s educational team.

For parents, the evaluation process can feel disquieting, the stakes uncomfortably high. However, the neuropsych evaluation with its educational focus, is not only about analyzing the ways that a child perceives and understands the world. It is also about enhancing the way the world perceives and understands that child. “Testing that is thorough, candid, and credible,” says Terri McLaughlin, “affords parents the opportunity to raise expectations, think big, and dream about what could happen, what could be—their child’s capabilities.”

**The Legal Perspective**

If a dispute between parents and school administrators moves from a school conference room into a courtroom, the neuropsychological assessment assumes another function. With its diagnosis, expert impressions and recommendations, this report is the key piece of evidence in establishing the legal rights of a student with AS to appropriate services at school.

“At a hearing, the hearing officers want a current neuropsych exam by someone credible, and if that’s missing the case is not going anywhere,” says Tim Sindelar, an attorney in private practice with fifteen years’ experience in special education law.

The likelihood of ending up in litigation is small. In Massachusetts, 160,000 students have IEPs. During fiscal year 2008, the Bureau of Special Education Appeals—which conducts mediations, advisory opinions and hearings to resolve disputes between parents and school districts—mediated 906 cases, most of which were settled. Only 34 resulted in full hearings and decisions. However, additional families might go to hearing if they were fully aware of their rights and could afford legal representation.

A strong neuropsych report provides the means to ensure that a child’s needs are addressed from the outset within the legal framework of the special education IEP process. The report provides parents and educators struggling to work out their differences with the means to do so. Educators are less likely to challenge a report that makes an airtight case for the student’s needs. “A strong report can give the team the information and motivation they need to unlock the puzzle,” says attorney Julia Landau, Director of the Autism Special Education Legal Support Center at Massachusetts Advocates for Children, a non-profit organization and leader in special education advocacy. “The stronger the report is, the more likely parents are to avoid the need for mediation and litigation.”

Several features make a neuropsych report particularly credible.

A clear and accurate diagnosis is essential. “Sometimes a neuropsychologist uses words like ‘Asperger’s-like’ but doesn’t actually give a diagnosis,” says Jean Stern, Director of Children’s Services at the AANE. This can be an obstacle to reaching agreement on whether or not a student has a disability, the first step to establishing eligibility for an IEP and services.

Next, the report must establish whether the student is making effective progress or could be expected to do so if its recommendations were implemented. Effective progress is legally defined as documented growth in the acquisition of knowledge and skills, including social and emotional development. Effective progress is evaluated with reference to developmental expectations, the individual potential of the student, and the standards set forth in the state and district curricula. A neuropsychologist can highlight a student’s progress or struggles by using comparable tests over time. “If a previous evaluation used the Wechsler, use the Wechsler again, unless there is good reason for doing the Woodcock instead, in which case describe that in the narrative,” says Tim Sindelar.

The impressions and recommendations presented in the report are most persuasive when rooted in the clinician’s knowledge of the child. “The neuropsychologist’s personal observations are a critical part,” says Beth Simon, Staff Attorney at Massachusetts Advocates for Children, who also practices privately. There are benefits; she adds, in working with the same neuropsychologist over the years. “The evaluator gains credibility by knowing the child better.” A thorough evaluator goes beyond describing the interaction in the office, also observing the child in school and perhaps at home or another social environment. “That’s particularly important with Asperger’s kids, because testing is usually their strong suit, but they have difficulty generalizing their skills in less structured situations,” says Joan Toussaint. Incorporating input from family, neighbors, teachers and other caregivers adds weight to the report. Tim Sindelar says, “The best evaluators will either visit the school program, have someone on staff who will do that, or have discussions with teachers and therapists. This improves the quality of the report and ensures that schools, having been consulted, will be more invested in the findings and recommendations.”

When the evaluator has targeted the testing and observations to specific goals and concerns about that student, the report can
offer more insight. “I don’t usually need another neuropsych report to tell me the student has Asperger’s,” says Tim Sindelar. “I might need to gather information about the student’s emotional rather than neurological state, and how to address that: whether this student is in turmoil or not, whether he’s grounded in reality, and what kinds of feelings are dominant.”

Similarly, neuropsychologists' recommendations should be closely related to the profile of the student in question, rather than cut and pasted from some generic list of accommodations associated with an AS diagnosis. “An evaluation is more persuasive when it is clear from the report how the program, services or accommodations recommended are necessary to meet the unique needs of the individual child,” says Julia Landau.

Recommendations can backfire if couched in terms of what is “best,” “optimal,” or “ideal” for the student. “The school might view those as nice suggestions but not essential, and discount them,” says Eileen Hagerty, an attorney with Kotin, Crabtree and Strong, LLP, a Boston practice with a notable history of advocating for children with special needs. “The law doesn’t entitle the child to the best available education, but one sufficient to meet his needs and make effective progress. As a judge said, this child is not entitled to a Cadillac, but is entitled to a Chevy that runs.” The report should state what the student requires in order to make effective progress. The more specific a report’s recommendations, the more effectively schools can be held to its standard. Ideally, the neuropsychologist should identify not just the type of service a child needs (such as social pragmatics instruction), but its frequency and duration, the qualifications of the provider, the size and composition of the group, and the setting. Even if the neuropsychologist thinks the child needs an out-of-district placement, he or she should not name a specific school in the report. Instead, a good evaluator describes the specific characteristics a program needs in order to be able to satisfy this student’s specific needs.

Stating the risks to the student if the recommendations are not followed can make an assessment more compelling. The child may become increasingly socially isolated, for example, or lose the motivation to keep trying at school. “It can be moving and helpful to include statements the child made, such as feelings of social rejection or thoughts of suicide,” says Eileen Hagerty. “One evaluation I saw commented that the child had bitten her fingers till they were red and bleeding. Or a detail to convey how anxious a child is: they erased the paper so hard they tore a hole in it. That picture of the child is helpful, especially for the hearing officer.”

However persuasive the report, the role of a skilled neuropsychologist goes further. Evaluators sometimes need to attend team meetings (or participate by phone) to explain and defend their recommendations. “As the process becomes more challenging, the family needs better communication between the evaluator and the team,” says Terri McLaughlin. Some evaluators may not expect to participate at this level. However, if a dispute goes before the Bureau for Special Education Appeals, a neuropsychologist who declines to attend the hearing seriously erodes the value of his or her report.

At the hearing, evaluators who establish their objectivity can advocate more effectively. “When I go to hearings and listen to neuropsychologists criticize a public school program or services, sometimes that’s warranted, but other times it looks like they don’t have an open mind about the program or the success the child has had there,” says Attorney Mary Ellen Sowyrda, who represents public schools and an educational collaborative. “They need to acknowledge the parents’ concerns, but if they approach the task with an open mind they will have more credibility.” The neuropsychologist can demonstrate objectivity by acknowledging the strengths of what the school district is offering as well as its weaknesses, by varying his or her recommendations (for example, not routinely advising out-of-district placements), and by avoiding potentially provocative statements such as: “This child cannot be served in a public school.” Neuropsychologists’ testimony is more persuasive—whether on the witness stand or in the written report—if they have observed the child in a non-clinical setting, talked to teachers about how the child functions at school, and reviewed the documented history, including previous evaluations and IEPs. As chief witnesses, neuropsychologists are an intrinsic part of the effort to ensure that children with AS receive an appropriate education. Despite its challenges, that effort is worthwhile.

Individual neuropsychologists vary in the way they practice their science or art, and may have good reasons for their methods and choices. The points and suggestions made above do not negate the value of neuropsychological reports that may vary from the standards and suggestions in this article. We invite the various members of our community to continue the discussion in the AANE online parent support groups, or on the AANE blog.

Watch the Parent Toolbox on the AANE website for a neuropsych tip sheet for parents.

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Destination Independence is a series of classes designed to foster independent living skills in the areas of Budgeting, Health, Household Management, and Relationships.

Funded by a generous grant from Autism Speaks.

For information on forthcoming classes, please contact: Dan.Croft@aane.org or Max.Sederer@aane.org.
Who’s on Your Team?
by Jamie Freed, MSW, AANE Director of Adult Services

Many children with Asperger Syndrome (AS) are fortunate enough to have a team of people to support and work with them. In addition to parents, the team can include any number of professionals who think about, focus on, and implement recommendations to address the specific needs that arise as a result of AS. Although some people on the team may work with the child in settings outside of school, a solid team of parents and educators is of critical importance, because school is a major focus of a child’s or teen’s life.

Developing a harmonious, effective educational team is not easy. Even when the team is in place, it doesn’t necessarily mean that their recommendations are always on target, always implemented, or 100% effective. However, by creating a team, there is at least an acknowledgment that children with AS have complex needs, and require sustained attention and targeted intervention to build on their strengths and to provide support in their areas of challenge. We see that children and teens with AS do better when teams meet regularly and work at providing interventions and supports to help students advance toward the goals in their Individualized Education Plans.

Now let’s consider adults. Do the needs of people with AS disappear when they achieve the magic age of 18 (age of majority) or 22 (when eligibility for public school funding runs out in Massachusetts)? Have they learned by this age all the basic skills they need to achieve success in life? Are they realistically prepared to handle the myriad of challenges adulthood presents? Some are well on their way to independent, successful lives. They know how to ask for the kind of assistance they need from college disability or student services offices, from a work supervisor or the Human Resources department. Many have figured out their sensory needs, and developed successful coping strategies: avoiding environments that are over-stimulating, or building into their days routines to calm an overloaded sensory system or activate an under-aroused one. Many have found the area of study or work for which they are appreciated and rewarded. Many find mates who value their unique qualities, and have satisfying personal lives. However, many adults we know—interesting, bright, funny, and talented people with much to offer—have challenges that, unaddressed for months, years, or even decades, feel insurmountable.

Most of the adults with whom we work at AANE did not have the benefit of an AS diagnosis and appropriate interventions as children. Even younger-diagnosed adults may have received inadequate transition services in high school, or “fell off the grid” when they exited the structure of high school or college. Many have gotten stuck, and are leading lives marked by failure and social isolation. They may be unemployed or underemployed, lonely and discouraged. But what if, as an adult with AS, you had a supportive team focused on your individual needs? Where would you start? What would you work on? Who would be on the team, and what type of support would each team member provide?

At AANE, we are attempting to begin answering these questions and addressing these needs through our new program, LifeMAP: The Life Management Assistance Program. Through LifeMAP, an adult with AS (or High Functioning Autism, PDD-NOS or Non-Verbal Learning Disorder) can receive intensive, individualized support from a life coach, in order to address specific, concrete issues of concern in his or her life. Each coach and client with AS (or Aspie as some adults prefer to be called) agree upon specific goals, and meet regularly (usually weekly) to take steps toward reaching the goals. AANE staff supervise coaches, and progress is evaluated by client and coach throughout the program. Currently, LifeMAP employs seven coaches, working with a total of 17 clients. From October 2008 through June 2009, some adults had slots funded through the Department of Developmental Services, while other slots were paid for by the adults themselves or their families. AANE is slowly growing this program, hoping that we can expand it more to meet the needs of the adult community.

However, if you are an adult with AS, you don’t have to be part of LifeMAP in order to make desired changes in your life. You can create your own team. (Likewise, if you have a family member or friend with AS, you can create a team with him or her.) Team members can help you accomplish tasks, learn new skills, provide encouragement, and give you respectful yet honest feedback. The truth is that in our complex society, even adults who are not on the autism spectrum assemble teams as well, and rely heavily on them for their happiness and success. That is, we all rely upon a variety of other people (and machines and systems) to provide certain expertise or perform certain tasks in our lives, whether it’s a dry cleaner, a car mechanic, a farmer, a chef, a tax accountant, a therapist, a best friend, a spouse, a trusted colleague at work, or a professional mentor. People with AS may just need some extra guidance or support in figuring out who should be on their teams.

Identifying your specific needs is the place to start. Self-awareness is key to determining your needs, and therefore identifying who should be on your team. First, it’s essential to be aware of the components that combine to create AS, and of how those components specifically apply to you. What is your “brand” of AS? How do AS traits manifest themselves in your daily life? Identifying specific challenges resulting from AS will guide you in figuring out what you want or need to work on, and what interventions would make sense for you. Then you can identify who might be available to help you.

Who would be on a team for an AS adult? A team can be made up of family members, friends, colleagues, acquaintances, social or interest groups, pets, community members, professionals (clergy, pharmacist, gym personnel), etc. Team members can be paid or unpaid, short-term or long-term members, and can be found in a variety of ways: referrals to professionals, Craig’s list, meetup.com, on-line interest-based or social networking communities, social groups, family gatherings and more. AANE offers a variety of support and social groups that could be part of the supports that an adult with AS might access.

In addition to team members who are people, you can identify tools or strategies that work for you, and keep them in your house or in your mental “toolbox.” Tools might include...
items to address your sensory needs, such as weighted blankets, fidget toys, soft clothing etc. Acclaimed author Temple Grandin built herself a squeeze or “hug” machine which settles her system down after intense sensory and social experiences. There are tools available to assist with executive functioning or organizational challenges such as personal digital assistants, calendars, cell phones etc. Some websites, such as www.napo.net or www.flylady.com, have tips to help with organizing things in your home. Any of these can be helpful to an AS adult, but the same things won’t work for everyone—you need to create your customized toolbox.

**Assembling Your Team**

What kinds of people or expertise might you need on your team? While each person’s needs are unique, there will probably be certain general areas in common. What follows are some suggestions of common areas of need for adults with AS.

**Help making safe, rewarding social connections**

(Social Director/Social Connector/Social Organizer)

AS is a social communication difference, so this area can be extremely challenging. Many adults with AS want to connect to other people, and have the ability to take part in reciprocal social activity, but don’t know how to get started. (The popularity of AANE’s pizza and game nights, social activities, adult-only conferences, and groups are evidence of this desire and ability to socialize and connect.) If you experience difficulty connecting, you may want to recruit a team member who can provide a bridge to a richer social life. Depending on your need, this team member might help you finding a social group, or attend an event with you, especially the first time, to reduce your anxiety. It may be easiest to pursue social opportunities that are based on common interests. Fortunately, there are on-line social networking sites which facilitate in-person meetings among those who share the same interests. Given the success of sites such as www.meetup.com, there are obviously others, not just those with AS, who desire social connection with individuals who share similar interests.

**Help with Social Skills/Thinking/Pragmatics**

(Speech Therapist/Life Coach/Friend/Family Member)

Social skills and conversation—so important in our society—do not come intuitively to people with AS. However, these skills can be learned through explicit instruction and practice by relying on the considerable cognitive skills possessed by many AS adults. While children with AS are likely to receive such social pragmatics training nowadays, adults often missed getting this help. It can still be very helpful for an adult to work with a speech therapist or life coach to anticipate or role play social situations before they happen, or review them when they are over.

**Help with organization or executive functioning**

(Administrative Assistant/Secretary, Organizational Coach)

Executive function skills enable people to handle life’s practical demands at home, at work, and in one’s social life: make and implement plans, organize physical things in one’s work or home environments, organize/schedule activities and manage time, get started on tasks or projects and persist step by step to completion. Adults need to use these skills, for example, to set up systems to pay bills, shop, clean house, and cook. Multi-tasking is often required even if you live on your own, but especially if you’re working and/or have a family and household to manage. Because of the pervasive nature of these executive functioning challenges, many AS adults may need on-going support in the form of team member who provides specific, targeted assistance in this area.

**Help finding emotional support**

(Therapist/Coach/Friends/Family Members)

Emotional support is sometimes indicated, because it is hard to live in a world where you feel different. Many adults struggle with depression and anxiety as by-products of their AS, as a result of difficult life experiences, or as an additional, co-existing mental health condition. Some strongly benefit from working with a therapist who has a solid understanding of AS in general, of the specific emotional needs of a client, and of the variety of approaches that work best for Aspies.

For some adults with AS, medication can be a helpful tool, especially to alleviate depression and anxiety. For this group, a psychiatrist or psychopharmacologist can be a key team member. For others, medication is not indicated.

**Help with employment issues**

(Employment, Career, or Rehab Counselor, Job Coach, Human Resources Professional, Supervisor)

Employment is another area of significant challenge for many adults with AS. Our community is full of gifted and talented adults—even many with advanced degrees—who are unemployed or underemployed. Even those who are employed often struggle with fitting in at work, or meeting others’ expectations. Working with a knowledgeable employment counselor or coach could be very helpful. An employment-focused team member might help to: organize the job hunting

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**Beaded Lizard Mask No. 1** by John Gieg from AANE’s “Seeing with a Different Eye” exhibit
process, identify good-fit jobs, help you prepare for interviews, assist with social or work challenges that arise while on the job, and work with clients around “strategic disclosure” of AS to employers.

**Health and Wellness**
(Doctor, Dentist, Personal Trainer, Cooking Teacher, Dietitian)

Health care can also be a challenge for adults with AS. Asking for help, in general, is a challenge as it places a social demand on an individual and involves recognizing one’s own needs. Communicating with health care providers can be especially daunting if there is a serious, anxiety-inducing health issue being addressed; communication abilities decrease when anxiety increases. Seek health care providers with an understanding of AS, or a willingness to learn about it.

A regular exercise or fitness routine can provide both physical and mental health benefits to adults with AS. There are many adults in the AANE community who practice meditation or yoga, or who walk longer distances and more frequently than the average person.

**Help with sensory challenges** can come from an occupational therapist, from consulting other adults with AS about strategies or materials they find helpful, or from looking at catalogs or web sites that sell sensory aids.

**The AS Adult Community**

Fellow Aspies may be your most important source of support and information through face-to-face contact, support and social groups, through the growing on-line community, or through organized groups in the Autistic Self Advocacy community including ASAN New England (http://asannewengland.blogspot.com) or GRASP New England (www.grasp.org/about.htm). Adults with AS are often best understood by other AS adults. Being connected to others who share similar qualities and difficulties may make you feel less isolated and alone, and more empowered. (Please visit our website for an updated list of on-line communities.)

**Ready, Set, Go!**

Everyone can’t be equally skilled at everything. The things that Aspies excel at are critical to the forward movement of society. If Aspies get the targeted assistance needed in their challenge areas, they can be freed up to work on the more creative areas in which their skills and expertise are sorely needed. You also can’t do everything or afford every possible intervention. Here are some suggestions of first steps:

♦ Identify your current team.
♦ List the team you’d like to have.
♦ Call the AANE Adult Services Team (Jamie Freed, Max Sederer or Debby Geheran). Either by phone or in person, we can help you identify your “brand” of AS, identify and prioritize your specific challenges, and think through who or what can be helpful.
♦ Be creative! Your team may, and in many cases should, include mental health professionals—but in some cases that’s not who is needed. Be open and creative when thinking of ways to address the specific needs that you have. Having a team member to help you figure out how to clean and organize your living space may significantly reduce depression, increase self-esteem, and free up energy for other things.

**For the parents of adults** (or siblings, or other concerned relatives and friends) who continue to play a major role—or many roles—in the life of an adult with AS: that’s okay! Since AS is a developmental delay, it’s not surprising that parents will continue to be more deeply involved in the lives of their adult children with AS than they would expect to be in the life of a neurotypical adult child. However, promote your adult child’s independence by helping him or her recruit a robust, trustworthy team. Then you can slowly step back to a distance that feels right to both parent and adult child.

What if someone is in denial, and does not acknowledge that s/he has AS? It may still be possible to provide assistance. Many individuals object to the label, but recognize their challenges. Don’t be hung up on making someone accept the label, if it’s possible to proceed with helpful interventions anyway. For those who are less aware of their own needs, getting the right interventions can still be very helpful. However, it may take a team member to decide what those interventions might be, and to persuade the adult with AS to participate. You will need to be persistent, creative, and patient, allowing the adult with AS to become familiar with new ideas, new approaches, or novel interventions. Sometimes when an adult with AS says “No,” the person really means, “I need more time to get comfortable with this idea.” Don’t assume it’s a flat out, permanent rejection of your idea—don’t be discouraged.

For the Aspie adult (or family member): Don’t go it alone! Remember that all of us humans rely on teams for support, encouragement, guidance, and assistance in the areas in which we are not skilled. For an Aspie adult, a versatile team skilled in the areas in which you are challenged may allow you to spend your time, energy and mental resources on pursuits which highlight your unique talents and skills.

**For more on adult diagnosis of AS, you can read Jamie’s article “Asperger Syndrome in Adults: Let’s Look Through a Broader Lens” at http://www.aane.org/asperger_resources/articles/adults/aspergers_in_adults.html. To make an appointment for an individual consultation with someone from AANE’s Adult Services Team, contact Max Sederer at (617) 393-3824 x 302, or Max.Sederer@aane.org. To get an application form for the LifeMAP program, contact Nataliya. Poto at (617) 393-3824 x 315 or Nataliya.Poto@aane.org, or see http://www.aane.org/aane_services/services_for_adults.html.
Why go to college? A high school student once told me that the reason he wanted to go to college was “You know, to learn stuff.” Like many students, this young man assumed that attending college is what one does after high school. Then (as the story typically continues), one either goes to medical, law, or business school, or one gets a job that will pay a great deal of money. Such goals are often formed without much self-awareness, and unfortunately tend to block further development of self-awareness while in college. By contrast, students who come to college with a better understanding of why they are there are far more likely to have an enriching experience. This understanding also helps with the transition to meaningful employment after college or to further education that capitalizes on one’s unique set of talents and interests.

This is the first in a series of articles intended to help students have the most meaningful, enriching, empowering college experiences possible. To begin, I will offer my thoughts about some of the main purposes of college. I will then explain why, given these goals, it is worth getting to know a few of your professors. I will conclude with some suggestions about how to initiate rewarding relationships with professors—it’s easier than you may think!

**Why go to college?**

One does not go to college in order to learn a set of facts. As you already know from your own experience with what interests you, motivated people can teach themselves a great deal by reading the relevant books or online sources on their own.

College offers you the opportunity to participate in a learning community. As learners, we strive to master academic material. Mastering academic material goes beyond mere memorization. It involves evaluating the information, making use of the information, and in some cases, contributing new information. Each of us has to be trained how to do these tasks, which is why we call our areas of study “disciplines.” So, what you do in college first and foremost is develop a set of skills which enable you to acquire, interpret, and apply information according to the dictates of the discipline being studied. The methods employed, the material studied, and the purposes of the disciplines vary considerably. Colleges often require you to take courses in a variety of disciplines, so that you can recognize the differences and make an informed choice about which disciplines you will delve into more deeply.

As learners in an academic community, we also strive to develop communication skills. Don’t panic. Remember, we go to college to learn how to communicate more effectively. You aren’t expected to already be an expert at it! Some of the communication skills you will develop include writing lab reports and research papers, making presentations alone or in groups, and taking exams. Most of your grade in a course will be determined by how well you demonstrate your mastery of the material through these modes of communication. Communication skills are also developed in class participation by learning to ask relevant questions at appropriate times, and to provide relevant answers when called upon to do so.

In addition to mastering material and improving communication skills, college offers a wonderful opportunity to develop greater self-awareness. Who are you? What are your interests and talents? What are your goals for the future? The more you know about yourself, the more likely you are to discover in which discipline it is best for you to major. The more you know about yourself, the more effectively and confidently you will communicate your ideas to others. The more you know about yourself, the more likely you are to develop a career path that is meaningful to you. When you think about work, you may tend to focus on a job as a means of earning income that will give you greater independence. However, you are much more likely to be successful in getting hired and staying employed in a field that really suits your talents and values.

At the beginning of this article I suggested that it helps to know who you are before you enter college. The reality is that most of us learn who we are as we encounter the challenges raised by participating in academic disciplines, student organizations, campus events and leisure activities, and by pushing ourselves to communicate our thoughts more effectively in each of these settings. Some of your most rewarding college experiences may occur when you take courses outside of your current areas of interest, join a student organization, or try new ways to have fun and relax.

**Get to know your professors**

Like dating or making friends, getting to know your professors is a numbers game—i.e., an activity that you might have to engage in many times in order to succeed a few times. In a numbers game, even a “failure” can be a success if you learn from the experience and remain open to trying again. Getting to know your professors is a numbers game because you will not like every professor, and not every professor will like you. Some professors may lack the time or ability to participate in a rewarding relationship with you. Still, ultimately, your efforts will be worthwhile if you befriend even one or two professors.

Why? One reason is that your professors are your gateway to their areas of study. They are the ones who have worked their way to the upper echelons of the learning community. They have sifted through great quantities of literature to identify what material is best for you to learn at this early stage of your academic career. You won’t always agree with your professors about what is interesting or important. However, the fact remains that they tend to be better able to recognize what is considered interesting and important in the discipline because of their greater experience. Even if your professors are not always right, you can still benefit greatly from working with them.

As I mentioned before, mastering a discipline is not just about learning facts; it is also about becoming a member of a learning community with shared norms about methods of inquiry and communication. Therefore, you are likely to get more out of your courses if you have gotten to know your professors and have worked with them above and beyond merely attending class and turning in the assignments.

Here is another reason. If you give your professors the chance to get to know you, and if you take the time to get to...
know your professors, you may find that you “click” with some of them. These are the professors who are particularly attuned to what you have to offer as the unique individual that you are. These are the professors who can become your mentors. Mentors let you in behind the scenes of the classroom, and connect with you on a more personal (but still very professional) level. Because they know who you are, and because they care about you and your academic development above and beyond what is owed to all their students, these professors are the ones who can best connect you to opportunities that will enhance your academic experience. For instance, mentors can make you aware of scholarships, conferences, essay competitions, and internships. Sometimes mentors even co-author articles with their students.

Professors who are mentors not only enhance the quality of your time at college; they can provide the kinds of references that you will need after college. Whether you are applying for a job, an graduate program, or a professional school, you will need recommendations from respected authority figures who can vouch for your qualifications. In order to write a letter or to make a phone call on your behalf, the professor has to be able to say something substantive about you, so that you will stand out from the competition. They can do that only if they know you well.

Taking the first steps

Now that you know a few of the reasons why you should get to know some of your professors, how should you to approach your professors? Be brave! Follow the suggestions below, taking small steps over time, and you’ll find that it’s easier than you may think.

Before I begin, however, I should mention the issue of disclosure. Whether and when to disclose to a professor is a complicated issue that cannot be adequately addressed in this article. I recommend consulting Dr. Stephen M. Shore’s book on disclosure, Ask and Tell, as well as the sample disclosure letters available in the AANE adult information packet, to help you decide how you will proceed. In the meantime, the following advice can apply whether or not you disclose.

1. Send an email. Email is a safe starting point because you can plan what to say and send it without having to interact directly with the professor. You might have a clarificatory question about the course syllabus, for example. Most professors are reliable about answering simple, specific questions via email within 48 hours.

2. Visit during the professor’s office hours. Your professors are unlikely to notice or remember you unless you talk to them face-to-face on a regular basis. Therefore, if you want a mentor or decent recommendations as you apply for programs or jobs upon leaving college, you must get out of your room and go visit at least some of your professors. Office hours are the best time to do this because the professor sets this time aside specifically to meet with students. That said, the office hours are meant for all of the students who might want to talk to the professor, so you don’t want to monopolize the office hours. Some good news is that office visits may last only 5 to 10 minutes each as you get to know the professor during the semester. What can you talk about when you come to office hours? I will give you three suggestions:

- Ask a question about the course material. Just about everybody gets nervous when they first approach a professor. It is OK to write your question down in advance. Not only can this make you more comfortable, but it also demonstrates that you care enough about the course to prepare for your visit to office hours. When you can, visit sometime other than the week of an exam or paper that is due in that class. You will be less likely to have to wait in line to talk to the professor and you will not be mistaken for one of the students who flood the office at these times because they care more about their grades than about learning.

- Here is an example of what I mean by asking a question about the material. In literature courses you are often expected to interpret a character’s intentions or feelings. Let’s suppose that you have difficulty recognizing the unstated intentions of others. In this case, office hours would be a good time to ask the professor for advice about how to interpret the reading. In this example, you could ask if there is a key passage that he or she might be willing to review with you, to show you what clues to look for as you read it. The question is about a specific passage, but the purpose of the question is to improve your reading/interpretation skills, not simply to get “the” answer about a specific character from a specific passage in a specific novel.

- Ask your professors about their work. This topic is appropriate if there are not other students waiting for help. When did they realize that this is what they wanted to do? What do they like about it? Many professors enjoy talking about their professional lives and their areas of interest. If you do decide to ask these kinds of questions, do a little research about your professors before you visit them. Many professors provide information about themselves and their work on their web pages, so you would want to look at that first. In the context of conversations like these, mentor relationships can begin to blossom. Another benefit is that what they have to say can help you decide what you want to major in.

3. Ask about your performance in the class. Many students only come to office hours when they want to dispute grades. However, disputing grades almost never succeeds and it typically gives the professor a bad impression of you. If you perform poorly on an assignment, however, it is very important to meet with the professor. Even though it is unpleasant to get a bad grade, you can benefit greatly if you can maintain a positive attitude. Instead of disputing grades that you do not like, a more productive strategy is to ask the professor what you could do to improve your performance in the future. Instead of creating tension between you and your professor, you create a positive relationship based on
acquiring the skills and the means to communicate those skills that you have not yet demonstrated in your graded work.

4. Participate in class. Some courses are lecture-based and the professor is only open to student participation when the professor specifically asks for it. Other professors are more flexible and welcome questions throughout the lecture. Still, other professors prefer a more casual, discussion-based format. Once you determine when it is appropriate according to the kind of class you are in, ask questions when you genuinely don’t know the answer, and believe that it is important. It is also good to ask clarificatory questions if you missed something the professor said. Avoid asking questions as a means to demonstrate what you already know, or simply for the sake of asking a question. It is best to limit yourself to asking only one or two questions per class period.

Sometimes you may think the professor is mistaken and feel the urge to interrupt. Sometimes you will be confident that another student is mistaken and feel the urge to correct him or her. Do your best to avoid interrupting the professor, or correcting another student in a way that may be perceived as condescending. Let the professor correct the student, or wait until the professor asks students for their input.

When you think that the professor is mistaken, instead of interrupting, write it down and ask about it after class or during office hours. Be prepared to be corrected, and be prepared for the fact that sometimes professors do not admit mistakes even when they are wrong. You have to ask yourself if it is important enough to jeopardize everything else that you could benefit from in the course if you alienate the professor. (Sometimes it is, but usually it is not.) This is not only about being right or wrong, but about getting the most out of a course for yourself, and maintaining your position as a member of the learning community who makes constructive and valued contributions.

In conclusion, getting to know some of your professors can greatly improve the quality of your college life. Their unique perspectives and life experiences can add a level of interest and excitement to a discipline. If you ask them questions and let them teach you, you will learn more. You will be less likely to have to cram for exams and papers, because you will have mastered the material along the way. You will also have given your professors the chance to get to know you. This will be a tremendous help when you need letters of recommendation or references for jobs. The professor needs to know who you are, what you have done, and what you are capable of doing if he or she is to stay anything substantial enough to make you stand out from competing applicants. Perhaps most importantly, you will have allowed some of your professors to become mentors, a vital source of the support and encouragement that everyone needs in this exciting and challenging time in life.

Shelby Weitzel is currently a coach in AANE’s LifeMAP program. A resident of Maynard, Massachusetts, Shelby has recently opened a private practice as a college transitions coach serving Worcester and Middlesex counties. You may contact her by email at shelby@collegetransitioncoach.com, or by telephone at (508) 954-3996.

“My daughter just completed her freshman year at Clark University. Disability Services has been great. The way we set it up first semester (because our daughter wanted to “do it herself”) was for her to check in with the Disability Services director (who is great) once a week, and check in with a grad student in the Disability Services office every other week. She also went to the writing center once a week, but we found that wasn’t working so well, probably because it was an hour-long session, which is too long for her at once. Halfway through the first semester, she was behind in her work and got two incompletes at the end of the term (which she has made up). So for second semester, we added a tutor, who we hire privately, but who works with several kids at Clark and understands AS. Our daughter agreed that this was the missing piece from her high school IEP—the daily accountability to someone who is completely aware of what her assignments are, and who can coach her to get them completed. She sees the tutor for two half-hour sessions per week, and more if needed. This has made a huge difference. It goes beyond academic support because the tutor truly cares, and she connects well with my daughter, more like a life coach really. My daughter still had some challenges second term, but all her work is done and she successfully completed freshman year with good grades. She also only took only 3 courses. Every kid is different, but we found that we had to recreate elements of the IEP that had worked for her. She has great support in Disability Services—I don’t think most colleges provide so much support. Our daughter also saw her psychiatrist monthly while she was at school. Part of the reason this all worked so well is that she is near by. If she’d gone to a school far away, I doubt things would have worked well. I think next term she will have a chance to join a student support group led by psychology grad students.”

### Congratulations to the Winners of the 2009 AANE A+ Awards for Excellence in Teaching Students with AS

1. **Ryan Plosker**, New England Academy, MA  
2. **Sue Campbell**, Lexington, MA  
3. **June Ridge**, Marshfield, MA  
4. **Constance Carson**, Kingston, NH  
5. **Marilyn Cunha**, North Easton, MA  
6. **Cheryl Boylan**, Huntington, MA  
7. **Kathy Condon**, Aucocisco School, ME  
8. **Christine Curry**, East Bridgewater, MA  
9. **Betsy Blanchette**, Providence, RI  
10. **Ellen Lavallee**, Somerset, MA

Read about these wonderful educators—and find a nomination form for next year—at www.aane.org.
Supporting students with High Functioning Autism and Asperger’s in Higher Education
The AHEADD Model

By Carolyn Komich Hare, AHEADD Executive Director

AHEADD (Achieving in Higher Education with Autism/Developmental Disabilities) is a private (for profit) community organization that provides support for college students with Asperger Syndrome (AS), High-Functioning Autism (HFA), Non-Verbal Learning Disorder (NVLD), Learning Disabilities, and Attention Deficit Disorder (ADD). Originally developed in cooperation with Equal Opportunity Services of Carnegie Mellon University in 2002, AHEADD is specifically designed to help students develop individualized strategies to manage their college careers with maximum independence. AHEADD’s mission is to establish and maintain best practices of support in a manner that respects students as adults, complements the traditional college accommodations plan, and maximizes use of existing campus resources. AHEADD currently offers services in Pittsburgh, Albany, Dallas, and Washington, DC, and is enrolling students in Miami, Baltimore, Long Island, Bakersfield, CA, and Boston for Fall 2009.

The AHEADD model of support can be applied within any campus environment, and is tailored to meet the unique needs of each student. Students must be willing participants in the program, and able to function with relative independence on a college campus. (Students who have difficulty navigating the physical campus or waking up to attend class, for example, may need more comprehensive support than AHEADD provides.)

The AHEADD model involves four core elements:
1. AHEADD Professional Staff Involvement
2. Development of Campus and Community Support Network
3. Utilization of Campus Resources
4. Peer Mentoring

Professional Staff Involvement

An AHEADD professional staff person meets with a student at the beginning of each semester to set personal and academic goals. Student and staff person then meet twice-weekly for 30-60+ minutes. Meetings may focus on increasing academic accountability, ensuring that the student is content with his/her overall quality of life, and developing individualized strategies for managing various aspects of college life, including:

♦ Self-advocacy.
♦ Faculty and classroom communication.
♦ Time management and organizational skills.
♦ Opportunities for social interaction/social skills.
♦ Utilization of campus and community resources.

Each meeting begins with discussion of upcoming academic obligations, entering those obligations into the student’s list of weekly responsibilities, and problem-solving for incomplete work or unmet obligations. AHEADD staff also assist students in drafting important communications with faculty, peers, and peer mentors, and in helping students identify and connect with appropriate campus resources. After the academic component of the meeting is completed, the student and his/her AHEADD staff member focus on broader quality of life issues: campus involvement, roommate relations, hygiene, diet, getting a job, etc. As the student and AHEADD staff member develop rapport, this aspect of each meeting becomes increasingly meaningful and productive.

Development of a Campus/Community Support Network

Outside of the twice-weekly meetings, AHEADD staff regularly liaise with the college’s Disability Services, faculty and related professionals, regarding accommodations, to:

♦ Raise awareness of the student’s strengths and needs.
♦ Ensuring that all team members are aligned in their perception of the student’s needs and performance
♦ Problem-solve, when there is a disconnect between student and professor’s perceptions of performance.
♦ Provide a consistent message from all team members to the student.

Utilization of Campus Resources

While AHEADD’s professional staff provide particular expertise in supporting students with, it is also important to engage natural supports through existing campus resources, including: Disability Resources; Student Health and local medical professionals; Counseling and Psychological Services; Academic Development/Learning Center (content tutoring, writing assistance); Academic Advisors/Faculty Mentors; Extra-curricular activities/Clubs; Career Counseling; Work/Study programs.

Peer Mentoring Program

Peer mentors are neurotypical students who volunteer their time to provide support and social opportunities/outlets for students enrolled in AHEADD. Peer mentors also provide us with valuable insight into challenges that our students may be facing during social situations; AHEADD staff can then incorporate these issues into discussions during the twice-weekly meetings with students.

Our peer mentors enter into the program though a comprehensive orientation program, and are then paired with an AHEADD student. The peer mentors and the AHEADD students make arrangements to socialize at least once every week or two, independent of AHEADD staff involvement. AHEADD also hosts a monthly “large group” mentoring activity during which all of the mentors, AHEADD students, and AHEADD staff members are invited to join in various events around town, including dinners, bowling, pot luck and board game parties, as well as picnics and athletic games.

Peer mentors are also asked to participate in two “decompression” meetings over the course of each semester, during which AHEADD staff provide professional guidance in response to any challenges the mentors are experiencing.

Response to AHEADD has been very positive. One college educator, Monica Andrews, Ed.D. said:

“I have known of initiatives from within the college/university, but to have a model that you can take anywhere is revolutionary—or maybe it’s “evolutionary.”
Adolescents and adults with Asperger Syndrome (AS) have arrived. Throughout the past two decades, the increase in diagnosing AS has led to much work in educational intervention, social skills support, research, and more. Initially, however, adult issues were not at the forefront of public attention. After all, many of those diagnosed were children, while many other people had already struggled and succeeded with their particular sets of strengths and challenges well into adulthood. Now however, without a doubt, the picture has changed: the adolescents and adults have arrived and are in great need of supports in order to access their career, educational, social, and recreational futures.

The Evolution

Over the last five years, after many years of running summer camps and other programs for children with AS, YouthCare (a Massachusetts General Hospital Program) has developed some special programs for teens. In 2008 we piloted our Transitions: Career Skill Development summer program and expanded it in 2009. The genesis of the program was unremarkable. YouthCare recognized that its campers were getting older and becoming less challenged by our social skills programming. So in the summer of 2005, YouthCare offered a modified schedule to its teen summer campers, in which campers aged 14-16 engaged in weekly off-site volunteer opportunities (mostly trail work and guiding), weekly age-appropriate trips into the community (e.g., movies, amusement parks), and weekly inclusion activities with teens from another day camp, all with the support of our therapeutic camp and experienced staff. We discovered that our teens and their families indeed needed and wanted specialized programming; moreover, we realized we should be doing much more to explicitly support their needs if we were truly to provide continuity of care as they got older.

Brainstorming with parents of teens with AS and related challenges helped us develop a truly overwhelming set of priorities for our work with teens, and during the summers of 2006-2007 the Summer Teen Program sought to address each of these priorities. The seven week program started each day in an office setting, and offered typical camp activities (swimming, ropes course, drama, field games), as well as volunteer opportunities, job site visits, age-appropriate community trips, experiences with public transportation, social skills training, life skills training, and fun for teens. If it sounds busy and complicated, that’s because it was! Teens and their families enjoyed the program and made gains. Despite these successes, however, we were concerned we’d never quite achieve the goals of teaching teens skills for the adult world if the program was perceived as a “camp.” So in the summer of 2008, we piloted a re-incarnated and re-focused program, Transitions: Career Skill Development. By virtue of its name, application process, program activities, and staffing, the explicit focus on career skills was evident.

The Program

In its first summer, Transitions: Career Skill Development served 11 teens (eight boys, three girls) with AS, Nonverbal Learning Disorder, and High Functioning Autism. In its second summer, the program served 15 teens (13 boys, two girls) with similar profiles. Teens were actively involved in the selection process for the program. They were asked to complete a questionnaire about their perceptions of their own strengths, weaknesses, career goals, and ability to utilize supports provided, as well as to interview in a group format, in which direct questioning and teamwork activities were designed to assess their fit, their social skills, their readiness for work training, and their openness to giving and receiving feedback. Teens involved in the program were motivated to engage in unpaid internships, receive significant feedback, and be part of open discussions addressing their challenges as well as their strengths. In both 2008 and 2009, the lengthy application process resulted in a group of enrolled teens with complementary profiles and compatible goals.

Teens were expected to attend every day of the seven week program, and were instructed to call in themselves if they would be absent or late (rather than having a parent call in for them). These and other expectations were made clear in the first few days of programming through discussion and the provision of a written contract to be signed by teens, their parents, and their Job Coaches (YouthCare program staff).

Throughout the seven week program, teens spent three days per week at internship sites, which were carefully selected based on site accessibility (social, structural, geographic), supervisor alignment with the program’s goals, and teen-internship match. At the internship site, one Job Coach supported two to three teens throughout their six hour workdays. Teens completed work largely independently, while Job Coaches spread their support across assigned teens. To date, internship work has included exhibit presentations and research at a medium-sized museum; photography, data entry, and program assisting at a camp; cleaning and receiving/delivery at a hospital; and software and hardware maintenance and repair at a college, a few public high schools, and a technology company. It was important to teens that projects and tasks at their internships were skill-oriented, linked to their career goals, and were absolutely not menial in any way.
On the two days per week when teens were not at their internships, the program participants came together for other activities. Career skill instruction topics included resume writing, interview skills, conversation skills, hygiene and personal presentation, reference seeking, job search techniques, conflict resolution, self-advocacy and disclosure on the job, the need for leisure interests to compliment work, and more. These topics were presented through games, discussion, role-play, video, and interactive lectures. Presenters included program staff, external expert speakers, and adolescents and adults with AS.

One morning each week, the program traveled to a local college for a tour. Colleges included two- and four-year programs, public and private programs, large and small campuses, technical and academic programs, and campuses with and without specific programs for students with learning and/or social disabilities. The intent of the college visits included developing teens’ awareness of college options and the application process, general community skills, and heightening their focus on future planning.

Explicit group development opportunities proved to be very important in forming long-lasting connections among the teens involved, and in facilitating social skills. These opportunities included weekly participation in team-building and group processing activities designed to connect teens’ internship experiences to their feelings, goals, social experiences, and self-awareness.

The final piece of the program proved to be one of the most important, and included various social activities, such as going out to lunch each week at a restaurant chosen by one or more teens. Structured and unstructured social activities throughout the program included games (recreational and career skill related) and time designed for teens to just hang out. One strong outcome of the program has been that many teens formed connections based on like interests and like career goals.

The Take-Aways

Transitions: Career Skill Development is an ongoing and growing program of YouthCare MGH. Teen, family, and staff feedback leads to fine-tuning of the program over time. Nevertheless, a few basic take-away points were clear after two summers:

1. Teens with Asperger Syndrome have Asperger Syndrome. Effective supports at internships and in the community were extended versions of effective supports provided at schools for students of all ages with AS. At internship placements, Job Coaches provided clear expectations, individualized schedules, appropriate breaks, visual supports (written directions, timers, etc.), and task analyses with fading levels of support as the summer went on. Site-based supervisors were coached to provide clear directions and clear feedback as often as appropriate in the work setting. Teens responded to their daily evaluations of their own performance and the written feedback from their Job Coaches. In the community and at program-wide activities, teens succeeded best when they were specifically rewarded for social/behavioral success, were provided ‘hidden curriculum’ information and sensory tools before engaging in community events, and when they received age-appropriate social coaching. And of course, social and career skill information was best delivered explicitly.

2. Teens with Asperger Syndrome are teens. For all the specific patterns of strengths and weaknesses teens with AS carry, and the very carefully crafted supports they benefit from, we recognized that these teens, like others, value social experiences, need to fit in, and must feel listened to and respected. A poignant moment in the pilot summer was after a college visit gone wrong, in which the teens were acting in ways far beyond quirky or informed by social misunderstanding; instead the teens were simply being rude. The teens, as a group, owned up to their behavior after the tour, and when asked what the problem was, they were quite clear. The college visit was on a Tuesday morning, and the teens hadn’t been together as a large group since the previous Friday afternoon. They said they had wanted to hang out with their friends, but had been asked to rush into a college visit, so they ended up goofing off during the visit. As a group, they determined that the solution was time to hang out after being away from the group experience for a couple of days. Indeed, they designed a wonderful intervention for themselves—adding some unstructured hang out time before community experiences allowed them to be teens and goof off as a group before being asked to use their appropriate social/behavioral skills in a public setting. Like other teens, our teens with AS wanted social feedback provided in non-public settings, and were thoroughly embarrassed by behavior they experienced as out of their control. Helping teens maintain privacy became an important issue. Allowing teens bragging rights for significant successes added to their pride and their connections to one another, just as most teens appreciate feeling noticed and important. Finally, our teens taught us that the best thing we can do is to listen to them, just as all teens want that their opinions to be valued. When we asked for teens’ feedback about their own behavior and goal attainment, the staff, and the program generally, they provided ideas that they and we learned from. When we asked where they wanted to be in ten years, how they wanted to receive feedback, and what they found motivating, they were invested in responding to us when we connected our work with their ideas and requests.

To find out more about the Transitions: Career Skill Development program and other teen Transitions Programs at YouthCare please visit www.mghyouthcare.org. You can reach Kelley Challen-Wittmer at kchallen@partners.org. Jenn Harber’s previous position was Program Director at YouthCare. You can reach her at jharber@thebridgectr.org (www.thebridgectr.org, formerly Handi-Kids).

We invite families of teens living in or near Plymouth county to look at the many special AANE events funded by the Edwin Phillips Foundation:
www.aane.org/upcoming_events/events_plymouth_county.html
Furries

You may or may not (probably not!) be familiar with “furries” on the internet, a community of around 50,000 artists, a surprising number of whom are on the Autism Spectrum, who draw animal-like characters. Most of the communities are focused around art, of which Artsots.com is a good example. There are also a surprising number of conventions around North America, the UK, and Japan. The largest of these is Anthrocon, which regularly has more than 3000 attendees from around the world.

Most furry fans have personal characters, known as fursonas, who represent themselves. In the drawing below are the two characters which represent ourselves. Some people feel a deep personal connection to them, but these two characters are simply avatars through which we represent ourselves in this world. My boyfriend is the actual artist, but we work closely together in creating each image; essentially he is the artist and I am a coach and director. He can create things without being able to articulate them, while I can articulate things I have no hope of producing personally.

The motivations behind the connection furries have with animals are difficult to pin down. Some people are more attracted to the idea of the simple interactions they have with each other, while others find they would like to have an actual animal form. A common theme for a lot of people is the idea that animals are highly accepting of their own kind. They enjoy insular activities that signify a very close community, such as making up their own words to use specifically within the community. If you have had the chance to read John Robison’s book, Look Me In the Eye, he describes people and things frequently in animal terms. People have “paws” rather than hands, and he gives people names such as “Rodent” and “Little Bear.” It is something I’d be curious to ask him about.

Anonymous

And actually, yes, I do attend AANE group meetings with Trish Huff. It’s been a pleasure to get to know and work with her over the past year. She does an awful lot for all of us here and we all appreciate her immensely!

Standing in the Yard at Night

Three fingers
Three stars
The scientists are wrong
Close, I see them
Close, I touch them,
Close, heart beats
Flicker in time
With their shimmer
Three stars
Touched
Home

There was still snow in the yard, the berm cast up from the snow plow still two feet high and dirty. The sky was indigo-black-raven, but it was not dark out. The moon was shiny and the stars in the clarity of cloudlessness danced in space, beckoning me to dance with them and to sing. So in my pajamas at 3 AM in the snowy yard I sang a no-word song and reached out my arm, extended my fingers, and touched the stars of Orion’s belt. Home.

CarolAnn Edscomb, April 21, 2009, Jaffrey, NH
Published online by GLIMPSE icdl.com.
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Greetings!

On a broiling-hot Saturday, July 18th, adults with Asperger Syndrome and related diagnoses gathered at Northeastern University’s Curry Student Center for a day-long conference entitled Know Yourself: The Key to a Better Life. In the morning, a powerful keynote lecture on self advocacy was delivered by Ari Ne’eman, Founding President of the Autistic Self Advocacy Network (ASAN). In the afternoon, adults attended workshops on topics varying from employment to meditation to understanding a neurotypical partner. Restaurant outings during the lunch hour, and a lively Ice Cream Social at the end of the day, gave adults the opportunity to socialize with one another and with the presenters and AANE staff—the only neurotypicals permitted to attend this uniquely validating event. Look for our next adult conference coming up next summer, 2010!

As Fall 2009 begins, AANE’s Adult Services continues to offer numerous Support Groups, ongoing Book, Art and Anime Clubs, a return of the Film Series as well as a variety of Pizza and Game Nights and weekly strolls. Additionally, we will try to offer events and activities that appeal to all of you in our community. Keep an eye out for upcoming trips to the Harvard Art Museum and the Museum of Science. On December 22nd join us for our Holiday Party and Yankee Swap!

AANE is always looking to expand the opportunities available to our membership. If you have ideas for new programs or opportunities, please do not hesitate to contact us with your suggestions. We look forward to seeing you all at upcoming events!

The AANE Adult Services Team

Above, left to right:
Jamie Freed, MSW, Director of Adult Services
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Max Sederer, MAT, Program Manager, Adult Services
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Yolanda Kolinski
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Queremos agradecer a los miembros del Comité de Asesores Latino (Latino Advisory Board) por su tiempo y dedicación.

Sara Diaz, Spanish Training & Outreach Support, FCSN
Richard Villavicencio, Intake Paralegal, DLC
Betzaida Fuentes, Supervisor, Family Services of Greater Boston
Charlie Remy, M.S.L.I.S. Candidate, Simmons College
Vivian Rodriguez, Special Education Teacher
Carolyn Meadows Marquez, Community Outreach Coordinator, BPS
Maria Gomez, Parent and Community Activist
Miriam Biurci Scrivener, Southeast Regional Coordinator, Family TIES
Diego Mansilla, Spanish Teacher
Maria Carrasco, School Committee, Lynn
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Marcelo en el Mundo Verdadero

Marcelo Sandoval (17 años) tiene el síndrome de Asperger. Vive en las afueras de Boston, duerme en una cabaña en lo alto del árbol en su patio trasero y siempre ha asistido una escuela privada. Un verano su padre insiste en que trabaje en la sala de correos de su firma de abogados. Siga el viaje de Marcelo cuando conoce a nuevos amigos y aprende de la envidia, la competencia, el amor, y la vida en el “mundo verdadero.”
Erika Drezner, MSW  
Coordinator of Teen Services  
(617) 393-3824 x 314  
Erika.Drezner@aane.org

Like so many of you, I discovered AANE as a parent who was looking for support and information. I have two school-age children with Autism spectrum diagnoses. I was a member of the AANE Program committee and I joined the staff this past July.

I am a social worker and have worked with children, teens and adults in a variety of settings. I have taught middle and high school and worked in a college admissions office. For the last five years I have been home full-time with my kids. I’ll admit that I probably learned more parenting my own children than I did in graduate school! Additionally, I have spent a lot of my time volunteering at my children’s schools and in other community organizations.

Since joining the staff, I have worked with Stephanie to bring Teen programming such as:

- Tuesday topic nights for parents of teens. The next topic night will take place December 1st. The topic is “Relationships with the Extended Family: Surviving the Holidays and All Year Round.”
- In lieu of a topic night in November, AANE’s own Jean Stern will offer her fabulous workshop “Advocating for Your Teen with AS in Public School” on Tuesday, November 3rd.
- Lynne Mitchell will be running her workshop “Welcome to the Teen Years: Making Life Work for Your Teen with AS” on November 10th.
- Monthly social events for high schoolers with concurrent workshops for parents of teens. These monthly events provide an opportunity for parents to learn about relevant topics while their teens socialize with others in a safe and comfortable setting. Our October, Lori Hodgins Brazell and Cari Feingold spoke on social skills for teens. In November, Bonnie Glickman will present on study skills and time management. In December, we will celebrate the season.

While I have worked with teens professionally, I have not parented any myself. So in addition to reviewing my own professional and personal experiences as well as my human development course work, I feel that I have enrolled in Adolescent Boot Camp. In a very short time I have been introduced to and become immersed in the concerns of so many parents of teens with ASD. It seems that the difficulties of these years can come on suddenly. Parents wonder what happened to their sweet little boy or girl. A child who was moderately social can become completely isolative. In the face of these behavioral changes, parents wonder “Is it AS or is it adolescence?” Many parents also find that the strategies that worked with their younger children no longer work with their teens. Parents are unsure of how to communicate effectively with their teens.

All of our services will address those issues in one way or another. I hope that you will sign up for workshops, come to Topic Nights, join the Google Group and/or contact Stephanie and me.
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Staff: Pathways Academy employs highly trained and specialized academic and clinical staff, supervised by a Pediatric Neuropsychologist with specialization in Autism Spectrum Disorders, Sensory Processing Disorder, and social pragmatics. Each classroom is lead by Master’s level Special Educator assisted by a School Counselor. The staff also includes Clinicians, Case Managers, Speech/Language Pathologists, and Occupational Therapists. Graduate psychology interns and fellows provide additional services such as pair (dyad) therapy and individual pragmatic training services.

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Education Bi-Monthly Hints
by Jean Stern, M.Ed.,

When your child gets special education services in elementary school, there are so many details to remember that it can be overwhelming. You wonder: What should I do—and what will people at school do? Where do I start? There is no list of hints that fits everyone, but here are a few ideas to think about each school month.

September/October is start-up time, so all hints are around getting off on the right foot.

♦ Take your child to visit before school opens, to meet and chat with any teachers who are around. Introduce your child and help the child to get to know the building: cafeteria, bathrooms, etc. (It is ideal to arrange this at the previous spring’s team meeting, so that the aide, guidance counselor, or other key team member meets you and your child by appointment during the week before school starts.)

♦ Make sure to get a map or other written materials such as class rules or a school schedule that will help you prepare your child at home for a school event.

♦ Give teachers a short paragraph or bulleted list of the most helpful hints for a good start, perhaps the “Top 10 Strategies for a Great Start” with your child. Involve your child in deciding what to include, and in speaking with the teachers if your child can.

♦ On the way home buy a good-sized monthly wall calendar for working on breaking down long-term assignments, time management, and life scheduling to prevent becoming overwhelmed. This will be in addition to the nightly assignment sheet or book that all students will be using.

♦ Two good reference books that will assist you with understanding sensory integration and self-regulation (both needed for start-up) are: Asperger Syndrome and Sensory Issues by Brenda Smith Myles and The Out-of-Sync Child by Carol Kranowitz.

♦ Help your child learn and practice self-advocacy statements.

○ Does your child know what bothers him/her a lot (loud sounds, pencil sharpeners, being overheated after gym, touching my book-bag, etc.)?

○ Does your child know what usually calms him/her and can provide a relaxing break (reading, computer time, head phones and music, looking at a phone book, drawing, etc.)? Help a child learn from your observations which events or activities are uncomfortable and which are desired.

○ The next step is for your child to learn statements to politely ask for what s/he needs (self-advocacy and independence).

○ A good book to use to help your child get “user friendly” with his/her body is Asperger Syndrome: An Owner’s Manual by Ellen Korin. As an adult guides the child through this workbook, the child learns his or her strengths and weaknesses, and establishes plans such as “My Personal Melt-down Prevention Plan.” Self-knowledge is the best foundation for success.

♦ Be sure your child has a good homework area set up for the year. Often this is a clear, uncluttered space used only for homework, quietly separated from everyone else for focus. However, some children want to be close to a parent, and may choose to work at the kitchen table. The child should have all necessary information about assignments, books and other materials at hand, and good lighting (natural and electric).

♦ Next discuss with your child the best time to do homework. If the child’s suggested time won’t work well for the family, or the child might be too tired, talk about it and explain why another time might be better. These conversations help the child learn time management and problem solving. Try to find a time without sibs around. Another approach is for everyone in the family do their homework together at the same time with quiet rules and a parent to facilitate. Remember that there is no one way. Customize your homework place to the needs and preferences of your child.

♦ Establish a home-school communication system. If the school does not provide this for you right away, take the lead and offer ways to start this vital two-way communication ASAP. Find out whether educators prefer written, phone or email communication. You might even offer to make up a simple example of a grid that can save the school a lot of writing time. Here is one example but customize your own:

| Child’s name ___________________ Date __________________|
| Staff recorder today __________________________ |
| Homework (A block for each class) |
| Please provide all visual supports such as creative writing charts. |
| Long term assignments: specific sub-tasks and due dates, required source materials, format, etc. |
| Current direct instruction skills being worked on for carry over at home (social, organizational, pragmatics, self advocacy, etc) |
| Upcoming change or event to prep for at home |
| Home questions or news school needs to know |
| School news or questions: upcoming meeting, notes from teachers, etc. |

♦ Decide how often you will communicate back and forth and then use your system consistently. Learn who you need to contact if information is not coming home or if the communication plan needs to change. Communication systems almost always need revision over time. A monthly face-to-face team meeting (parents plus key educators) opens channels of communication and builds positive relationships.

November/December: Continue to hone all the systems you started

Article continues on the next page.
in September. With October’s increase in academic focus and establishment of each teacher’s own system, you will need to be sure these new details are included in your communication and self-advocacy support at home. With the fall fully under way, there is increased academic and social pressure, so be sure your child has a Calm Down Plan in place at school, if needed, which describes where the student can take a break, how to notify the teacher that s/he is overwhelmed, and what activities s/he is permitted to do there (with no negative repercussions).

Good books that help children learn self-regulation are: The Incredible 5 Point Scale by Kari Dunn Buron, and Replays by Karen Levine and Naomi Chedd.

Your child should also be equipped with a plan for what to do if anyone teases or bullies her/him. Many neurologically different children are bullied. They can also misunderstand peer interactions and perceive that they are being bullied. They will need help in understanding these situations, and knowing what to do. All plans need to be worked out with the school, and all adults need to support their use. If the school hasn’t included some “acceptance of differences” program, encourage them to set aside a time for classmates to discuss “Children Who Think Differently” and how they can be good friends to them. A good video to help the class and the facilitator is Intricate Minds by Dan Coulter. (This video is available on the AANE website Parent Tool Box under Staff Shopping Picks.)

Be sure that by November you have been given the basics of the writing program that your school uses, so you can help your child get his or her thoughts down on paper using the plan and the expectations that your child’s teacher has set.

As the holiday season begins, be sure that you know about any special events and changes in the regular schedule that are coming up. Holiday concerts, special plays and all the rehearsals can raise your child’s anxiety. You can help your child with changes in the routine if you can preview them at night. Post any of these changes on the large monthly calendar you use for time management and assignment break down. Remind your child that if changes in school raise his/her anxiety, s/he can use the calm down plan. Around Thanksgiving, please remember to thank the staff for all their extra efforts.

January/February: Check the communication system and tweak if necessary. Is everybody using it? Is there any teacher you need to contact? Is there a new area that needs to be included now? If monthly face to face check-in meetings have not been written into your IEP, try to schedule at least one by mid-year. Discuss with your liaison or team facilitator who should attend. These meetings are great for you to learn what the school is working on, find out the best ways to carry over new skills into the home, and share your concerns.

How are social connections and friendships coming along? The winter months have many events and opportunities for a friend to come along to something your child will attend. Is there someone with a similar interest in your child's class? Is there an activity they both might enjoy together? Setting up structured play dates is an important part of practicing the social skills your child is learning in school. Remember that generalization of social skills is all about having opportunities to apply the skills that the child is being taught in his/her social skills group as many times in the community as you can. See “Nobody likes me:” Helping Your Child Make Friends by Elaine McEwan.

Now is the time to choose and apply for summer programs. Good programs fill up fast. Start to think about what your child’s summer options may be. Does your child usually get offered a summer program from your town? You may want to speak to the educational team about eligibility for year-round programming to ensure that there is effective progress toward social goals in particular. Are there other weeks you would like to fill? Does your child need time off from the structure? Do you want to focus on remediating lagging skills or giving him/her a great experience in the area they are most interested in (such as computer camp, theater camp, etc.)? Working parents want, if possible, to cover all the weeks of the summer (outside of family vacation weeks) and it usually requires a few options to cover the 10 weeks of summer. (However, this may be too much for some children.) If you would like AANE’s camp list, please just contact Children’s Services and we’ll be glad to email it to you.

March/April is time to get ready for IEP time. Soon the educational team—parents plus educators—will review your child’s progress and make plans for both the summer and the next academic year. Hopefully the home/school communication system has kept you informed about your child’s progress toward his/her goals.

With this information in hand, think about next year. Has your child made successful gains with his/her current services and program, or is something more needed? Will your child be staying in the same building, with the same support staff, or is it a year for a transition to a new building? Is it time for a complete re-evaluation (e.g. neuropsychological evaluation, generally every 3 years; possibly also academic achievement or other assessments, such as Assistive Technology, OT, Speech/Language)? Asking these questions will help you decide how much preparation will be needed for your IEP meeting. If your child is doing well, communication between home and school has been good, and there will be no major program or building changes, your preparation will be less for the upcoming meeting. Most transitions within a building are small, and it’s easier to assure that they go well. Transitioning from one building to another requires good preparation and communication to the receiving staff as they plan for your child within their setting. (See Dot Lucci’s excellent article, “Familiarity = Safety” on the AANE website.)

If your child is having significant difficulties with the present placement, the program is not going well, or any other option for placement is being looked at, a re-evaluation should be thought of. A change in placement will require it. If it is unclear to the school staff why the child isn’t doing well, think of asking for a Functional Behavioral Analysis to investigate the situation, or ask the team to call in an AS expert to help figure out what needs to be done. For AS experts, use the neuropsychologist who did the evaluation, an AS-savvy Educational Consultant (call AANE Children’s Services for referrals) or other professionals you know, who have demonstrated their AS expertise and experience. If you would like support in this process, call us for suggestions for Educational Advocates or special education lawyers who will guide you.

May/June is time to finalize the plans for the summer and the next school year, at the end-of-year IEP meeting. To maximize chances of collaboration and a smoother meeting:

♦ Read all reports ahead of time if you can. Prioritize, so that
Every skill needs both check whether the IEP.

♦ Check whether the IEP for the new year, and bring it to the meeting. Make sure the statement focuses on the areas of greatest concern for your child, e.g.: ability to demonstrate age-appropriate social skills, ability to maintain calm and focus so that s/he is ready and able to learn.

♦ Mention all points of agreement first to get them off the day's agenda quickly, and to start the meeting on a positive note. This leaves time for discussion and resolution of disagreements.

♦ Try to bring someone with you to every IEP meeting. Another set of eyes and ears is always helpful. Have your companion keep the notes while you focus on the conversation.

After the meeting, when you get the IEP, consider:

♦ Check whether the IEP has measurable goals, defined as: “What behavior do you want, under what conditions, and to what criteria.” All methods of evaluation in an IEP need to be easy for you to understand and observable. E.g.: “Having been given direct instruction in using a greeting before starting a conversation, Daniel will say the greeting first, in 4 out of 5 observed beginning conversations.”

♦ Every skill needs both direct instruction and a plan to generalize the skill out into the community. Children with AS don’t learn social skills simply by being with their classmates—they need direct instruction in specific social skills, perhaps in a small group setting with a Speech Language Pathologist or other professional trained in social pragmatics. However, it’s not enough for a student to be able to demonstrate a social skill in the speech therapy room—s/he needs support and coaching to generalize that skill: to apply it in the classroom, cafeteria, afterschool club, or summer camp. Generalization is defined in a 2007 Massachusetts Department of Education Advisory as “repeated instruction and practice in multiple environments with a variety of materials and people, in order to master a single skill.” Be sure the home/school communication system for next year is set up so that all skills taught next year will be sent home, so you the parent can reinforce their practice and generalization.

Advocating for your child is an ongoing process. Take it one step at a time. AANE is offering ten parent workshops this year—including “Advocating for Your Child with AS in Public School”—and eight topic nights. Feel free to call me or Brenda Dater for referrals or advice. We are only a phone call away. Have a great year!

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

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

you can ensure that the most critical topics get covered in this time-limited meeting.

“Plugged In is based in Needham, Massachusetts. Its dual focus is to give young people a venue through which they can channel their creativity, learn to work in a group, and improve their music skills while learning about the value and importance of social activism.” In spring of 2009, Hunter Fellman-Greene persuaded his Plugged In band to dedicate their end of term fundraiser to AANE, and invited Dania, AANE’s Executive Director, to speak to the band and attend the event. Below is the speech he gave at the event. (See www.pluggedinband.org.)

“I’m Hunter Fellman-Greene and I’m glad to support the Asperger’s Association of New England (AANE) for the Plugged In concert tonight. AANE specializes in programs for kids and adults with Asperger Syndrome and helping their families. Asperger Syndrome cannot be cured, but those of us who have it can work with it. Many kids with Asperger Syndrome have trouble in school, and their parents need to find the right place for them, or get a classroom aide until they become more independent. Here is my story:

I was born on May 21, 1990 – a cute baby. I smiled, cried, and made fussy noises. I said my first bad word at age two. My parents laughed so hard. A couple years later I wasn’t functioning as a normal kid. I hated loud noises—but look at me now—I love rock and roll! I was diagnosed with autism at age four. My parents were startled, scared and they didn’t know what to do. They found a school called the May Center in Arlington, Massachusetts that specialized in helping kids with Asperger Syndrome.

In 1996, I went back to the Medfield Public Schools and had a classroom aide, but I wasn’t really doing that well. I needed a school that specializes in teaching kids that have learning disabilities like me. So, in 2003 I started at the Learning Prep School where I went to classes without an aide and made friends. I went to social programs at AANE and met others who also have Asperger Syndrome.

I have been at Learning Prep School for six years, and now, I am only one week away from graduating from that school. It was great to be there. This spring four Plugged In students came and we all played at a school dance. Schools like Learning Prep and programs run by AANE help people with Asperger’s to live happily in the typical world. So tonight is the night for the Plugged In benefit concert for AANE. Thank you all for coming. Your support of AANE and Plugged In is very much appreciated!”
An Evening with Tim Page  
by Debra Cash

In fifth grade Tim Page fulfilled a class assignment requiring him to write about “something we had at home.” His essay listed every band on a series of old opera records, including the RCA label number and the cast and date of each recording. At around the same age, he repulsed an 8 mm print of the 1903 “The Great Train Robbery” to match a description of the director’s original conception. He even began directing his own oeuvre, in the process becoming the subject of an award-winning short that Esquire Magazine described as profiling “an 11-year old who used a camera to become the Fellini of his suburban neighborhood.”

Brilliant, quirky, and sometimes self-hating, Tim Page was a boy whom AANE members would now quickly recognize as a child with Asperger Syndrome (AS). Yet, like many adults, Page waited a long time for that diagnosis. In the summer of 2000 he was relieved to discover there was an explanation for many of the struggles he had faced in his life. He was 45 years old. Three years earlier he had won the Pulitzer Prize for the music criticism he had written in the Washington Post.

Tim Page came to Boston for a special AANE benefit at Regis College on September 15, 2009. The writer is now a professor of journalism and music at the University of Southern California, and divides his time between Los Angeles and Baltimore. “An Evening with Tim Page” launched the book tour for Parallel Play, the autobiography that grew out of his stunning 2007 article for the New Yorker. That essay generated a remarkable outpouring: thousands of letters and emails responding to his vivid, funny and heartbreaking description of growing up with undiagnosed Asperger’s.

Former Boston Globe classical music critic Richard Dyer introduced his colleague, Tim Page, as a man who shares his own interest in “writing about things that cannot be put into words.” The two men met in the 1980s when Page was hosting a much talked-about classical music radio show in New York. Dyer picked him up hitch-hiking on the hill leading up to a much talked-about classical music radio show in New York. Dyer even began directing his own oeuvre, in the process becoming the subject of an award-winning short that Esquire Magazine described as profiling “an 11-year old who used a camera to become the Fellini of his suburban neighborhood.”

Tim Page’s musical interests range from grand opera to “claustrophobic rock and roll.” For him, music incorporates an innate synaesthesia, its pitches and rhythms suggesting words and thoughts that can be enriched by his formal analytical musical training. As he writes in Parallel Play, “It has been my extraordinary good fortune to find work that makes use of my strengths and doesn’t test my weaknesses.” He notes wryly, “It would be easier for me to improvise an epic poem before a sellout crowd at Madison Square Garden than to approach an attractive stranger across the room and strike up a conversation.”

Clear that he’s no medical expert—“I’m not a psychologist, I don’t know that much about Asperger Syndrome except that I have it,” he explained—Tim Page nonetheless says that for him, Asperger’s has been a genuine gift. It has granted him with remarkable powers of concentration and “a sensory melding of words and music…that continues to provide me with a privileged and other-worldly ecstasy into my sixth decade.”

Tim Page’s appearance at Regis was a gift to AANE as well. The evening raised over $6,000 for AANE’s Life Management Assistance Program (LifeMAP).

Debra Cash who, like Richard Dyer, is a former arts writer for the Boston Globe, now presents preconcert talks at dance events throughout New England. You may purchase Tim Page’s book through AANE’s online bookstore, and read his New Yorker article at www.newyorker.com/reporting/2007/08/20/070820fa_fact_page.

AANE PROGRAM UPDATE: LIFE MAP

Nataliya Poto, M.A.  
LifeMAP Program Manager  
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Nataliya.Poto@aane.org

Hi, some of you may already know me from my days as an AANE intern last year. Originally from the Ukraine, I lived in the Czech Republic and moved to the U.S. in 2002. I speak four languages fluently. I love traveling, skiing, skating, hiking, gardening, and reading.

I am a graduate student at UMass/Lowell. In December ’09 I will receive my second Master’s degree, in Community Social Psychology. My background is in linguistics, but after my son was diagnosed with PDD-NOS, I returned to school, hoping to understand him better. While trying to understand and help our son, my husband and I have met a lot of incredible people, including members of the AANE community. Because services for young children with ASDs are rapidly improving, I decided early on to focus on learning about and working with teens and adults on the autism spectrum. I’ve been working as Dr. Ashleigh Hillier’s Research Assistant at UMass/Lowell, helping with interventions for adolescents and adults with AS. I’ve also been working as a Research Assistant for the Graduate Certificate Program in Behavioral Intervention in Autism at UMass/Lowell, and will earn my certificate in May 2010.

Now I am very excited to start my new part-time position at AANE as the Life Management Assistance Program Manager. I am joined by UMass graduate student Nisha Narvekar, who will assist in LifeMAP.

As you may already know, LifeMAP provides one-on-one coaching for adults with AS, to address practical issues in a person’s life. For links to the LifeMAP brochure and application form, go to:

http://www.aane.org/aane_services/services_for_adults.html

—or just contact me directly. I will be happy to speak with you and answer your questions!

Photo right: Nisha Narvekar, LifeMAP Assistant
Meryl Kahn, age 25, just completed her sixth year at the College Internship Program (CIP) at the Berkshire Center in Massachusetts. Meryl came to CIP as a way to continue her post-secondary education while developing career, social and life skills, areas often overlooked for students with learning disabilities. During her years at CIP, Meryl faced and overcame a myriad of obstacles. Meryl’s lifelong dream was to work with young children as a teacher’s aide, but that dream required credentials that Meryl did not yet possess. Meryl is diagnosed with PDD-NOS, ADD, and motor skills deficits. Her college learning skills assessment placed her in remedial reading, writing, and math. In her first year at CIP Berkshire Center, Meryl attended an enrichment program at a local business school, where she demonstrated such determination and such a great work ethic that Margaret Markham, Meryl’s tutor and academic dean at the Berkshire Center, encouraged her to take on remedial college courses. “Meryl has more determination than almost any other student I have tutored,” says Mrs. Markham. “Her positive can-do attitude is one of her greatest assets.”

After passing these basic reading and basic writing classes, Meryl was ready to enroll in an Early Childhood Education Introductory Certificate Program. Meryl’s talents and love for toddlers earned her unequivocal acclaim. Mrs. Markham guided Meryl through the maze of course requirements, assisted with course work, and orchestrated Meryl’s internship at a local children’s center, where Meryl learned to apply classroom theory to the real world. In the spring of 2006, Meryl’s family and friends watched her cross the stage at graduation to receive her Introductory Certificate. But Meryl was only getting started.

The next semester Meryl enrolled in an Intermediate Certificate Program in Early Childhood Education. “I was nervous at first, but once I got comfortable I knew I could do it,” Meryl said. Right on schedule she received her Intermediate Certificate in the spring, and parlayed her practicum at the Children’s Center into a paying job. Meryl decided that she was going to reach for the sky and enrolled in a Liberal Arts Associate’s Degree Program in Elementary Education, a program with many general education requirements. After this final test of her determination, Meryl again walked across the stage at graduation, receiving her Associate’s Degree. Meryl has achieved at a level that no one but Meryl ever expected. Passing psychology and Conservation of Natural Resources took Herculean efforts from Meryl as well as from tutors willing to go the extra mile for her. As an alternative to the insurmountable wall of college algebra, CIP helped guide Meryl to a statistics course offered by the Massachusetts College of Liberal Arts.

At CIP, Meryl’s therapist, tutor and residential staff provided incredible support day in and day out, enabling her to receive her college degree, expand her social realm, and develop a support system and lasting friendships. In Meryl’s own words, “The Berkshire Center helped me achieve my Associate’s degree in Early Childhood Education. The staff here are great and supportive.”

And finally, if it were not for Meryl’s parents, who offered their unwavering support, Meryl might not have had the chance to achieve her dreams. “We have followed and supported Meryl’s lifelong efforts to excel at everything, from sports to academics to social activities. CIP provided the structure and independent support within which she could thrive without parental interference.”

After receiving her degree, Meryl moved to Charlottesville, Virginia, where she now lives independently, and has been offered employment at a local day care center and preschool. Meryl stated, “If CIP taught me anything, it was never give up—reach for your dreams.”

Jeff Wheeler provides academic support to individuals with ASD, NLD, and other learning differences. He is currently working on a book “Proprioception and Asperger Syndrome—A Balancing Act.” Dan McManmon grew up in western Massachusetts and received his B.A. in Multimedia and Graphic Design from Champlain College in Vermont. He began working at the Berkshire Center in Lee, Massachusetts in 2005, and more recently moved to Berkeley, California for the opening of CIP’s fourth center. The College Internship Program offers academic, internship and independent living experiences for college-age students with Asperger Syndrome and other Learning Differences. CIP serves the growing number of students who are aging out of public school systems but still need support after high school. Many of these young adults need to develop self-advocacy skills and learn how to function independently before they can be successful in college or careers. CIP provides a bridge for these young adults, easing the transition to college and independence by offering comprehensive instruction in academics, life skills, social skills and career development. Students live in apartments with independent support within which they could thrive without parental interference.

For more about CIP, visit www.collegeinternshipprogram.com.
Asperger Marriage: Viewing Partnerships thru a Different Lens
by Grace Myhill, LICSW and Dania Jekel, MSW

The excerpts below focus on interventions and suggestions for relationships in which a man with Asperger Syndrome (AS) is partnered with a woman who does not have AS (or a non-AS woman). The article in its entirety may be found on the AANE website or at http://www.naswma.org/associations/8381/files/FCE_AspbergerMarriage.pdf. (AANE can also assist non-AS men partnered with women with AS.)

Several times a year AANE offers support groups for non-AS spouses/partners of people with AS. The six week group gives the [non-AS partner/spouse] increased knowledge of AS and how it is affecting their relationships, improved self-awareness of their part in the relational issues, as well as new techniques for coping and communication. Still, many need follow up or ongoing support beyond the six week group. Group members are invited to continue to meet monthly and/or seek support from a moderated online group.

What else can be helpful to non-AS partners of people with AS? When it comes to AS, thinking outside the box is usually beneficial. It is important to hold on to and present to the group members the hope that AS + non-AS marriages can work—but probably not as traditional partnerships. The outcomes are best when both members of the couple learn about AS and communicate with each other about how it affects their relationship, recognize where their individual needs differ, and are open to working out alternative solutions—arrangements that may be original or unique to them, rather than meeting conventional expectations.

Even in marriages where neither partner has AS, couples may marry expecting an unrealistically high level of togetherness—that they will do everything together—and it is important as the partners mature to let go of that fantasy. It is even more important for AS + non-AS couples to let go of such unrealistic expectations. Some AS + non-AS couples have separate bedrooms, separate sections of a house, or even separate houses. Women should be encouraged to have their own work, social networks, and places to turn to get their own needs met, and is no longer overly stressed or depressed. AS. Prescription medication or individual psychotherapy may also be helpful for a non-AS wife until she is able to get more of her needs met, and is no longer overly stressed or depressed.

Recommended books:

- **An Asperger Marriage** by Gisela and Christopher Slater-Walkter
- **Asperger Syndrome: A Love Story** by Keith Newton & Sarah Hendrickx
- **Love, Sex & Long-Term Relationships, What People with Asperger Syndrome Really Really Want** by Sarah Hendrickx & Stephen Shore
- **Asperger Syndrome and Long-Term Relationships** by Ashley Stanford
- **Alone Together: Making an Asperger Marriage Work** by Katrin Bentley & Tony Attwood
- **Solutions for Adults with Asperger’s Syndrome: Maximizing the Benefits, Minimizing the Drawbacks to Achieve Success** by Juanita Lovett
- **Loving Mr. Spock** by Barbara Jacobs

To learn about AANE spouse support groups, including our online group, please contact Grace Myhill at (617) 504-3116 or gmyhill@gmail.com.
As I look back on my teenage years and early twenties, some themes emerge in my transition to adulthood. I gradually took on more and more responsibility for my own welfare. Because it was gradual, I never felt overwhelmed. I was also able to get advice from others to help me at various points. This advice helped me immensely. Unfortunately, there were areas where I was not able to get the kind of advice that I needed, and it did have adverse effects.

High School – The Base

Academically, high school provided me with a strong foundation. It was a Catholic high school. The discipline that was part of the school culture made it an excellent place to learn. Some may have thought the discipline stifling; I found that it allowed me to focus.

Another feature of my high school years was a commute of about an hour. I lived in Jersey City but went to a high school in Manhattan. To get there, I had to take a bus and two trains. This meant that I had to learn how to navigate the New York City subway system. After an elementary school that was only three blocks from my home, the experience gave me a chance to learn how to take care of myself without a parent nearby.

My high school was an all boys school. I think that this had some advantages for me. Without girls, boys did not engage in behaviors meant to impress them. There was also no competition among my classmates for particular girl friends. This made it easier to form friendships with my classmates.

The absence of girls did also have its disadvantages. My contact with the opposite sex was severely limited during my high school years. Therefore, I did not learn how to interact with or date girls. This would create problems as I transitioned into adulthood.

College Years

After going to high school in Manhattan, I returned to New Jersey for college, attending the Stevens Institute of Technology. I ended up commuting my first two years, and then living on campus for the last two. I think that this arrangement helped me to adjust to college life a little bit at a time. Being able to commute meant that I could return to familiar surroundings in the evening. When I finally did move to campus, I had friends and knew the environment.

Stevens was also an all-male college. (It would become co-ed the year after I graduated.) After an all-male high school, I did not find this a problem. It did limit my contact with girls, however, and so my inexperience with the opposite sex continued.

I was fortunate in starting college to be offered a work-study position at Stevens. I ended up sorting and delivering mail in the college post office. This gave me an opportunity to learn my way around campus and also to meet many of the administrative personnel. I continued in this position for all four of my years as an undergraduate.

One of the high points of my work/study job was when I was asked to join Tau Beta Pi, the national engineering honor society. As part of my initiation, I had to get signatures from current members. One of them was the President of the college. I asked his secretary for his signature during one of my mail runs.

I think that the President was quite happy to see one of the work/study students, particularly one that he had been seeing for a few years, being inducted into Tau Beta Pi.

Early Twenties

My post college career was complicated by a number of factors. The first was the end of the Apollo program. Even before the program ended, many engineers were being laid off; there was simply no work for them in the space program. Their entry into the job market increased the competition for the available jobs. As a result, I did not get the quantity of job offers that had been considered commonplace only a few years earlier, but I eventually did find something.

My first job was working for General Electric in Schenectady, New York. I spent the first couple of weekends commuting back to my parents in New Jersey, but eventually I had to spend a weekend in Schenectady. That meant that, as a Catholic, I had to go to church. I checked a list of the local churches and found that the closest one was St. Mary’s. They had a convenient time for Mass, so I decided to go there. It turned out that St. Mary’s was one of two ethnic Polish parishes in Schenectady. Since all my grandparents had been born in Poland, I was rather pleasantly surprised to find that out.

There were other surprises. One of the ladies in the choir, Reggie Anderson, recognized me from work. On Monday, she asked if I had enjoyed the music. I was interested in singing, but had only lasted one half of a rehearsal in the college glee club. This didn’t stop Reggie from recruiting me, however. The director of the choir was Joseph Antos, who had gotten his start playing the organ in silent movie houses in Troy, New York. He was willing to work with me and his patience was rewarded. I have been singing in church choirs ever since. It seemed that, in the glee club rehearsal, I had become confused when I heard the other parts. By taking the time to rehearse me in my part without the distraction of the other parts, I was able to learn my part. Sometimes it is not lack of talent, but an inappropriate teaching technique that prevents someone from learning.

It is often said that school is only an introduction and that real learning starts with your first job. That was my experience to some extent. My studies in college had given me an excellent technical foundation. My first job, however, was where I learned the work habits that would serve me well for the rest of my career. I had entered a work culture that prized understanding how things worked and paying attention to detail. This fit nicely with my Asperger traits.

Once I had settled in, I soon found the local singles club. As befitted a club in upstate New York, it was about skiing. I didn’t know how, so I had to take lessons. Fortunately, I was able to learn enough in a few lessons that I could get myself down a mountain without too great a risk of killing myself. I did fall frequently, but this is to be expected when you are learning something new.

Unfortunately, my ability to learn quickly did not extend to dating. It often seemed that, by the time I realized someone might be interested in me, she had moved on. This was frustrating, but the alternative seemed to be for me to make a commitment before I even knew the woman. I was not prepared.
to do that.

I eventually concluded that the dating scene was beyond my capabilities, since I was not being given an opportunity to learn from my mistakes. Women were simply not interested in helping me—or if they were, the advice that they were getting from their peers and authority figures was simply to say or do whatever it would take to make me go away. If lying was the easiest thing to do, then they would lie.

Later Life

After my initial job, I became interested in microprocessors. The personal computer was in its infancy so I had the opportunity to work with both the hardware and software of very early microprocessor systems.

I started calling the group in which I worked the “Beyond Help” office. Our job was to develop computer systems for people with requirements that could not be met with a traditional mainframe computer system. We would learn what people needed to do, and then we would develop a system that met their needs. I would find out what was commercially available for the system. I would get those items and then build whatever components we couldn’t buy. I found that I had to learn the job of the person I was helping almost as well as he or she knew it. The ability to become obsessed with something was definitely an advantage!

Speaking of obsessions, I acquired a couple in later life. In my early thirties, a cousin invited me out to Iowa to ride in the RAGRBAI (Register Annual Bicycle Ride Across Iowa). I accepted the invitation, and became hooked on bicycling. I have since done quite a few long distance bicycle rides, but the most important result was that I joined the local bicycle club. This shared interest gives me something to talk about. There is also plenty to learn about bicycles: how they work, and how to fix them. I found this last item particularly appealing. I am not a fast rider, but I can help other riders when they have problems on the road. There is more than one way to excel at something.

I have also developed an interest in community folk dancing. I started out in New England contra-dancing and later moved on to English country dancing. I like the lack of complicated footwork in these dance styles. Also, since it is customary to change partners after every dance, asking a woman to dance is not a big deal.

I have been able to combine my interest in dancing with my electrical engineering background by volunteering at a number of folk music festivals in the northeast. These festivals always need volunteers. My electrical engineering background makes me especially valuable in that I can help with the sound equipment. It is not a bad deal: get in for free and get to play with electronics.

I went back to school about 1991. I had always wanted to get a doctorate and it seemed like a good time to do so. Graduate school turned out to be very much like my job in that I had to learn a new field, solid modeling. In graduate school, however, I spent a lot more time learning about solid modeling than I had for projects in my previous job. I spent about three years reading technical papers. It was only then that I was able to work on solving the problem that became the basis for my doctoral dissertation. After getting my doctorate, I moved to Boston where I started working in modeling and simulation.

Some time after moving to Boston, I was reading an article in Forbes magazine. The article was about Temple Grandin and there was a sidebar about Asperger Syndrome. It stated that many computer programmers had this condition. This intrigued me, and I did a little more research. What I learned seemed to answer some questions about why my life had gone the way it had. I then made an appointment with a psychologist. I was too old for the diagnosis to be certain, but she told me that I “probably [had] mild to moderate AS.” I continued researching Asperger Syndrome online after the diagnosis. I found a number of web sites that offered information and an online community. One of these sites was that of the Asperger's Association of New England. That is how I found AANE.

In Memoriam Todd M. McDonald

On Monday, June 8, 2009, Todd M. MacDonald, a resident of Stoneham, Massachusetts, died at Tufts Medical Center in Boston after a brief illness. He was 38 years of age. Todd earned a degree in Communications from Middlesex Community College and a bachelor’s degree from UMass Boston. He worked for IBM and Unisys as a computer technician. Possessing a strong interest in computer animation, he enjoyed his involvement as a member and volunteer for Anime Boston. Todd was also a supporter of animal rights. His parents, John H. MacDonald and Janet (Storlazzi) MacDonald, have generously donated Todd’s collection of anime to AANE so that other adults with AS can enjoy it. (See http://forums.animeboston.com/showtopic.php?tid/8561/.)

In Memoriam Bronwen van der Wal

I learned last week the sad news that Bronwen van der Wal had passed away.

She had been battling cancer for a year, but had told none of her friends on the ‘Net.

She was a brilliant and eloquent ally.

She wrote both under her own name, and under the nom-de-plume Alyric.

She was a non-autistic parent of a child on the spectrum, a public health administrator and researcher, and the wife of an Australian diplomat, posted for the last couple of years of her life to Ottawa, Canada.

Several of her friends in the autism blogosphere have written posts in her memory. My favorite is this one, by Lindsay from Kansas:


(Lindsay’s own blog, very well-informed and incisive on matters of neurodiversity, psychotherapy, and feminist theory, is a treasure trove in its own right.)

Bronwen’s husband and daughter have graciously decided to keep her blog online. It can be found at http://alyric.blogspot.com and is also well worth browsing.

As Michelle Dawson wrote, upon hearing the news of Bronwen’s death, cancer is a horrible disease. Bronwen was taken from us way too soon.

She was only a couple of years older than I am. Zichronah l’brachah -- may her memory be a blessing.

Phil Schwarz
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We are very grateful to the advertisers who help subsidize the printing and mailing of the AANE Journal. For information on advertising in the spring issue, please contact Carynn Meyers at Carynn.Meyers@aane.org.

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

Staff photos by Dania Jekel.
Miscellaneous photos by Carynn Meyers.

Copley Square, location of AANE’s 2009 Connections Conference
In August I sent out a plea by email to my family and friends. I was starting a new teaching job working with middle school students with Asperger’s and Autism. I didn’t own enough books, games, arts and crafts and school supplies to stock my new classroom. I asked if there were any kind souls out there who had such materials that were no longer being used at their houses, and who would be willing to donate them to my classroom for the benefit of my nine new charges. My email eventually ended up with Stephanie at AANE. She posted my message to the online support group for parents of teens, and the response was remarkable! Offers of help came pouring in from people I’d never met, and who’d never met my students. I’ll never forget the experience of having a whole community of virtual strangers, bonded by a shared love for individuals on the Autism Spectrum, come together to make my classroom whole in time for my students’ arrival. I can never really thank you enough!

Ms. Taube’s class thanks:
Robin Buratowski, Lisa Campbell, Ann Mullen, Barbara Sikes, & Betty Smithline
for their kind hearts and generous donations!

Special Projects—Thank you!
Special thanks to Robin Keller for moderating the Teens’ Parents online support group during the spring and summer.

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Thank you
to Julie Betters for designing advertisements for AANE, and to the Improper Bostonian for donating ad space in order to help raise awareness for AANE and Asperger Syndrome.

Thank you to Robin Keller for moderating the Teens’ Parents online support group during the spring and summer.
My first six months at AANE have been a whirlwind of fundraising activity! I first came on board in April to help out with AANE’s annual Laugh Out Loud Gala, and am happy to report that the Gala Committee is already hard at work on next year’s event. The 2010 Laugh Out Loud Gala will be held on May 1st at the Newton Marriott Hotel, featuring comedian Bob Marley. It’s shaping up to be a fantastic night, and I hope to see you all there!

AANE has had quite an exciting summer and fall so far. We were invited to a screening of Max Mayer’s film Adam, about a young man with Asperger’s who falls in love with his neurotypical neighbor. Check out our website for our interview with the stars of the film! We were also fortunate enough to host Pulitzer prize-winning music critic Tim Page in celebration of his new book, Parallel Play: Growing Up with Undiagnosed Asperger’s. Tim spoke for an audience of 250 at Regis College in September, and helped us raise over $6,000 for AANE in just one evening!

I have had the pleasure of meeting many of you at these events, as well as working with some of you on committees or as volunteers. If you are interested in volunteering at a fundraising event, or hosting an event of your own to support AANE, I would love to hear from you! In the meantime, keep in touch! Be sure to check out our page on Facebook or follow us on Twitter – @AANE09.

See page 34 to learn about Tim’s talk, and page 4 for an article by Lucy.

Photo by: Dania Jekel.
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