An Introduction to Asperger Syndrome:

Information for Families of Children and Adolescents

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About AANE

The Asperger’s Association of New England (AANE) was founded in 1996 by a group of parents and professionals dedicated to improving the quality of life of people with Asperger Syndrome. AANE’s mission is to foster awareness, respect, acceptance, and support for individuals with Asperger Syndrome and their families. Our members include families, friends and professionals who support our mission. We invite you to become a member.

What AANE Provides

Consultation, Information & Referral for:
• Adults with AS
• Families of Children and Adults
• Educators/Professionals
Support/Social & Activity Groups
Conferences
Workshops/Seminars
Family Grant Program
Speaker Bureau
Adult Programs
Newsletter
Information Packets
Special Programs
Legislative Advocacy

Chapters: ● Home Office/Watertown ● Western Massachusetts ● Rhode Island
● Maine ● New Hampshire ● Vermont

The articles in this booklet were compiled from the Asperger’s Association of New England’s information packets and newsletters. Please contact AANE for more information, resources, or referrals for specific services or programs.
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Section One

When Your Child is Diagnosed: Understanding AS and Your Own Feelings

“If you've met one person with Asperger Syndrome — you've met one person with Asperger Syndrome.”
— Stephen M. Shore, AANE Board Member
I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this......

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, “Welcome to Holland.”

“Holland?!?” you say. “What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.”

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven’t taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It’s just a different place. So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It’s just a different place. It’s slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they’re all bragging about what a wonderful time they had there. And for the rest of your life, you will say, “Yes, that's where I was supposed to go. That's what I had planned.”

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very, very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

Emily Perl Kingsley has been a writer for Sesame Street for 36 years and has won 17 Emmy Awards for her work. The parent of a son who has Down syndrome, Ms. Kingsley has become an internationally known lecturer on Down syndrome and developmental disability. “Welcome to Holland” has been reprinted in hundreds of books, newsletters, journals and parent support packets and appears on scores of Web sites.
What You Need to Know about Asperger Syndrome

If your child has been diagnosed with Asperger Syndrome (or “Asperger’s Disorder” or “Autism Spectrum Disorder”), we welcome you to a community of pioneers. In the United States, people have only been able to get this diagnosis since 1994—so no one has all the answers. You will find that individuals with AS can differ widely from one another—and that parents, teachers, doctors, and other people are still learning about AS. It’s not easy being a pioneer, but the journey of discovery can be rewarding, and you can find some great fellow travelers. Working closely together, families, teachers, and other professionals have already learned some useful things about AS, and a lot about how to help people with AS overcome some of their difficulties and grow toward their full potential.

AS is not a mental illness. It is a neurological condition, with associated sensory issues. That means that people with AS are born with brains and nervous systems that attend to, process, integrate, and interpret sensory input differently than most people do. As light enters the eyes of a person with AS, or sounds come into his or her ears, that person does not perceive these stimuli in the same way as others do; he or she does not get the same messages, draw the same conclusions, or react in the same way that others might. For example, one boy with AS had very sensitive hearing. He constantly heard banging and scraping noises at school—sounds his classmates did not perceive or were able to screen out. He worried that he was hearing rumblings of an impending earthquake. The noises were actually caused by children in the classroom upstairs moving their chairs around. Once the boy with AS was reassured that the noises were real but harmless, and the metal legs of the chairs were covered with tennis balls, the boy could finally relax and attend to his teacher’s voice!

Many people think that AS is part of the autism spectrum, along with High-Functioning Autism, and Pervasive Developmental Disorder Not Otherwise Specified; much more brain research is needed to confirm or disprove this hypothesis. However, it is very important to say that, despite some overlapping issues, the characteristics and needs of these higher-functioning children are significantly different from the needs of children with “classical” or “Kanner’s autism,” who have severe cognitive and language limitations. Therefore, children and teens with AS should be diagnosed, taught, and treated by professionals with specific training and wide experience in AS.

People with AS are considered “high-functioning” meaning that they are of at least average intelligence; some children with AS have much higher IQs. Children with AS usually learn to speak at approximately the same age as other children. (Some acquire language more slowly, but have typical foundation language skills by age seven or eight.) Most are able to attend school, often being included in regular education classrooms with the support of an aide or paraprofessional. Many have an excellent memory for facts (although they may not be able to remember faces). Some have cognitive, technical, or artistic gifts (visual arts, music, writing). It is possible that high achievers like scientist Albert Einstein, mathematician and code-breaker Alan Turing, musician Glenn Gould, composer Zoltan Kodaly, artist Michelangelo and many others may have had undiagnosed AS. High achievers with AS living today include professor/
AS is considered a “pervasive developmental disorder,” meaning that a child with AS will be slower than average to develop skills in a number of areas. A child with AS will probably be less mature than others his/her age in social/emotional development. For example, a smart nine-year-old with AS may act in many ways like a six-year-old—including having temper tantrums or meltdowns—behavior that many nine-year-olds would have outgrown. At the same time, the child may have difficulty with sensory integration: extreme sensitivity to some kinds of sights, sounds, tastes, textures, or smells—or in some cases a lack of sensitivity in one or more of these areas—resulting in difficulty coping with sensory input. Such children may be unable to tolerate a classroom with flickering fluorescent lighting, or cafeteria full of noisy classmates. They may abhor certain tastes, or refuse to wear a scratchy sweater. They may need significant down time for “sensory breaks” in order to replenish their energies and to avoid feeling overwhelmed and “melting down.” Most also have difficulties with executive functioning (the ability to organize oneself, to plan, initiate, carry out and complete tasks). They may be slow to develop large motor skills (walking, skipping, riding a bike, playing sports) or fine motor skills (e.g. legible handwriting). Many people with AS are highly anxious. They tend to be rigid, concrete, literal thinkers. They often have intense special interests—though the focus generally changes as the child grows. They cling to routine for a sense of order and stability in a world that can seem confusing and overwhelming.

The main area where delays show up is in social development and communication, especially the ability to use both receptive and expressive language in context. Children with AS are more comfortable with facts than with feelings. Although they like to follow rules, they generally fail to intuit important unwritten social rules, and need to be taught them explicitly. They don’t understand how to carry out casual conversations or make friends. They may have trouble starting, participating in, or ending conversations—especially in a group. (It’s a bit easier one-on-one.) They may stand too close to others, talk too loudly or in a monotone, talk too long, use stilted expressions or overly sophisticated vocabulary, interrupt, and hold forth on their favorite topics even when others have lost interest. Because they tend to ignore or misinterpret other people’s body language, facial expressions, and tone of voice, they often miss the real message someone is trying to send. They are “tone-deaf” to the subtle rules governing social boundaries, authority, and hierarchies. They may unintentionally offend people or appear rude. Many children with AS desperately want friends, but do not know how to make or keep them. After many rebuffs, they may withdraw in despair. Others are more introverted and self-sufficient, finding satisfaction in solitary pursuits.

What causes AS? Although there may be some environmental “triggers” that bring on AS or various forms of autism for some children, there is currently no solid research to confirm this hypothesis. Some research indicates that AS might be an innate, inherited, genetically determined neurological condition—that some children are just born with it. Genetics researchers confirm that families with one member who has AS are much more likely to have several members—parents, grandparents, siblings or others—who have AS or other forms of autism. Often, when a child gets an AS diagnosis, parents realize that other relatives (or even they themselves) may have AS, or certain traits of AS.

How common is AS? AS is very widespread; although studies are incomplete, as many as one in two hundred people may have AS—more people than have such more familiar condi-
tions as Multiple Sclerosis or Down syndrome. For reasons not clearly understood, more boys than girls receive a diagnosis of AS—four boys for every girl. Possibly more girls have AS, but do not get identified.

Some people with AS may also have other diagnoses, such as ADD or ADHD, OCD (Obsessive-Compulsive Disorder), Tourette’s Syndrome, or Bipolar Disorder. When a child genuinely has two or more distinct conditions at the same time, these are called “co-morbid” conditions.

Parents’ feelings and the prognosis: Many parents feel discouraged when their child first gets a diagnosis of AS—especially when they hear the word “autism.” As a parent, one naturally wonders: “What kind of future will my child have? Will he be able to make friends? go to college? get a good job? have a girlfriend? marry? have kids?” It is not easy to predict the outcome for a child with AS. However, a better understanding of AS, increased public awareness, earlier diagnosis, better education of parents and teachers, and the development and use of more effective interventions all seem to point toward a brighter future for today’s children with AS, compared to that endured by adults who have grown up undiagnosed and with less help. Even though they are out of step with their peers, children with AS do continue to learn and grow—especially if they are understood and appropriately supported at home and at school. There is reason to hope that most children with AS can eventually grow up to achieve some kind of success, even if the lives they create are atypical and not what parents originally expected. One can work toward helping the child find his or her niche in the workplace (ranging from volunteer or part-time to full-time professional work), develop skills for independent living (perhaps with certain supports), pursue some positive leisure activities, and possibly have meaningful friendships or even a successful marriage, with or without children.

We believe that it is very worthwhile for parents to read about AS, to attend classes and conferences about it, to share their experiences and parenting strategies with other parents and offer one another mutual support, and to seek out the best professionals, with the widest and deepest experience of AS, to help them raise their children. It is also good for parents to read about or meet adults with AS who, despite their struggles, have found ways to survive and even excel in their lives, using their significant strengths to compensate for their areas of weakness. The complex challenges of living with AS are best met by uniting with an AS community.

What to Do

Because you are a pioneer, you will need to become your child’s advocate. We encourage you to learn as much as you can about AS, so that you are well prepared to educate other people in the family, at school, and in the wider community about this relatively new, little known, and sometimes puzzling diagnosis.

● First of all, get your child a full evaluation and an accurate diagnosis from a neuropsychologist, neurologist, or psychiatrist, or from a team of professionals who have a wide experience of children with AS. (The Asperger’s Association of New England or your local state-funded autism agency can refer you to someone appropriate.) Evaluation is generally done through interviewing parents about the child’s past development and current behavior, meeting the child, and doing several hours worth of neuropsychological testing, including IQ tests and projective tests. You should get a detailed report with recommendations.
• **Start a loose-leaf notebook or binder** to keep the evaluation reports, other information about your child, articles on Asperger Syndrome, contacts and resources, education plans and other school materials together in one well-organized, accessible place. You will use this notebook often to educate, communicate, and negotiate with others on behalf of your child.

• **Learn about AS—and find a supportive community**—by contacting your local autism agency or AANE. Autism agency staff can talk with you, put you in touch with other parents, and tell you about parenting classes or an AS parent support group. They can also refer you to professionals who have the training and experience to work effectively with children with AS. Read books, and look at sites on the Internet. All care-givers (e.g. both parents) should ideally learn about AS together, so that they can support one another, agree on parenting expectations and strategies, and work together in harmony to help the child.

• **Find professional allies who know about AS**, who can follow your child’s progress over time, and help you determine and advocate for the services the child needs in any given period. Your team might include: a teacher, guidance counselor, or principal who understands your child; a psychologist or psychiatrist; an educational advocate and/or an educational consultant; a speech therapist trained in social pragmatic language and able to teach a social skills group; an occupational therapist for a child with strong sensory issues.

• **Medication? Maybe**: Some children with AS may need medication, generally prescribed to moderate their anxiety or depression.

• **Adjust your own expectations**. This may not be easy, so be patient with yourself as well as with your child. Try to remember that the child is younger than his/her chronological age, and that it is difficult and draining for him/her to deal with life’s daily demands. Understand that the child generally is doing his or her best, and does not intend to be difficult—it is his or her unusual neurology that is causing him or her to become overwhelmed, melt down, or not know how to navigate a social situation. Your child needs down time, and probably cannot handle the number and variety of activities other children may engage in.

• **Teach your child about AS and how it affects him or her**. There are some good books available to share with your child. Talk about what is hard or successful in everyday life, and how it relates to AS.

• **Disclose to others**. It is important that family members, teachers, and other people in the child’s life understand that his or her unusual behaviors, however difficult, generally spring from the child’s different neurology, not from psychological motives such as defiance or a desire to manipulate others.

• **Plan ahead. Simplify your family life. Develop skillful parenting strategies** to make your child’s life (and your own!) manageable, and to keep your child’s anxiety down and his/her self-esteem up. Children with AS do their best when they know what to expect, and when you ask of them only what they are capable of performing.

• **Create a calm, orderly home environment**. Children with AS may be unable to share a bedroom with a sibling, or put away a lot of toys.
• Set up predictable daily routines and a reliable, streamlined schedule. Make a calendar or chart with pictograms so the child can see the schedule. Include a regular bedtime and a comforting bedtime routine.

• Prepare your child for transitions, or for any necessary changes in the usual daily or weekly routine, by discussing them with the child, and putting these on the chart.

• Work with the child’s strengths. Use his/her special interests to provide fun and motivation, and to help the child connect with potential friends. Use his/her intelligence to prepare the child for an upcoming difficult social situation or brainstorm creative solutions.

• Figure out what is hard for your child, and how to read his/her “distress signals.” Prevent crises by avoiding toxic situations when possible, or be prepared to offer the child the extra support s/he needs. If the child does have a tantrum or meltdown, try not to talk to or touch him/her. Instead, give the child plenty of time and space to calm him or herself. Later on, you may be able to discuss what triggered the meltdown, and avoid that trigger in the future.

• Keep social interactions at tolerable level. If there are play dates, family visits, or company, keep these experiences short and structured for the child.

• Build in plenty of down time. If your child has been very active or social, s/he will need a break. Even a fun activity can wear the child out, using up part of his or her “sensory budget” for the day and lessening his or her ability to communicate.

• Teach social skills in an explicit fashion (or reinforce the teaching of a private or school-based speech therapist). Coach the child in advance on what to say or do in a particular social situation.

• Teach independent living skills patiently and persistently, in small, concrete steps.

Work closely with your child’s school.

• Bring in the diagnostic report, and request a formal meeting with an educational team to ensure that an appropriate Individualized Education Plan (IEP) is written, one that addresses your child’s social learning needs, sensory issues, and executive function difficulties.

• Choosing an educational placement, and specifying educational supports/ accommodations, are the decision of the educational team, including parents. Many children with AS can be successfully included in a regular education classroom with appropriate supports, often including the services of a well supervised, trained, full time one-on-one aide. Other children may need smaller, self-contained classrooms.

• Regular, open communication among the adults—educators and parents—is key to a student’s success. Agree to exchange daily or weekly messages by journal, e-mail or telephone (whatever the educators prefer), and hold regular (e.g. monthly) team meetings to monitor progress, set new goals, and decide on issues such as modification of services or alternative educational placements. You may need to hire a educational advocate to help you. (Please see the AANE anthology or Web site for detailed, expert education articles, or to request an information packet.)

• If your school has not had much experience with AS, encourage personnel to attend professional trainings, and/or to hire an educational consultant to do an in-service training, or to work with the team a couple of hours per month. Consultants can observe your
Raising a child with AS is challenging, and you may often feel overwhelmed. Don’t try to do it alone. Reach out to find the people who understand AS and appreciate your efforts. With support, perseverance, and luck, your reward will be seeing your child outgrow some of his or her struggles, and become a unique, valuable person with a worthwhile, satisfying life.

*AANE thanks Elsa Abele, SLP/CCC, for reviewing and strengthening this article.*

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**Stephanie Loo, M.Ed.,** has worked at AANE since 2001. She serves as grant writer, Director of Teen Services, and AANE Journal editor. She is the parent of a young adult with AS.
If you have just found out that someone in your care has Asperger Syndrome (AS), you may feel as bewildered as Alice in Wonderland, just after she fell down the rabbit hole! It’s a whole new reality now, and you are probably going to need a guide or two to find your way around. You may feel confused and overwhelmed as you struggle to absorb a lot of new information, decide what you need to do, and figure out where to turn for help. You may find yourself asking: “What kind of help do we need? What is the right combination of services and supports to ensure the best possible future for my child? And where can I turn to obtain these services? What kinds of people, with what kinds of titles and training, can help us most effectively?”

AS is a very complex condition; individuals with AS differ widely in their needs—the needs of each “Aspie” (individual with AS) will probably change significantly over time. Most individuals or families whose lives are affected by AS benefit a lot from having one knowledgeable professional who gets to know your child well, follows the Aspie’s progress over time, sees the “big picture,” and can help you choose which interventions and therapies will be most helpful in the current situation or stage of development. This person might be a social worker, psychiatrist, behavioral psychologist, or education consultant. He or she should be someone who knows a lot about AS, and with whom you have a friendly and mutually respectful relationship, so that you can call with questions or problems as they come up. This person may also be able to serve as an advocate for you or your child, since personnel in school systems and government agencies sometimes respond better to other professionals who “speak their language” or have clout.

You may find, however, that you wish to seek the expertise of specific type of professional for advice on handling your child’s behavioral issues, coaching on social pragmatics, assistance with sensory integration, or to discuss the possibility of medication. We have asked several such specialists to describe in brief essays their role in supporting and serving someone with AS. Please note that others in the same profession may offer different services or take a different approach, but we hope that these essays by the various professionals will prove helpful. We thank all our contributors.

The following list of professionals is by no means complete. For each title that appears in bold type, a description of that individual’s role follows. Hopefully this article will serve as a guide indicating where to start looking for an appropriate professional. Individual choices will necessarily be based on logistics, cost, and your personal rapport with the doctor.
**AANE’s Synopsis of Private Professionals**

*For an Initial Diagnosis, Evaluation or Re-evaluation:*

- **Psychiatrist** (some)
- **Neuropsychologist**
  
  Neurologist (usually to rule out other neurological issues, although some may give a diagnosis)

*Behavioral Issues:*

- **Social Worker**
- Behavioral Psychologist
- Behaviorist
- **Clinical Psychologist**

*Speech Pragmatics/Social Skills:*

- **Speech and Language Pathologist**
- Psychologist
- **Social Worker**

*Sensory Issues:*

- **Occupational Therapist**

*For Questions about Medication:*

- Psychopharmacologist
- **Psychiatrist**

*Family Issues:*

- **Social Worker**
- Clinical Psychologist
- **Psychiatrist**

*Issues with School Providing Services:*

- 766 Advocate

*Help Figuring Out What to Do in School:*

- **Educational Consultant**
- Social Worker

*Employment Issues:*

- Employment Specialist
- Job Coach

*Assistance with Integration of Needs:*

- **Interdisciplinary Team Assessments**

**The Psychiatrist**

*By Teresa M. Kohlenberg, M.D., Belmont, MA*

The psychiatrist is a medical doctor who has trained in the diagnosis and treatment of emotional disorders, using both “talking” therapy and medication. Psychiatrists usually complete at least a year of basic medical training (internship) and three years training in mental health care of adults, after which Child Psychiatrists add two years training with children and adolescents. There are also some Child Psychiatrists whose initial training is in Pediatrics. Child Psychiatry training provides a great exposure to the developmental issues involved in Asperger Syndrome and related disorders, as well as the different medications available and their proper use in children. Many (but not all) psychiatrists who work with children with these disorders have gotten additional training or exposure in specialized settings.
What a child psychiatrist offers depends to a certain degree on his or her training and areas of expertise. The following list starts with the services most child psychiatrists offer, then includes services some, but not all, will offer.

Most will:
- Perform a thorough evaluation of a child’s/adolescent’s emotional functioning.
- Make a diagnosis of AS and associated emotional or behavioral disorders.
- Suggest further appropriate medical and psychological testing.
- Prescribe and monitor medication as part of a treatment team.

Some will:
- Provide ongoing individual or group therapy to the child.
- Provide family treatment, developmental and behavioral guidance, and support to parents.
- Outline a comprehensive treatment plan in collaboration with psychologists, educators, social workers, and others involved in the child’s care.
- Provide consultation to the schools and attend planning meetings.
- Advocate for the child and family with schools and other agencies.

The Psychologist

By Gary Eisenhower, Ed. M., Marblehead, MA

Appropriate treatment planning for a child with Asperger Syndrome involves a constellation of individuals--including informed parents, teachers, psychopharmacists, pediatric neurologists, behavioral psychologists, neurophysiologists, clinical psychologists, etc. In my experience, it seems that the clinical psychologist often plays a coordinating role in the overall treatment plan for the child with Asperger’s.

The clinical psychologist may be initially involved in the diagnosis of Asperger Syndrome and associated disorders. Common secondary diagnoses include ADHD, depression, generalized anxiety, or more specific anxiety disorders such as OCD or panic attacks. Treatment of these disorders involves specific therapies and consultation with other professionals.

The clinical psychologist also must help identify and reduce stressors in the environments in which the child functions. As stress is lowered generally around the child with Asperger’s, the child will be able utilize his/her own talents and interests, rather than having to generate inappropriate defenses against troublesome stressors. At a minimum, this will include necessary informational discussions with the child’s family and school regarding appropriate expectations for peer group interactions, family interactions, learning style, etc. Family therapy, Chapter 504 plans, special education plans and summer planning are common interventions at this level of treatment.

The clinical psychologist will likely be involved with the child and family for several years, sometimes on a monitoring relationship two or three times a year, sometimes doing family therapy, and sometimes more frequently and regularly with the child as new concerns emerge.
The Neuropsychologist

By Suzanne Dowdall, Ph.D., Wellesley, MA
and Kathleen Curran Ph.D., Newton, MA

A neuropsychologist is a licensed psychologist who has received a doctorate (Ph. D., Psy. D.) or Ed. M., signifying extensive instruction and supervised training, and has received additional specialized training in behavioral, psychological and emotional aspects of neurological disorders. The work he or she performs includes diagnosis, treatment, as well as consultation regarding a variety of disorders, including Asperger’s.

Evaluative tools employed by neuropsychologists include interviews with both the client and significant others, observations, as well as a wide array of “standardized” tests where an individual’s performance can be compared with their peers’ and may include academic and personality tests. This information is integrated to paint a complete diagnostic picture of neuropsychological strengths and weaknesses in a variety or areas (for instance: social-emotional functioning, expressive and receptive language skills, visual/spatial organization, problem solving, memory and learning, attention). Recommendations are created and neuropsychologists will often work collaboratively with a variety of other professionals to share and communicate their findings.

Basing their work on an understanding of the impact of brain functioning on behavior, thinking, learning, and emotion, neuropsychologists are able to help individuals, their families, and others working with them to capitalize on strengths and address difficulties.

The Interdisciplinary Team Assessments for Children with AS

By Ellen Perrin at the Center for Children with Special Needs, New England Medical Center, Boston MA

An interdisciplinary team evaluation aims to identify children’s strengths and weaknesses in medical, cognitive, emotional, academic, linguistic, social, motor, and sensory domains, and to integrate them into a coherent picture.

Most interdisciplinary teams are composed of some combination of developmental-behavioral pediatricians, psychologists, or neuropsychologists, educational specialists, speech/language pathologists, clinical social workers, physical therapists and occupational therapists. An advantage of working with an integrated team is that the information and advice that you will give is consistent and not contradictory.

Developmental-behavioral pediatricians take a long-term development and ecological view of children and families, and are particularly familiar with the necessity to work together with other professionals and parents. They also can evaluate and treat some of the psychiatric symptoms that often contribute to children’s difficulties. Developmental-behavioral pediatricians may be especially helpful in pulling together the various evaluations and recommendations, and in following the child’s and family’s progress over time. Psychologists evaluate the child’s cognitive or intellectual strengths and weaknesses and can identify aspects of the child’s learning and emotional style. Children with AS are often quite bright, but may have subtle organizational problems or rigid thinking styles that affect independent work, organization, writ-
ten output, and abstract thinking. **Educational specialists** look at children’s academic skill development in reading, writing, spelling, and mathematics. This assessment helps to determine what educational interventions will be most likely to be effective.

Many children and adults with AS have difficulty with **pragmatic language**, the ability to use language appropriately for social communication and reciprocal social interaction. **Speech/language pathologists** look at the child’s language functioning, not only in terms of linguistic development and receptive and expressive language, but in the areas of higher-order language and pragmatics. **Physical and occupational therapists** evaluate and help children to improve the motor clumsiness or visual-motor integration problems which affect their strength, muscle tone, ability to participate in sports, and writing tasks in school, and address their sensory integration problems.

**Clinical social workers** assess how the child is functioning at home and the stressors his/her difficulties may be causing within the family. They help the family identify these issues, provide individual and family therapy, assist with information about resources and referrals to community agencies, and provide support and advice for advocating within the school system.

The advantage of a team of professionals who work together is that you will get one comprehensive evaluation with recommendations that are consistent with one other.

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Coping with my Daughter's Diagnosis

By a Parent

I can't pinpoint the exact moment that I realized that my eight-year-old daughter had Asperger's. When she was three, I moved her from a family day care to a larger center, hoping that she would meet children her age and make friends. Though I anxiously wanted her to have play dates, she seemed to prefer roughhousing with the boys instead.

I remember wondering if I was crazy to argue with her well-intentioned lead teacher, who thought she was perfectly fine. How could she be fine, when every time I came to pick her up she would be walking around in circles flapping her arms? My daughter never gave the staff any trouble, so they didn't notice that she wasn't paying attention. I was so relieved when I had the chance to take her to the town preschool for an evaluation; however, the were unable to complete the testing because she couldn't stay still and concentrate. They didn't think I was crazy, but rather thought that I should get some help to find out what was going on. The day I moved her into the next class at the day care center, the teachers were horrified to think that her previous teacher thought she was normal!

I gave up practicing direct care social work when my daughter was one year old. I found it too taxing and, after fifteen years of giving counsel, it left me without enough energy to give to my daughter. In my career, I was so good at identifying what was wrong with others, but with my daughter, I assumed I was looking for problems that didn't exist. Even family members thought she was fine and did not agree with me when I thought there might be problems.

With my background, I figured that I knew best about getting the services my daughter needed, yet it was too hard to think that there was something wrong with her. No one ever told me that life wouldn't just work out once you got married, had kids, and moved to the 'burbs.' Meanwhile, my child was in the preschool program and I was content that she was getting help for her language-based problems.

We were very fortunate to find Dr. R, who tested her and diagnosed Asperger's. After going to conferences for several years, I can now say the word, Asperger, without softening my voice, or yelling it angrily as if the word would make her a leper. I heard Dr. R. give me the diagnosis, and I read his report several times. Finally, I knew I had to get the services for her.

I had slipped into denial, thinking, "Well, she is getting help at school. That will take care of it." My mother, to this day, keeps telling me she thinks her granddaughter is just like other children and that no one can tell. She says that when her little brother follows his sister around, it looks just like she is playing normally and no one would see a problem with her circling the yard while moving her arms in circular motions.

I have gone to AANE conferences twice a year to hear more, and been fortunate that my in-laws attended the grandparents’ workshop one year. I finally made my husband attend one conference and the look of sadness in his eyes said it all. I usually buy two or three books each conference and have amassed a nice library that I find too painful to read through completely.

What day did I accept my daughter's Asperger's? I am still accepting and understanding now. We can go from one day hearing her telling a friend on the phone not to be upset to another day hearing her scream in the park because a neighbor won't let her help plant a bush because she was told she doesn't know enough. Can I accept what I read about Asperger's happening because of family genetics? My husband and I have gotten past this, as anger and finger pointing about who has the craziest relatives leaves us painfully isolated. I know now that there
is nothing I could have done to prevent this (you know… maybe if she hadn’t bumped her head…) but I feel confident that I can read her and understand when she is confused, drifting off, or anxious. I know that I can help her understand these things, and that I am smart enough to make sure she gets the services she needs.

When she grows up… will she be self-supporting? Will she be happy? Will she get married? Or will I be like the happy mom I saw on 20/20 who was really glad her adult son with Asperger’s would always be living with her? I think what is important is that I will always be proud of the things she can do well, or pleased that she sometimes seizes more happiness from a moment than most people.

I know I will always be critical of a diagnosis that could limit her, but then she does seem to be limited by her difficulty with transitions. To ease my daughter’s distress, it has become second nature to me to organize each day’s activities around the degrees of stimulation. I am a mother bear, on the constant lookout for the enemy (stress), which will hurt my cub. That is how I have to cope and that is how she will get the best out of me.
FAMILY—Make Way for a New Definition
By Anne Patterson

“Plant a radish, get a radish, never any doubt.
That’s why I like vegetables; you know what they’re about.”
Words by Tom Jones from The Fantastiks

Commonly Shared Family Expectations

1. Children will eat what is served.
2. Dinner is eaten as a family.
3. Families take vacations together.
4. Parents need time to discuss family issues without kids around.
5. Parents need time alone without the children.
6. Socializing with other families and relatives is a part of growing up; children become socialized through experience.
7. Doing chores, such as helping with meals and cleaning up, help children be contributing members of the family.
8. Children need to learn to share with others.
9. Children need to consider other people’s feelings.

Most couples with children have certain, sometimes unspoken, expectations about their children and how they want them to grow up. These expectations are largely based upon their own upbringing and the family life they experienced in their youth. Were there family dinners every night? Did the family attend church every Sunday? Did they take a yearly skiing trip as a family? Did the children learn to fish or hunt or play baseball from Dad? Did both parents work outside the home? Some of the expectations are so strongly rooted in our culture that they have become societal expectations of how a family operates, as well.

Parents of an autistic child often struggle with these “family norms” as they begin to realize that much of what was assumed to be normal within a family is not easily attainable. As a result, adults may experience some level of low-grade grief almost constantly. Suddenly, the dreams about having a “normal” family life shatter into thousands of pieces. Parents find themselves constantly questioning both their parenting skills and their assumptions of how daily life should unfold. Frequent worries of “Is this supposed to be happening like this?” or “This just can’t be the way it should go,” become almost pervasive thought patterns. Disputes arise about “right” and “wrong” family dynamics, further fueled by well-meaning, but often misplaced, comments by family members, friends, and acquaintances. Lack of control over this shift and change in family interaction patterns can be alarming, frustrating, confusing, and downright depressing.
On the bright side, however, these challenges provide opportunities to add dimension and surprise to our lives. Parents of special needs children can pave the way for redefining “normal” and create family structures that embrace the differences that accompany autism, thus creating a more tolerant society as a whole.

**Parenting**

“Why does Ben always get away with ________?” my daughter laments on a regular basis. It was often difficult to explain to her, a younger sibling, that she was, in fact, more mature than her elder brother at times. “Life isn’t fair” can be particularly true in a family facing autism/AS, with often challenging emotional repercussions among siblings. This was especially true for our family through the years before Ben’s diagnosis. My son simply did not learn the same way my daughter did. She often interpreted what I did as condoning Ben’s problematic behavior. Even today, there are times I know I must handle some situation in a completely non-conventional manner, perhaps in a way she can’t understand.

For parents to join together and provide a consistent parenting style is challenging, even with typical kids. Throw in the challenges of a special needs child, and family life can easily deteriorate into what often feels like a guessing game. Friction between parents commonly occurs, sometimes with devastating consequences. We didn’t receive the AS diagnosis for Ben until he was 12; by then my husband and I were divorced. We had no idea why he was the way he was and had no one to blame but each other, perhaps. I grieved over not only the loss of my partner and our marriage, but the expectations I had carried with me, for years, of how we would raise our kids and what constituted being a “good” parent.

**Family Trips**

“I will only go if we can spend at least three nights in one place,” was the qualifier Ben gave me about family trips. In later years it became, “I will only go if they have high speed Internet.” Over the years, his conditions resulted in his staying home at times instead of going on a short trip with us. Although this decision often resulted in all of us feeling happier and more relaxed, I still felt I was being robbed of quality family time. But as we parents have come to learn, if an experience is meaningless to the AS child, then nobody wins.

Most often the trips we did take together were visiting my parents either in Baltimore or at their camp in Maine. While Ben’s quirkiness was tolerated, the vacation was far from being relaxing and enjoyable. Everyone was affected by Ben’s needs for particular foods, cooked a certain way. Keeping him occupied with appropriate activities was even more of a strain. The entire family felt the tension of Ben’s presence as he was driven to analyze the safety of my mother’s electrical outlets, cords, appliances, etc. Anything electric mesmerized Ben. Why couldn’t he just play in the sand at the beach like the other kids? Why couldn’t he just go outside and play? Any sense of “togetherness” was fractured by this child, who unpredictably found ways to irritate everyone. As the mother, I absorbed the brunt of his behaviors, trying to anticipate and head off any impending disasters and misunderstandings between Ben and his grandparents. I felt like an interpreter on 24-hour duty. Although we may have been physically together, it rarely felt like the “togetherness” I had envisioned for our family.

The solution that worked for us is that either I go alone to visit my family or both my daughter and I go together. When I do travel with Ben, the trip is usually focused on something that interests him or will benefit him. On these trips he does very well. Overall, we simply don’t travel much anymore, preferring to stay at home as a family.
What Social Life?

If you ask my daughter how having a brother with Asperger’s most affects her, she will talk about how awkward it is socially. For four years they attended the same school. For three of those years, we still did not have a diagnosis for him. In sixth grade, he was finally diagnosed with Asperger Syndrome. Despite extensive disclosure about Ben’s situation and in-service for the staff and students, friction among Ben and his classmates continued. Ben’s behavior was disruptive, odd, and scorned by most of the kids in the school. Many of the kids asked my daughter if she really even liked her brother. Put into uncomfortable situations like this left my daughter resenting Ben. (She would probably use much stronger words here.) Inviting friends over was stressful for her and just provided further opportunities for others to ask her more questions about her brother’s strangeness. She is very embarrassed by his behavior and feels it has affected her social status at school. This year they will both be in the high school. She is still uncomfortable with his public behavior. Hopefully the school will be big enough for them to feel separate from one another.

When Ben was young, we had a wide circle of other families we gathered with at times. Ben’s actions were fairly well accepted by them most of the time. However, he was rarely invited over to play with friends. His impulsive actions were often viewed as intentional on his part. I had no way of justifying his behaviors (Ben had not yet been diagnosed), but I sensed that his behavior was not ill-willed. I suspected that he was responding to some unspoken fear or over-stimulation. Our family coped by having Erin go to friends’ houses frequently. We also did not entertain other families at our house. The family stress level was lowered with fewer outer distractions.

Now that both kids are teenagers they lead very separate but adequate social lives. It is still awkward for my daughter to have friends over, but more often than not, Ben is at a job site or with a friend.

Food and Eating Issues

A child with autism is likely to have a limited number of foods he will eat. Sensory issues seem to be the main culprit. Textures and tastes rule the child’s ability to tolerate certain foods, often making mealtime a real test of wills. Couple that with the socialization issues that are a hallmark of autism, and assumptions about dinnertime being a chance for quality family time together can fly out the window.

Many years ago I stopped cooking just one meal for dinner. By the time he was three or four, Ben’s tolerance for a variety of foods was severely affected by a diet he was put on for multiple food allergies. Whatever he ate, he became allergic to. As we watched our son become rail-thin on the doctor’s diet, we as parents decided to let him enjoy the foods he loved most again and deal with the consequences. Every night he wanted pasta. As a family we could not tolerate such a mono-diet, so I started preparing two meals for dinner every night. Pasta still remains a staple of Ben’s diet today, at age sixteen.

Several years ago I let go of Expectation #2 – dinner is eaten as a family. At our house, the family dinner was NOT working. Ben’s inability to carry on pleasant conversation created tension; foods were too hot, too cold, or too close to one another. His younger sister’s stories about her day were met with his sarcasm and belittling. Ben had no friends, no stories to tell of his own. He wanted to be in front of a screen (TV or computer), not sharing the day’s events. My daughter resented his interruptions, which led to fighting, stress, and, often, tears. I decided that my expectations had to change. In order to maintain strong relationships with each of my
children (and my sanity) I no longer insisted that we all eat together. My daughter and I now eat together, most often the same foods. For the most part, Ben eats on his own at his computer – his link to the world and his source of relaxation. Meals are less contentious; my daughter gets a chance to share her day with me without disdainful looks and comments from her brother. Surprisingly, Ben usually joins us once or twice a week on his own accord. My quality time with Ben happens mostly in the car or in his room. These settings are more relaxing and, therefore, he is more apt to talk to me.

It’s Who They Are That Matters

Getting a diagnosis helps everyone in the family. Getting professional counseling to sort out differences in parenting styles, expectations and to deal with the need to “blame” someone is also critical. Often, once a diagnosis is made, relatives with similar quirks or behaviors may become more evident. Sometimes just identifying these individuals creates a sense of acceptance of autism/AS and re-establishes some degree of normalcy for a family. As the opening quote suggests, when we plan a child, we get a child. The mystery lies in who they are, not what they are. It is who they are that helps weave the tapestry for their family.

In the end, love is what binds families together. Living with a child with autism/AS may create some extremely challenging moments. It tests our ability to be flexible in our thoughts, our actions, and our dreams. It demands that we reevaluate core beliefs and develop new ones, if we are to survive happily. Our unconditional love for one another is what pulls us through the hardest times.

In closing, I would like to share an experience my daughter had at the close of music camp this year. Attending was a boy who she was sure had Asperger’s. On the final day they talked about the struggles he had been experiencing in school, particularly in middle school. The isolation and social ostracizing he described reminded her so strongly of her own brother’s struggles that she was moved to tears. Despite the years of frustration and anger that my daughter had felt towards her brother’s autism, it had planted in her the seeds of compassion and they had grown so that she was deeply affected by this boy’s story. Her life will be forever enriched by the compassionate spirit that has blossomed within her. Perhaps our family has not been that bad after all.

Recommended reading: And Don’t Bring Jeremy by Marilyn Levinson

Anne Patterson lives on the coast of Maine with Ben (16) and Erin (14). She is self-employed as a tutor, massage practitioner, and a writer. She is currently a graduate student working toward an M.S. in Education. Ben is self-employed as a computer specialist. The high school hires him in the summer to work on their 200+ computers. Erin is a freshman in high school. She is very active in music (trumpet) and theater. In the summer she works as a deckhand on a ferryboat.

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Sensory Processing and the Sensory Budget
By Alex Michaels

How do we know anything at all about the world? Our sensory system is responsible for accurately taking in information so our brain can interpret this information and then do something with it. For everyone, this process happens instantaneously and continuously throughout the day. (“I see red, I see round, I hear bouncing, I smell plastic…it’s a ball.”) In essence, our sensory system is the first line of information interpretation. In order to interpret information correctly, we must perceive it accurately.

But what if your sensory system short-circuited somewhere in the process--what would happen to this information? Imagine if a minuscule piece of information, such as color, texture, or smell, was incorrectly interpreted. For example:

Until I was about 27 years old, I hated wearing pants. The texture irritated me. Jeans felt like razors on my legs, and pants felt slimy. It was as if something was grabbing me all day long. On top of wearing these pants, I was supposed to be concentrating in school and acting nice to people--what were they thinking?! The sensation of pants or jeans would highjack my sensory system, and I would become progressively disregulated, ultimately leading to a meltdown. When I was a child, as a coping skill, I started wearing tights that were too small under my pants. This provided me with deep pressure and a barricade between my legs and my pants, allowing me to last longer during the day.

Another example:

As a child I would only eat meat and plain tan/white food (bread, crackers, potatoes, etc.) Prior to eating my meat I would need to wash it to minimize the flavor. When meat is washed it all tastes the same, so there was no element of anxiety-provoking surprise!

Now multiply the above experiences by dozens of events each day—and then multiply again by each one of your senses: touch, taste, smell, sight, sound, movement, and position in space. What happens to your world now? When you’re about to sit in a chair, how do you know when to shift your weight from your legs to your buttocks so you don’t fall? How do you know not to touch a hot stove? How do you know if you’re hungry? When driving through a small tunnel, how do you know not to be anxious because your car won’t smash into the bottom of the arch?

Your sensory system is constantly providing you with feedback to help you make good decisions throughout the day—but if you are a person with Asperger Syndrome, you may be unusually sensitive—or relatively insensitive—to various stimuli. This may lead you to over-react or under-react, and will probably lead to discomfort, confusion, and anxiety. If you perceive a “neutral” stimulus (walking down a school hallway) as threatening (heightened noises, overwhelming smells, disorganization, etc.), your body will interpret the sensory information as dangerous/threatening, and anxiety-provoking. With this type of faulty sensory system, it is virtually inconceivable that people with sensory disregulation can master the environment and navigate their days calmly.
In the book, *Sensory Integration: Theory and Practice* (by Anita C. Bundy, Shelly J. Lane, Anne G. Fisher, and Elizabeth A. Murray) the authors quote this definition by A. Jean Ayres, the pioneer of sensory integration:

“[Sensory integration is] the neurological process that organizes sensation from one’s own body and from the environment and makes it possible to use the body effectively within the environment. The spatial and temporal aspects of inputs from different sensory modalities are interpreted, associated, and unified. Sensory integration is information processing...the brain must select, enhance, inhibit, compare, and associate the sensory information in a flexible, constantly changing pattern; in other words, the brain must integrate it.” (p. 11)

Sensory processing can be broken down into two categories:

- **Internal**: processing what’s going on inside your body, such as temperature, respiration, arousal, circadian “sleep” rhythms, pressure and pain.
- **External**: processing information from outside your body, such as smells, tastes, feeling things (texture, temperature), sounds, and the appearance of objects.

Internal processing is much more disturbing and disorienting than external processing. Inside myself I feel a change, but have extreme difficulty accurately interpreting what the change is. For example, when I was younger and felt hungry, thirsty, hot, cold, tired, excited, angry, bored, frustrated, anxious, or needed to go to the bathroom, all my internal sensations registered as the same signal. I knew something had changed, but I didn’t know what the “something” was—all I knew was that it felt like I was trapped inside a burning building. I didn’t know what I needed to do to fix the problem. By the time I figured out what my body was trying to tell me, it was often too late. By then, a tidal wave of sensation had begun: I was exhausted, starving, really needed to pee; a small emotion had escalated into anger or frustration; anxiety was now intense and pervasive.

For most people with AS, sensory issues lessen in intensity over time—but they do not vanish. As an adult, I still have to work hard at reading my own internal signals and regulating myself. It has been relatively easy for me to develop coping skills to help me process or escape from external stimuli. For example, when I hear a painful siren, I can immediately cover my ears. When I am flooded with internal stimuli, however, I can’t escape; I just have to ride out the wave and pray it doesn’t drag me under! Years ago, I realized I had to developed a system to prevent both internal and external sensory overload. I did develop a system that works: it’s called a sensory budget.

**Sensory Budget**

If you keep filling a water balloon, it will eventually burst—and it’s the same for your sensory system! To manage my own sensory environment and modulate my own sensory system, I created a budget. I outlined all activities that I engaged in and assigned a numerical value to each one. Some activities eat only a few points. For example: eating a non-offensive food like bread equaled one point. Social interactions equaled from four to twenty-six points, depending upon the topic of conversation, the familiarity of the people, and the location where the interaction occurs.
Each day I start with a budget of 100 sensory points, and I know I must live within my budget in order to remain stable and not melt down. Every activity, from getting out of bed in the morning to attending a concert in the evening “eats” sensory points—and this is true even if an activity is pleasurable or fun. Surprises or unexpected events tend to eat away at my budget, because anxiety, unpredictability, and needing to be flexible are high point-eaters!

Once I’m getting close to using 100 points, I need to end my day by going to sleep or retreating—unless I can find a way to neutralize some of my points. Just as exercise neutralizes caloric intake, certain activities can replenish or neutralize sensory points by evoking the “relaxation response.” I call these neutralizing activities “sensory preventions.” The only way I have found to keep myself regulated and stable is to prophylactically (preventively) partake of sensory preventions multiple times each and every day.

**Sensory Preventions**

If you are raising or working with a child with Asperger Syndrome, it is vital to apply these preventions prior to the child’s becoming overstimulated (using up too many points) and disregulated. Once the child is disregulated, the anxiety response is ignited. Then it takes significantly more interventions for the child to return to a neutral state—not to mention that it’s kind of cruel and inhumane to the child. The added anxiety stemming from disregulation itself can further disregulate the person, leading to a negative, self-perpetuating cycle: “I get overstimulated which leads to anxiety which leads to further disregulation which leads to further anxiety, etc.”

Preventions or interventions are most useful if the child can take them along wherever s/he goes. Since one never knows when or where sensory overload may occur, relying on specialized equipment to facilitate the relaxation response can sometimes be counterproductive. As a child, when I would get upset I used our swing set to calm down. However, when I became upset during the wintertime or in the middle of math class, the swing was not an effective intervention! Therefore, having “pocket interventions” is helpful.

**Sensory Activities**

When seeking appropriate sensory activities, it is important to think in terms of each sense individually, and whether the person needs to increase input (to stimulate) or to decrease input (to calm). Following are a few examples of regulating activities that may help certain children:

<table>
<thead>
<tr>
<th>SENSE</th>
<th>WAYS TO INCREASE STIMULI</th>
<th>WAYS TO DECREASE STIMULI</th>
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</thead>
<tbody>
<tr>
<td>Sight</td>
<td>Video games, anything symmetrical (i.e. patterns in nature), hang items from the ceiling (mobiles, etc.), paint walls bright colors or white.</td>
<td>Baseball hat, blurring vision, remove all hanging things from the walls and ceiling of the classroom, clear blackboard of extraneous stimuli, turn off fluorescent lights, paint room soft soothing colors (no patterned wall paper).</td>
</tr>
<tr>
<td>Taste</td>
<td>Spicy or salty foods, foods with smooth or rough textures, hard candy or gum</td>
<td>Bland food with calming texture</td>
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<tr>
<td>Touch</td>
<td>Chin-up bar, wall push-ups, rubbing textures on skin, small pocket toys, weighted vest, play tickle games, or lotion/cream.</td>
<td>Ask before touching the person; weighted vest or blanket, long or short sleeves; don’t make the child wear socks</td>
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I hope this article will help adults with AS create your own sensory budgets, identify your own sensory preventions, and use them as tools for living more comfortably and successfully. Parents, teachers, and therapists can work with children to create sensory budgets, and identify preventions. It will also be helpful to use the chart above to adapt the basic home and school environment—and plan the child’s schedule—to meet the child’s sensory integration needs.

**SENSE** | **WAYS TO INCREASE STIMULI** | **WAYS TO DECREASE STIMULI**
---|---|---
Hearing | MP3 player (music), headphones in the classroom, or FM System (wireless sound transmission) | Ear plugs or noise cancellation headphones; tennis balls on the bottom of chairs so they don’t scratch across the floor; shut doors and windows in classroom; rugs or carpeting.
Smell | Wear perfume, eat strong smelling food, or wear shaving cream | Wash clothes in chemical- and fragrance-free detergent; let clothes go without washing as long as they are not really dirty; open windows when using cleaning products or use fragrance-free products
Motion | Treadmill, walking up/down stairs, basically, anything that involves moving | Staying still; closed dark places (i.e., sensory break room)

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Adults with AS Speak about Their Lives

John H.
I’m like a house without a door. Anybody can just walk in.

Elizabeth
Finding a place where I can be me and not be judged.

John H.
I don’t get any information from faces.

Mark
No drum I could relate to—lonely.

AS is like tunnel vision.

I journey towards the light, meet briar patches along the way.

John H.
Hard to change direction—like moving a big rock.

Mark
I fine-tune myself to other people—if I can.

Nomi
When I say, “No,” I mean, “Wait, I need to think about it.”

Mark
AS is like having a million dollars but you can’t use it.

Roving random blind spots, not seeing the obvious.

Nomi
AS is not a side thing—it changes the whole thing.

Thomas
Doctors do “Dry Cleaners therapy.” They don’t understand sensory overload, how I can be suicidal after two hours of television.

We’re not broken—it’s our culture that’s broken.

Mark
Used to just see stone walls, dead ends. Now I look the other way and see flowers, wisdom, hope.
Nomi
Always a big effort to connect.

What is smart when things don’t work?

Bekan
Sense of being behind glass watching.

Looking at your green garden and the rubble at my feet.

Coming from another country—don’t speak the language or know the customs.

Mark
The world is an uncertain, dangerous place.

It’s as if I’m invisible.

It’s as if I’m on an alien spaceship.

My AS mind keeps learning.

Loneliness is so strong that any port in the storm will do. To extricate self is to go back to loneliness.

Nomi
I’m lonely but not for people.

I don’t want other people to organize me.

John R.
What a horrible thing it would be if you really could read other people’s minds.

How to preserve intellectual honesty vs. social rites.

Mark
I am a walking cauldron of rage.
It’s Not a Secret: Why Disclosure is Important

By Lynne Mitchell, MSW

In the general culture of the United States the hidden meaning of the word secret is shame, something bad that shouldn’t be discussed. When someone wants to keep “good” information private, it is more likely to be called a surprise. Asperger Syndrome is not, and never should be something shameful or embarrassing in and of itself. If someone behaves in an embarrassing way, it is totally different than labeling his or her whole way of experiencing the world as bad. As the parents of children with Asperger Syndrome, we must ensure that the message the children get is that they are not shameful or embarrassing for just being who they are. Then, as adults with Asperger Syndrome, they will be more likely to be able to embrace their traits of AS as simply a part of who they are and not as something to be kept “secret”.

There is a difference between not keeping something a secret and hiring the Goodyear blimp to make a huge, ongoing announcement to all who will listen. I am advocating that as the parents of children with AS we see ourselves as having a number of obligations:

● to understand how our child experiences the world
● to share our understanding with our child
● to find ways to comfortably share information about our child with the other key people in our child’s life
● to help our child learn how to share information about him/herself as desired and as needed

In many ways these obligations are no different than the obligations all parents have to their children who do not have AS. The main difference for many parents of children with AS is that they do not happen to have AS themselves, and so the experiences of their child with AS are more foreign to them. As parents, we love our children. It is our job to work harder to “get it” about AS, and then share the understanding with him/her and with others. While s/he is a child, parents choose who needs to have a greater understanding of what makes him/her tick. As s/he grows we hope that s/he is able to comfortably make those decisions because of what s/he has learned by watching his/her parents share their understanding and pride in him/her with others.

Disclosure is not one thing at all times and in all situations. In fact, it is more likely that disclosure, as it relates to AS, will be different in each individual instance. The point of disclosure is almost always to give someone a more accurate and complete understanding of who the individual with AS is, what his/her strengths are and what s/he may need as modifications to compensate for areas of weakness. This is also the rationale for the most important disclosure of all, the times the parents sit down and talk to the child him/herself. There will not be a time for “The Talk.” Rather, there will be a million instances as the child develops when the parents will have the opportunity to discuss what AS is and how it relates to the child. (There will probably be a first time, however.)

For many parents this is a very daunting task. They are frequently afraid of what the child’s reaction will be. They worry about having “all of the answers.” They worry about being too emotional or too unemotional or too exact or too general… I have good news! This is not a one-time conversation. Each parent will have plenty of times to “get it right.” Disclosure is a process of growth and greater understanding of who we are as individuals. No one learns that kind of information in one conversation or from reading one book. It takes place over a lifetime for all of us, including those of us with AS.

There is no single answer to the question: “At what age do I tell my child he has Asper-
ger’s?” The most important criterion is that the parents are comfortable with saying the words Asperger Syndrome. The parents should feel comfortable with their level of knowledge about AS. In addition, they need to be clear in their ideas of how AS is a positive aspect of who their child is, as well as an understanding of how AS is challenging for their particular child. For most of our children talking about specifics is more understandable; thus “You know how you memorize all of the words to Disney movies without trying? Well, Asperger Syndrome helps with that talent” works better than “Children with AS have strong rote memorization skills.” Similarly, “You know how it is really hard for you to learn to ride a bike? Well, Asperger Syndrome makes it harder for you to learn that skill than other kids, so I give you a lot of credit for not giving up (or I can see why you are so frustrated that you want to give up).” (As opposed to “Asperger Syndrome is usually associated with delays in fine and gross motor skill development.”)

Another common question parents ask is “Do I have to use the words ‘Asperger Syndrome?’” The answer is, you don’t have to do anything. However, I have found that most children feel a sense of relief knowing that there is a real term for their profile of strengths and weaknesses. That they belong to a group. That they are not alone. That there is a body of knowledge about how to compensate for areas of difficulty. That this is not laziness, or stubbornness, or a character flaw of some type. We all, as human beings, have a sense of relief in knowing that we are not alone. By not using the term Asperger Syndrome, you deny your child that sense of belonging to a bigger picture.

Finally, a common question is, “My child is an adolescent and we recently got the diagnosis. How can I tell a teen?” Well, there are no two ways about it; it is trickier to tell a teen anything, particularly something that has to do with his/her sense of identity. Although teens are more likely to initially deny or become actually upset with the label, over time all of the rationale for using the label with younger children applies to teens and adults as well. Although teens often have a gut reaction that having AS means that something is “wrong”, there is also a sense of relief that the child is not imagining things. For years the teen had no way of understanding why the lights in class hurt his eyes so much, and yet no one else even noticed. If s/he did speak up s/he was seen as a complainer or a liar or a troublemaker. Thus the others around him did not validate his/her reality and s/he began to isolate himself from others, or became angry with others in anticipation of not being understood.

One way to tackle the issue of disclosure to the child with AS is to use children’s or young adult novels that have a central character with AS. (See list below.) The plot may involve three magical wishes or an alien landing in suburbia, but the experiences of the central character are colored by his/her AS and thus give the reader a gentle, matter-of-fact way to begin to explain what AS is and how it affects someone day to day. As the child listens to you read the book, you can gently, matter-of-factly, point out similarities and differences between your child and the child with AS in the story. Your child may not agree, and may or may not extend the conversation. However, the conversation has begun. Something called AS exists. Other kids have the diagnosis. It is just a part of life. It is NOT a secret.

These novels, or one of the growing number of biographies of people with AS, are also a great way to introduce the concept of AS to siblings or classmates. The discussion of “the character has AS and so does our classmate” does not need to be heavy handed. Kids will see the similarities. A discussion may or may not begin spontaneously. The point that you’re trying to make is that AS is a fact of life and a way of being. Knowing the term provides a way of understanding some individuals better.
Another way to pursue disclosure for children with AS is to appeal to their tendency to enjoy non-fiction and fact-based learning. Books that explain concepts such as social communication, theory of mind, and great rote memory may be helpful. Once the concepts are described in a general way, parents can help their child apply these ideas more specifically to themselves. No two people are the same. This includes any two people who have AS. Characteristics will also change as the child matures and develops. When you first talk to your child the conversation may focus on awkward motor skills and an amazing amount of knowledge about Pokémon. A few years later the conversation may focus on an incredible understanding of mathematical concepts and difficulties in organizing homework, a bedroom, and a desk at school. Later still, the conversation may focus on the feat of being on the honor roll in high school combined with incredible anxiety about poorly handled job interviews.

What is AS and how does it affect me? That is the question. The answers are amazingly positive and hopeful as well as unsettling and regrettable. The important message here is that it is essential that your child be told about all aspects of who s/he is so that s/he can ask her/himself this question. It is the only way for your child to truly understand who s/he is, accept her/himself and advocate for her/himself in the world.

Be brave. Be creative. Know your child. Be comfortable with your own knowledge of AS. Draw on your excitement about your child’s strengths, and the hope offered by a better understanding of your child’s differences.

The following suggested reading list is meant to be a guide to some of the books that can be used to introduce the concept of AS and begin the discussion of your child’s diagnosis.

**Suggested Readings**

- **Disclosure and Asperger Syndrome: Our Own Stories**, edited by The Asperger’s Association of New England
- **The Curious Incident of the Dog in the Night-Time**, by Mark Haddon
- **Asperger’s and Self-esteem: Insight and Hope Through Famous Role Models**, by Norm Ledgin
- **Asperger Syndrome, Adolescence, and Identity: Looking Beyond the Label**, by Harvey Molloy and Latika Vasil
- **Pretending to be Normal**, by Liane Holliday Willey
- **Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome**, by Stephen Shore
- **Asperger’s...What Does It Mean To Me?** by Catherine Faherty
- **Asperger Syndrome, the Universe and Everything**, by Kenneth Hall
- **Blue Bottle Mystery**, et al. by Kathy Hopemann
- **Buster and the Amazing Daisy: Adventures with Asperger Syndrome**, by Nancy Ogaz

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Oh I love the word eccentric
and how it rolls off the tongue
so much better than
neurologically challenged.
There’s a much longer name for it,
a diagnosis if you will,
found in books
he will no doubt read someday
if only to find amusement
in typographical errors.
He loves to draw timelines
and anatomical sketches,
and to know the detailed life stories
of his everyday heroes
Leonardo DaVinci and Charles Darwin.
Sometimes he draws maps
of Pangaea and the world today as well.
He sings songs to his dinosaurs in the bath
explaining to them with great scientific accuracy
how they became extinct.
He is seven years old
and keeps me on my toes
challenging me
to think within his box.
“The most difficult thing about having Asperger Syndrome is that so many people expect you to know these rules and live by them as they do, even though no one has told you what these rules are.”
Some Useful Educational Interventions for Students with Asperger Syndrome

By Dania Jekel, MSW

Based on what we hear from families, the majority of children with Asperger Syndrome can succeed in school provided they receive sufficient, appropriate support. However, it is important that not only the teachers, aides, and specialists working directly with the child, but also everyone in the school and special education hierarchies be willing to take on the challenge of learning about a whole new kind of student—one for whom familiar educational techniques may not work at all. This requires a certain humility—and a lot of time and hard work.

Once the challenge is accepted, the whole team must work closely together to create an environment where the student can succeed. The team must also be proactive rather than reactive. That is, everyone must work together in advance to develop an educational plan that will prevent crises from occurring—and then dependably carry out the plan in all its details. They must also be willing to learn from direct experience what does and does not work with this particular student, and refine the original plan accordingly. They must find ways to capitalize on the student's strengths and to offset his/her weaker areas.

Below is a list of some interventions that have proven effective. You may want to think about getting some of these measures written into your child's Individualized Education Plan (IEP).

Basic Requirements:
1. Training about AS, including appropriate educational supports, interventions, and modifications, for all educators involved with the student
2. Effective and regular communication between school and home, and among all educators working with the student
3. Parents must be regarded and treated as an integral part of the educational team

Continuum of Options for Placement:
1. Inclusion in regular classroom with appropriate supports and modifications
2. Integrated classroom setting where there are five or six children with special needs within a regular classroom setting
3. Smaller, separate classroom for bright children with social or non-verbal learning needs (Inappropriate placements include classrooms for students with behavior problems or cognitive disabilities.)
4. Placement into another school in the home community, a multi-district collaborative, or another community
5. Out of district placement into a private 766 day school
6. Out of district placement into a private 766 residential school

Note: Some families have found homeschooling a viable option.

Who May Deliver the Needed Support, Modifications, and Interventions within a School Setting:
1. Regular classroom teacher with additional training in AS, or special educator
2. Dedicated aide, teaching assistant, or paraprofessional (i.e. devoted just to this student); training desirable
3. Classroom aide for two or more children
4. Occupational Therapy to address sensory issues
5. Tutor or educational specialist to address special academic needs related to subject content or learning skills
6. Speech therapist for pragmatic speech, social skills, and communication intervention
7. Inclusion facilitator or adjustment counselor for social and emotional issues

School Interventions that Can Be Put in an IEP (Individualized Education Plan)

To help with Social Skills
1. Social skills groups (e.g. 3 times a week for 20 minutes)
2. Social stories (Carol Grey—see bibliography)
3. Comic strip conversations
4. Scripts
5. Lunch Buddies or other friendship group
6. One-on-one speech therapy (pragmatic social language)
7. Drama class/activities
8. Structured social opportunities during recess
9. Structured activity during lunch (e.g. help in library or office)
10. Social “autopsies”
11. School-wide or system-wide training in prevention of bullying and teasing
12. Disclosure: teaching classmates about AS (elementary school)
13. On-going teaching of unwritten school rules
14. Buddy of the week (peer mentors)
15. Social communication coaching during classroom time

To Help with Academics
1. Modification of length or focus of some assignments
2. Tutoring
3. Help taking notes (aide/peer recorder, computer, teacher-provided, etc.)
4. Priming (previewing work)
5. Structured and regular communication between parents and teachers about assignments, expectations, skills, progress, and problems
6. Projects and papers related to student’s area of intense interest
7. Assistance in gym class
8. Present subject matter using visual aids
9. Present work and homework broken down into small steps

To Help with Lowering Anxiety:
1. Transition preparation
2. Home base for beginning and end of school day
3. Proactive intervention if child shows signs of stress
4. Sensory breaks
5. Flexible teachers who can tolerate different ways of doing things
6. Classroom with routine
7. Advance warning of changes in schedule
8. Priming (preview of lesson content)
9. Preparation for new things, places, students or teachers
10. Training teacher in AS
11. Assistance or alternative activity during less structured school time such as recess, lunch, gym, music, or art
12. Modification, assistance, or preparation for projects done in groups
13. Environmental manipulation of classroom to prevent sudden loud sounds, movement, distraction, lights
14. Preferential seating away from distractions

**To Help with Executive Functions (organizational issues):**
1. Classroom aide can help student attend to the essential task, prioritize tasks, break assignments down into steps, understand teacher expectations, record homework, remember essential papers, etc.
2. Graphic organizers can help students grasp concepts
3. Provide two sets of text books, one in classrooms and one at home
4. Communicate homework to parents
5. Post assignments on a Web page
6. Homework buddy
7. Provide a map of the school
8. Post the student’s schedule in a few places (e.g. notebook, desk, fridge)

To better understand some of these recommendations, you might wish to consult the following books:

The Asperger’s Diagnosis within the School Setting

By Samuel J. Moncata, Psy.D.

Overview

Since becoming an official diagnostic category in 1994 (American Psychiatric Association’s Diagnostic and Statistical Manual, Fourth Edition), more and more children and adolescents are receiving an Asperger Syndrome (AS) diagnosis. This is particularly true in larger metropolitan areas where medical schools, teaching hospitals, and child development training programs abound.

However, while the diagnosis is being made with more frequency, there is still much confusion about diagnostic criterion and etiology (causes). Is AS distinct from the autistic spectrum, or does it exist in the higher, milder end of the continuum? Is it a synonym for Higher-Functioning Autism (HFA), or is it more closely related to Nonverbal Learning Disability (NLD)? These are the current questions being examined in the high-functioning, pervasive developmental, social disability literature.

While the answers to these seminal questions are undoubtedly important regarding diagnosis and treatment, a pragmatic challenge remains. Amidst the controversy and debate, an ever-growing number of families, school systems, teachers, and clinicians are encountering this diagnosis with individuals that they love, fund, teach, and treat, respectively. With minimal agreement surrounding the AS diagnosis, how can one effectively address this disorder within a variety of settings?

Due to space and time constraints, this current article will focus upon the AS diagnosis within the school setting. Attention will be given to both common and uncommon responses that this writer has observed school systems offer when dealing with the complicated cognitive, affective, social, and academic “fingerprint” that marks the learner with AS. The diagnostic testing process, and school-based interventions will also be highlighted. Particular emphasis will be given to academic and learning style approaches. This avenue of promise for the AS student lags significantly behind the behavioral management and social communication strategies that are most often the bedrock of the AS student’s Individualized Education Plan (IEP).

Background

Asperger Syndrome (AS) is a pervasive developmental disorder (PDD) initially described by Hans Asperger in 1944. His articulation of the syndrome, similar to Leo Kanner’s earlier description of autism, featured deficits with social communication and odd patterns of interest. However, there were key differences. Most notable, language acquisition was not delayed, the onset of social problems came later, and motor difficulties were more commonplace in those individuals diagnosed with AS. Further, the majority of AS children tended to have IQ’s in the average range and above. While Asperger first reported the condition only with boys, instances of females with the disorder have become more frequent in the literature, but are still less common. While Kanner’s work with autism became well-known within the English medical literature, Asperger’s theorizing remained obscure for many decades. Only in the last twenty years has the syndrome appeared in English text, and only in the last decade has it gained a foothold within the diagnostic literature.

From the recent Asperger literature, a clinical profile has emerged. Salient features of AS include the following:
1. An inability to take alternate perspectives and points of view leading to both lowered levels of empathy and a diminished capacity to attribute mental states, particularly emotionality to others (theory of mind);

2. A poor nonverbal skill set, with a diminished ability to recognize and respond to subtle social cueing;

3. A lack of appropriate reciprocal exchange within social interactions, leading to a paucity of friendships and social isolation;

4. A flat and often idiosyncratic style of speech;

5. An intense fascination and eccentric attraction to over-learned, rote topics such as baseball statistics, subway systems, road maps, television shows, movie dialogue, the weather, etc., with minimal depth of understanding;

6. A poor sense of the body-self, often accompanied by problems with physical coordination and posture;

7. A lack of appreciation for simile, metaphor, irony, and subtle forms of humor; and

8. A propensity for disruptive behavior as a response to unstructured social settings or novel contexts that demand quick thinking, social savvy, and/or resiliency.

Within any population there is variability and difference. Not all AS children manifest all of the behaviors described above. However, more often than not there is overlap and commonalities do exist. Like any of us, each AS child possesses his or her own unique cognitive-affective “fingerprint”. Any intervention or treatment strategy is predicated upon elucidating that unique profile. Only a thorough assessment of a child’s relative strengths and weaknesses across a variety of domains can confirm an AS diagnosis. Further, AS as a diagnostic label is often a necessary prerequisite to garner the level of services needed by these children within school settings. Let us now turn to the diagnostic testing process as a means towards acquiring those services.

**Diagnostic Testing for Asperger Syndrome**

In order to get services for a suspected AS child, a team effort is often required. Because the syndrome is still relatively obscure and often misunderstood, even by those that claim to be experts, the coordinated efforts of parents, teachers, school officials, clinicians, and in some instances, advocates, are often needed to get school systems to provide the appropriate services. In the vast majority of cases, a CORE evaluative process that results in a tailored IEP under Massachusetts 766 law is a necessary first step. While school systems generally do a fine job with the academic, intellectual, and speech and language components of the testing that can contribute to an AS diagnosis, the neuropsychological, personality, and vocational arenas are domains that are often less familiar to the typical school psychologist. Hence, parents may want to exercise their rights to procure out of system second opinion testing. While this legal option may soon change, further testing within those more specialized areas is crucial to the overall diagnostic process.
In summary, neuropsychological testing with its emphasis upon cognition, intelligence, brain-behavior relationships, and learning style differences is an important component of the CORE evaluation. Likewise, social and interpersonal assessments, including pragmatics, speech and language, and communication issues are warranted. Personality testing should include measures of self and self in relation to others. Theory of mind tasks, the capacity for empathy and alternative points of view, the attribution of mental and emotional states, and the ruling out of psychotic process are critical for differential diagnosis. Academic measures, including grade-level achievement testing across core curricula, and vocational testing and adaptive functioning tasks should also be part of the assessment battery. Finally, observations in a variety of school settings, data gathering with teachers, parent interviewing and home visits round out the optimal CORE evaluative process for the suspected AS child.

**The AS Child within the School Setting**

Presently, area public school systems are becoming more and more aware of the compromises associated with AS. As more of their students are receiving the diagnosis, many teachers are beginning to educate themselves accordingly. It is not uncommon to see representatives from our local schools at workshops and conferences on AS. This occurrence was unheard of even several years ago. These enlightened educators are not only learning what their AS students cannot do, but more importantly, they are learning what they can accomplish with support and strategic interventions. However, more teachers need to avail themselves, particularly those educators in the higher grades. Furthermore, public school systems need to more fully support the continuing education of their employees. Regarding private schools, it has been this writer’s observation that aside from the handful of area independent specialty schools that work with pervasive developmental disorders, more traditional independent school settings lag significantly behind their public school counterparts in their working knowledge of AS.

Public school systems are beginning to recognize students with AS as higher-functioning individuals who nonetheless present with pervasive developmental social learning disabilities. These schools are beginning to address social disabilities as a curriculum need for their AS students. Yet, despite these gains, the majority of the planning and the primary focus of intervention associated with the AS student still appears to be behavior management and response prevention strategies. Unfortunately, too often AS students are still segregated in behavioral classrooms with more socially sophisticated, conducted-disordered peers. These more savvy cohorts are poor role-models and often take advantage of the socially inept AS student. Further, the disruptive behaviors of the AS student are still frequently mislabeled as willful and manipulative, rather than more accurately seen as a response to unstructured, novel, or complex social or academic situations.

A secondary focus of the AS student’s educational plan is an emphasis upon social communication and strategic skill-building, particularly as it relates to peer and teacher interactions. Since all learning is embedded within relationships, it makes sense to increase social awareness and to model more appropriate reciprocal exchanges. In fact, this social synchrony component is expanding quickly within the educational plan of the AS student. It will soon overtake behavioral management and response prevention as the primary focus of intervention.

Lastly, continuing to receive little attention in the AS student’s educational plan are actual academic strategies and learning style accommodations that reflect the unique cognitive “fingerprint” that characterizes the syndrome. Over the last several years, a body of research has emerged that distances AS from Higher Functioning Autism (HFA) and ties it more closely
to a cluster of neuropsychological strengths and weaknesses often labeled Nonverbal Learning Disability (NLD). These recent findings relating AS to NLD bode well with regard to the introduction of fitted learning style strategies for the AS student. Much has been written in the educational literature on approaches to NLD management. It appears that these academic strategies can be borrowed to more effectively meet the learning needs of students presenting with the AS diagnosis.

Academic Strategies and Learning Style Accommodations for the AS Student

During the last decade, parallel fields of literature have existed that documented purportedly separate syndromes, each involving neuropsychological, academic, and social-emotional correlates. As mentioned, the melding of the AS and NLD databases yield a comprehensive cadre of classroom strategies and accommodations for the AS student. These interventions are predicated upon several core assumptions regarding the underlying cognitive “fingerprint” of both the AS and NLD student.

The primary assumption suggests that these students possess significant right-hemisphere weakness. This deficit makes it difficult for these students to learn from their visual environments. They tend to give poor attention to visual detail, and often misconstrue that which they do attend to. This relative difficulty identifying and understanding various types of visual information not only impacts academic performance, but dramatically affects social skill-building and peer relations. The visual nuances of social exchange, and the subtleties of facial expressions and body language, place these children and adolescents at risk for establishing insufficient social connections. A weaker right-hemisphere can also create difficulties with nonverbal problem-solving, plan of attack, and organization.

A secondary assumption suggests that these students excel with more automatic cognitive processes. They are strong rote verbal learners who find little problem with reading and spelling. Further, they can utilize language to guide their hands-on performances. Also, their short-term memory skills are often robust, garnering them success with various memorization tasks. However, while they can decode text and read with fluency, these learners struggle with aspects of the reading process that underscore sequencing, organization, cause and effect, and higher-level reasoning. These struggles with the subtle nuance of written language can often result in overly concrete and literal interpretations of what they read.

Regarding intervention, a high degree of structure, consistency, and continuity within any learning setting is mandated. Whether at home, in school, or in the therapy office, clear expectations, the establishment of routine and ritual, and unfailing support are key components towards successful strategy-building. AS students can learn strategies that utilize their many strengths to compensate for their relatively weaker areas. While this article does not permit a detailed accounting of all that is possible regarding intervention, a general outline is feasible. For example:

1. Break tasks down into manageable pieces, with clear, concise, step-by-step directions. Clarify language concepts to avoid rigid, vague or confused interpretations, particularly with language that describes space, time, proximity, and other right-hemisphere constructs.

2. Emphasize verbal feedback strategies, particularly with tasks that are more hands-on and nonverbal by nature. Repeating directions, learning to talk oneself through a problem (subvocalization), and self-questioning and monitoring are examples of strategies that can facilitate nonverbal problem-solving.
3. Utilize templates and models to guide learning. However, these aids need to be simple and clear. Stay away from visually-overwhelming schemes. They will derail rather than organize learning.

4. Increase these students’ capacity for written output. Encourage the early acquisition of key-boarding skills and teach them how to effectively outline material. Encourage them to initially dictate material so as not to lose any seminal ideas due to the arduous task of writing.

5. Improve social communication. Provide direct instruction in social skill-building (individual and group formats). Pragmatic training with proximity, vocal tone, body language, and the reading of facial expressions is warranted. While social competence can be fostered through role-play, it has to be simultaneously addressed through curriculum design. For example, “social stories” and other materials that teach social cognition and awareness are often helpful. Provide these students with opportunities to interact with younger children in supervised settings. These corrective experiences will encourage leadership and engender a sense of responsibility.

6. Increase the competence, esteem, and sense of personal effectiveness for these students. This can be accomplished through the consistent application of the aforementioned interventions, enabling more victories from day to day. These students may also benefit from an ongoing therapeutic relationship that supports them in their ongoing neuropsychological, academic, and social-emotional challenges.

7. Finally, these students have difficulty both anticipating and understanding the consequences of their actions, particularly as it relates to others. Consequently, they are often punished without a clear understanding of “why”. As a matter of practice, avoid punitive responses and instead focus upon positive, corrective experiences that tailor constructive feedback to the individual student.

For more information regarding AS and related topic areas, the reader is referred to several sources. The first source is the PDD web site at the Yale Child Study Center (http://info.med.yale.edu/chldstdy), and the second source is the Learning Disabilities Association of America (LDA). The LDA has a “Guidelines for Parents” series pamphlet that addresses AS and related disorders. They can be reached Mondays through Fridays from 8:30 a.m. to 4:30 p.m. With national headquarters in Pittsburgh, Pennsylvania, their phone number is (412) 341-1515. Good luck.

Dr. Samuel J. Moncata is a licensed psychologist and Health Service Provider in the State of Massachusetts. He is on the Attending Staff of McLean Hospital, and is a faculty member at both Harvard Medical School and the Massachusetts School of Professional Psychology. He is also the Director of The Center for LifeSpan Development in Waban, Massachusetts. At the Center, Dr. Moncata specializes in the assessment and treatment of children, adolescents, and adults with suspected developmental disorders.
Familiarity = Safety: Transition for the AS Student

By Dot Lucci, M.Ed., C.A.G.S.

Transition planning generally begins in the spring in most school systems. There are many steps that make this process run smoothly and help inform people so that everyone is on the same page. In an ideal situation much of this process can happen in a timely fashion and with careful input and planning by all players.

The basic tenet is that you want the receiving team to know the child as well as possible before s/he transitions into his/her new class and/or new school. The child needs to feel as relaxed as possible and as safe as possible and the parents also need to feel comfortable and knowledgeable about the new staff and/or building. If the individual with AS, the parents and the receiving team feel comfortable, then the new school year will begin more smoothly.

The more complicated the transition, the earlier the process and planning should start. If a child is approaching what I call a major transition (preschool to elementary school, K to 1 (in most elementary schools), elementary to junior high, junior high to high school, or from school to school at any grade) then the process should start in January or February. Typical transitions are defined as transitions within the same building with most “players” remaining stable and most classroom experiences being similar. The process for typical transitions can start later in the school year. However, both typical and more challenging transitions involve similar types of tasks.

Both kinds of transition rely on the current team having a good working knowledge of the student and parents. From this knowledge a “working document” is written that describes the student’s needs regarding his/her learning style and guidelines for teacher style. I have found that there are a few main ingredients that are necessary for teachers to possess for successful inclusion of students with AS. They are: humor—the ability to laugh at one’s self and others in a respectful way; an ability to work with an “entourage of other professionals,” flexibility, good communication skills, good team-building skills, sharing one’s classroom with another adult, and to be a proponent of inclusion, and have a liking for “quirky kids”. These attributes usually increase the likelihood of successful inclusion experience.

When the transition is within the same building, usually the special education team knows the receiving teams very well and can match learning and teaching style to the child’s advantage. They can also match environmental structures to the child’s need if necessary. Matching the child’s learning style with the teacher’s teaching style is also to the team’s advantage. Matching kids with teaching styles makes for minimal problems as the upcoming year unfolds. Rarely do teams sabotage themselves by mis-placing students!

If there is a major transition, then the sending team needs to be as honest, direct and clear in the “working document” as possible so the receiving team has a clear picture of who the child is and who his/her parents are. This allows them to plan more realistically for his/her move.

If the transition is major, then meetings and observations need to start early. Multiple observations should take place. The student should be observed by the receiving team, in classes that go well and classes that are difficult for him/her. Observations of therapies by therapists are also important so the receiving therapists can see specific interventions being utilized and how sessions are structured. (Familiarity brings safety for kids with AS.) The sending team should also observe classes at the receiving school so they are familiar with what’s next, how things are done, what will work, what s/he will have trouble with etc.
Parents should also meet with the principal and special education team at the receiving school. They should also write a letter introducing their child to the staff. This letter in my experience has taken many forms; one parent wrote it as an analogy to a waiter balancing a tray of glasses. However, it usually is a more directed letter that conveys the child’s strengths, areas of need, likes/dislikes, motivators, and the parents’ desires for the upcoming year. What is included is basically whatever the parent wants the school to know about his/her child.

Placing the student with one or two (or more) familiar peers who are “friends” is important. These students should be kind and accepting and be willing to help the student with AS in the new environment; as well as shed some insight into who s/he is to the new teacher(s). For instance a student with AS may engage in a behavior that is “unacceptable” and the new teacher may not understand it. A student who has been with him before can provide the language if the student with AS is getting agitated. For example, “Tom likes to keep his hat on during class because the lights bother his eyes.” If it is a major transition having “friends” in his class(es) is even more critical.

During the summer it is important for the student with AS to connect with one or two classmates. This can be arranged formally (a structured event/setting) or informally (a play date or family get-together).

During the spring two books are written for the student to assist with the transition. These books should be durable (laminated, heavy paper/cardstock etc.). One is called a Transition Book and the other is called a Goodbye (___grade) Hello (___grade) Book. Both are written by an adult at the sending school with input from the receiving school.

The Transition Book’s purpose is to familiarize the student with the things that are the same and different about the environment and structure. Photographs, a map, and a sample schedule may be some of the things included. Highlights might involve, for example, tables to desks, bathrooms in the room to bathrooms in the hall with multiple stalls, cubbies to lockers, five-day rotation to a seven-day rotation, one core teacher to four core teachers etc. The Transition Book is most important for major transitions.

The purpose of The Goodbye/Hello Book is to identify the more personal aspects of a transition. It includes such things as the student’s progress in concrete terms (i.e. At the beginning of the third grade when you were frustrated you use to hide in your locker. Now at the end of third grade you use your words. You say, “I need a break” or “Leave me alone.” When you are in fourth grade you can still use your words.), what s/he learned about, what s/he will continue to learn about, what will be new, who helped him/her this year and who will help him/her next year, etc.

What’s important about these books is that they help foster a sense of safety between the old and new. If it is not a major transition then the Goodbye/Hello Book and the Transition Book can be combined into one book because the changes aren’t as dramatic. These books should not be given to the student too early as they may increase anxiety. Usually they are read to or the student reads them during the last week or two of school. Then they are given to him/her on the last day, sent home and read again at the end of the summer.

If it is a major transition that involves a new building (elementary to junior high), then it is beneficial if, during the summer, the student has access to the building. Possibly the student could have some portion of his/her summer program take place there. This affords the student an opportunity to familiarize him/herself with the layout of the building, how to use the lockers, get used to the bell system, etc.

Most schools have “Step Up Days” for students going to a new school. This usually in-
volves traveling to the new building with one’s class, going on a tour and familiarizing oneself with the new environment and people. Sometimes an assembly is held by the principal. The student with AS can go on this trip but s/he will need his/her own individual or small group tour as it gets closer to the end of the school year. This tour takes place with a “trusted adult” from the sending school and once at the receiving school they are introduced to “key players.” They experience the change of classes, bell system, observe the hallways and sit in on a class. During this visit, or at a more convenient time, photographs of places and people may be taken to be used in the Transition Book or Goodbye/Hello Book.

The student should know who his teacher will be before s/he leaves school for the summer (at the pre-K-elementary level) as well as who will be in his/her class. If known in June, then the student should meet his/her assistant as well and see his/her new classroom. However, usually assistants aren’t hired until the end of the summer. If the assistant can be identified prior to the start of the school year, then an overlap/training period should take place between the current assistant and the new one. For the upper grades, the student should know which team/cluster s/he will be placed with and meet these teachers prior to the end of the school year. S/he should revisit classroom(s) and teacher(s) prior to the start of school (August) when other students aren’t there. This visit should occur once the desks are set up; so s/he can see where his/her seat will be and how the room is set up. Some elementary teachers schedule a date for all students and parents to visit prior to the start of school; if this is the case then s/he should attend this date as well.

Older students may want to write/dictate/type a letter to their new teacher that focuses on what they want their new teacher(s) to know about them. This takes whatever form the student wants (CD, video, written work, art etc).

A box of tools, visuals, social stories etc. that were used with the student should move with him/her to the next grade/school (even if they are no longer in use but were once helpful). This box is a history of where the student once was and what tools helped him/her progress to where s/he is now. If after the observations and meetings, new areas of need are identified that will need supports (i.e. changing and showering for physical education classes), then as many of these supports should be created prior to the start of the new school year as possible. They may include any number of things (rule boards, visual schedules, calendars, social stories etc.) Identify areas of potential difficulty and modify if necessary. Also create structures (i.e. homework folders, home/school communication systems, etc.) prior to the start of the school year or during the first month or so.

Students with AS need a “safe person” and a “safe place” when they are overwhelmed. During a major transition it is critical that especially the “safe place” is identified prior to or at the very beginning of the start of the new school year. The child may need two spaces, one that is in the room and one outside the room (elementary level). At the upper grades usually the safe place is outside the classroom spaces. This allows it to be built in proactively into behavioral plans. The safe person may be identified as well but s/he may unfold as the year progresses. The person who was identified may not be the person the child has chosen, so be flexible. As much as possible should remain consistent from one year to the next regarding expectations, etc. Utilize “tried and true” methods/approaches (behavior, social, emotional etc.) from one year to the next, if still appropriate, and then adjust as the year progresses.

Another useful tool is a “Helpful Hints Sheet”. This handout is passed out at the beginning of the school year to all staff that has contact with the student including regular ed., specialists, special ed., recess and lunch monitors, etc. (with parent permission). This is a two-page
document that typically includes the following: 1) a description of what AS is and what it is not (i.e. the aberrant behaviors are not malicious, intentional etc.), 2) a description of the student’s strengths and interests, 3) a description of how the disability affects the child (i.e. attention, sensory issues, organization, etc.) and 4) includes key areas that are impacted and how they are addressed (transitions, unexpected change, fire drills etc.). After giving people a chance to read it (about two weeks), the team chairperson or a primary service provider goes back to each person to check in (i.e. Do you have any questions? Has the information impacted your teaching style, classroom structure, expectations? Can I/team help you in any way? Etc.)

Usually, staff training by someone with knowledge of AS should be provided during the summer or at the start of the school year and ongoing to help facilitate the success of the student and the team working with the student.

Make sure the student’s sensory diet/needs are identified in terms of what interventions are calming and which ones are alerting. If the new building does not have an sensory integration space, then begin early to identify how the student’s needs will be met and what will be done to address the problem of space. Prior sensory diets should also be written up and passed on to the receiving team.

Students with AS usually require a lot of planning and modifications. It is important to build into the new IEP consultation time among team members (at least 30-45 minutes a week).

The following sheet, Planning for the Future, was created by Judy Gooen, O.T. (Occupational Therapist). It also helps in the transition planning process:

Think back to September; what information do you wish you had been given about your student?

What strategies do you think have been successful?

1. in the classroom
2. during lunch
3. socially
4. during PE
5. during music
6. during art
7. with transitions
8. with organization

What helps your student to calm down?
What is likely to set your student off?

As you can see there is much to be done to assist the student with AS with his/her transition. Hopefully, these guidelines will help you in your planning.

Dorothy Lucci is a national consultant to schools and families of children with Autism Spectrum Disorders. She has served as a research associate/project manager at BU Medical Center, Director of the Autism Support Center, a general and special education teacher and a school psychologist. Currently she is Director of Consultation at MGH/YouthCare and an adjunct faculty member at Framingham State College and Lesley University. She is a Board Member of AANE and the author of numerous articles in the field of autism.
Social Skills and Behavior in Children with Asperger Syndrome: An Educational Perspective

By Hannah Gould, M.Ed.

Children who experience social success are those who are able to accurately assess a situation, recognize what is expected and appropriate, and act in a way that “goes with the flow” of what is going on. Some children seem to be able to do this almost magically. As social dynamics shift subtly from one situation to the next, these children adjust and thrive. For these children, social skills are learned quite naturally through experience and observation. For children with Asperger Syndrome this kind of social “learning by osmosis” does not effectively occur. Children with AS tend to miss much of the information conveyed by non-verbal social cues (body language, tone of voice, etc.) They may simply not attend to this information and often misinterpret the cues that they do notice. This leads to frustratingly awkward social interactions and ineffective behavioral responses.

Effective strategies to teach social skills and address behavior are as varied and diverse as the unique individuals who make up the AS population. The intention of this article is to provide a frame of reference through which to view and respond to the challenges our children face. Several areas of difference in the typical learning profiles of children with AS make learning social skills difficult:

- **Visual spatial processing:** Children with AS tend to rely on language as their primary source of information. They are less tuned in to visual information and less able to process it effectively. They do not naturally “watch and learn.”
- **Holistic processing:** Children with AS tend to notice details, but miss the big picture. It can be difficult for them to get an accurate read on the situation they are involved in. Holistic processing also involves making connections, applying past experience, generalizing information from one situation to another, and making inferences. Deficits in any of these areas make it difficult for effective social learning to occur in a “natural” way. Children with AS have an especially hard time inferring the intentions of other people. This can lead to inappropriately harsh or defensive reactions, and can also leave these children vulnerable to being manipulated by more savvy peers.
- **Abstract reasoning and problem solving:** When a situation becomes problematic, children with AS often have no idea what to do. They may have trouble recognizing what their options are and making a choice. This results in getting “stuck”—locking into an ineffective behavior or becoming frustrated and melting down.
- **Slow processing speed:** Despite their generally strong language skills, children with AS can be overwhelmed by the rapid flow of information in a social situation.
- **Emotional vulnerability:** Because it is difficult for children with AS to generalize what they have learned from one situation to the next, the world can seem chaotic and overwhelming. Efforts to reach out and connect with peers can be awkward, unsuccessful, and even painful. Children with AS often have difficulty recognizing their own emotional states, and lack effective coping skills to help them deal with overwhelming emotions.

The patterns of behavior that result from these learning differences are familiar to anyone who knows a child with AS.

- S/he misses social cues and misreads a situation.
- S/he reacts to the situation inappropriately.
• The result of his/her behavior is something s/he did not anticipate, leading to anxiety and perhaps another inappropriate reaction.
• The higher her/his anxiety level becomes, the more rigid and emotional s/he is likely to get. S/he has gotten into a difficult situation and now is “stuck”.

Strategies and Interventions
The good news is that children with AS are very capable of learning and developing their social skills. They can make effective progress with appropriate interventions that capitalize on their many strengths. These skills will not be learned by observation as they often are with “typical” peers, so they need to be directly taught. Children with AS often have excellent verbal skills. Their strong language skills, auditory attention, and rote memory for rules and strategies can help them to access social information.

Direct verbal instruction: Skills will need to be taught directly and intentionally, just as academic curriculum is presented. Practical rules and strategies should be presented to the child in a clear, verbally explicit, logically sequenced manner. Once taught, strategies should be reviewed and practiced in a variety of settings. Parents can find ways to reinforce these skills at home using the many challenges and learning opportunities that daily life presents. Flexible teachers and specialists can take advantage of the time that may be freed up by rapid rote learning. For example, while other students are drilling and practicing spelling words, the student with AS might be studying idioms or reading and responding to social stories.

Specific skills and strategies should be taught based on the most immediate needs of the individual child. Some areas of focus might include:
• Social cues, including body language, social distance, eye contact, and tone of voice.
• Speech pragmatics, including introductions, conversational skills, tone of voice.
• Non-literal language, including slang, idioms and expressions.
• Problem solving skills, including how to identify a problematic situation and apply specific learned strategies; how to use prior knowledge to make inferences; how to predict the outcome of different possible actions.
• Emotional coping skills, including learning to identify feelings of anxiety and frustration, manage stress, and apply effective strategies to respond to their emotions.
• Functional life skills, including taking care of oneself and one’s space, eating at restaurants, going shopping, etc. All of these life skills can be broken down and taught as systems of logically sequenced steps and rules. Remember to teach back-up plans for when things don’t go as expected!

Effective Consequences
While the behavior of children with AS can seem odd at best and downright unmanageable at worst, it is important to keep the perspective that inappropriate behavior is not likely to be intentionally disruptive or defiant. In fact, children with AS rely heavily on rules and clear expectations in order to feel safe. These children frequently misinterpret situations, resulting in out-of-sync and ineffective behavior. They may become easily overwhelmed or feel threatened by unfamiliar social situations or seemingly chaotic surroundings. Structure and predictability is their safety net, and unexpected glitches in their routines can send them into a tailspin.

Inappropriate behaviors offer important opportunities to help children reframe their understanding and to teach alternative responses. Once the child’s emotional state is defused enough to hear it, the situation and behavior should be processed with an adult in a calm and
direct way. A more appropriate response should be presented verbally, and the child should be
given the opportunity to practice this response in a safe setting (such as role-playing with a par-
et or counselor or with peers in a social skills group). Punishment without this type of proc-
essing is likely to add to the child’s feelings of anxiety and confusion. Punishment involving
taking away preferred activities such as computer time or reading is not likely to be effective
and can deprive the child of a much needed outlet for stress.

Consequences should be as consistent and predictable as possible. Set clear limits and
give warnings to let the child know exactly what the consequence will be if the behavior contin-
ues—and follow through! This takes away some of the feelings of unfairness, and also helps
the child develop an understanding of cause and effect. Natural consequences should be
pointed out whenever possible (e.g. “When you yell at John, he does not want to give you a
turn.”). Communication between home and school is crucial to address behaviors with
consistency. Knowing that adults at home and at school are on the same page will also help to
alleviate the child’s anxiety.

Conclusion

There are many services available to help children with AS develop their skills and be-
come more successful. Social skill groups, pragmatic speech and language therapy, occupa-
tional therapy, and special education services may all play a role in meeting the needs of your
child. Whatever approach is taken, be clear and consistent in your expectations. Patience,
flexibility, and creativity combined with a realistic perspective on the needs of your child will
pay off. Parenting or teaching a child with AS is hard work—but remember that our children
are working hard too!

Hannah Gould works as an activity group therapist at Academy MetroWest in Natick,
MA. The Academy provides weekly social skills groups in a gym-based setting for chil-
dren ages 6-14, including many with AS. Ms. Gould is also a certified teacher of stu-
dents with special needs. She provides educational consultation and private tutoring
services.
Buddy-of-the-Week Program

By Anne Reel

In order to facilitate friendship and understanding in my son’s first-grade classroom, we started a Buddy-of-the-Week program. My son is now entering the fourth grade in a middle elementary school. He has high-functioning autism. The program has helped him make friends and helped his classmates understand how to be his friend. The best thing about the program is that the Buddy skills have carried over outside the classroom and school. As one non-classmate noted to his mother after a birthday party my son attended, “Everybody is nice to him.”

Where to Begin

The first step of the Buddy program is to meet with the immediate team prior to the start of school to explain the goals of the program. The three key players in the program are the teacher, the aide, and the school adjustment counselor. Our three main goals for the program are:

1. To help children feel comfortable with the child.
2. To teach children how to interact with the child.
3. To instill pride in the other children that they can make a difference to the child.

On the first day of school the teacher briefly explains what the Buddy-of-the-Week program is and posts a sign-up sheet with the responsibilities listed. The teacher tells the class that sometimes the child needs a helper and that the program is totally voluntary. S/he can ask previous classmates to tell the class how they helped the child and ask who of these children would like to be the first Buddy. Usually these children are honored and eager to show the new classmates what to do, and they may all want to be the first Buddy. In that case, a name is drawn out of a hat. The sign-up sheet looks like this:

Buddy-of-the-Week Sign-Up Sheet

Responsibilities
1. Say hello to the child at the beginning of school.
2. Help the child in line.
3. Eat snack and lunch with the child.
4. Play one game at snack and lunch/recess with him/her.
5. Give the child a compliment each day.

<table>
<thead>
<tr>
<th>Week</th>
<th>Name</th>
<th>Substitute</th>
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<tbody>
<tr>
<td>Sept. 4-6</td>
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<tr>
<td>Sept. 9-13</td>
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<td>Sept. 16-20</td>
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<tr>
<td>Sept. 23-27</td>
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</tbody>
</table>

We added on a substitute list this year because if a Buddy was absent, the other children flocked around the aide eager to take his/her place. The substitute list takes the pressure off the aide.
The aide explains the details of the Buddy responsibilities for the Buddy and models them for him/her. For example, my son does not always respond to a greeting or request if he is engaged in an activity. The aide models how to greet him in a way that assures his attention:
  a. Say child’s name and gently tap him/her once on the shoulder.
  b. Wait (count 5 seconds) for the child to look at you.
  c. If s/he doesn’t look, try again.
  d. Then talk to the child.
A complete list of responsibilities is detailed at the end. This list changes each year depending on the interests and abilities of the child.

If there is enough time, the teacher can pass out an information sheet for the children to fill out. This sheet looks like this:

-------------------------------------------------------------------------------------------------------------------
Name: ___________________________________ Age: __________________
Address: ______________________________________________________________________________________________________
Favorite Game: ___________________________ Favorite Food: __________________
Favorite Video Games: _____________________ Favorite Sport: __________________
Pets: __________________________________________________ Sisters or Brothers: __________________
-------------------------------------------------------------------------------------------------------------------

The aide takes a picture of each child and attaches it to the info sheet. The child has a sheet filled out as well. The aide and the child make the sheets into a Buddy Book and keep it in the classroom. At the beginning of each week the aide, the child and the Buddy go over the Buddy’s and child’s info sheets, adding or changing information as the year progresses. If possible, I arrange to have the Buddy over to play during his/her week. This hasn’t always been possible with everyone’s busy schedules, but it helps to reinforce friendship. I sometimes have the Buddy and one of his/her class friends over to make sure I have as many children over from the class as possible. The play date only lasts about an hour or so and I plan a craft or baking activity according to the interest of the Buddy. I ask the Buddy’s parent about likes and dislikes before the play date.

This Buddy Book is helpful in finding common interests for the child and other children in the classroom. For instance, it gives ideas for topics of conversation, games to play and activities such as drawing, sharing books or writing stories.

Open House

Another way to make things go smoothly is to talk about the Buddy program to the parents at open house night. I explain to the parents a little bit about my son and tell how autism affects him. I also invite people’s questions or comments during the year if they have any. Since many of the parents volunteer in the classroom, this information helps them feel more comfortable interacting with my son. I also tell them I would like to have their children over to play sometime.
Class Meetings
During the first few weeks of school the adjustment counselor visits the classroom once a week to address friendship skills. S/he arranges to come in at a time the child will be out of the classroom for a special activity (i.e., PT, OT, Speech, a special library visit). At times I have picked up my son early in order to facilitate the class meeting. The adjustment counselor talks about making friends, activities and interests, strengths and weaknesses, similarities and differences, etc. S/he then turns the topic to the child, pointing out some of the things discussed as it relates to him/her. It is good to have the aide present, if possible, so s/he can help explain some of the child’s actions, idiosyncrasies and special interests. If all three members of the team are new to the child, the parent should be present at the meeting to give accurate information about the child. It might also be better to have that specific information meeting a month into the school year as everyone gets to know the child.

At the specific meeting, the team invites the children to talk openly about things they’ve observed about the child. For instance, sometimes my son will speak out of turn or jump up to get something or make a silly remark. Talking about these things helps the children feel comfortable with them. The adjustment counselor, teacher, and aide assure the children that they understand why the child does certain things and that the whole class can help teach the child what to do in different situations. They emphasize being positive with the child and praising him/her when the child does a good job. As the school year progresses the adjustment counselor visits less frequently or on an as-needed basis.

Each year the Buddy-of-the-Week program changes to fit the age, interests, and abilities of the child, the style of the teacher and aide and the rest of the children in the classroom. As more and more children participate in this program they model friendship skills to people inside and outside the classroom. My son benefits immensely from this program. He acquires the modeled friendship skills and becomes increasingly involved in a supportive school and community.

Buddy-of-the-Week Responsibilities

1. Greet the child every morning by saying, “Hi, ______. I’m your buddy this week.” To get the child’s attention:
   a. Say the child’s name and gently tap him/her once on the shoulder.
   b. Wait (count 5 seconds) for him/her to look at you.
   c. If the child doesn’t look, try again.
   d. Then talk to him/her.
2. If there is time before school, you may tell the child a joke, read or play a game with him/her.
3. Give the child at least one compliment a day. Wait for him/her to say thank you. Remember, get the child’s attention first.
4. During snack give the child two choices for recess. For example, say, “______, should we play on the swings or play tag at recess?” Some things the child likes to do at recess are:
   a. Outdoor Recess
      1. Swing.
      2. Play with the hula-hoop.
      4. Play catch.
      5. Play basketball.
   b. Indoor Recess
      1. Play with Play-Doh.
      2. Draw.
      3. Play Connect Four.
      4. Play checkers.

5. Eat lunch with _______.
   a. Before lunch, wash up at back sink.
   b. Go to lunch early with the child and the aide.
   c. Sit at the same table.
   d. At lunch, the child will ask you what you are having for lunch. Tell him/her and then ask the child what s/he is having for lunch.

6. On Friday, the Buddy goes to lunch and recess at the Adjustment Counselor’s with the child and the aide.

*Anne Reel is the parent of a child with AS.*
Homework Help for Your Student with AS  
By Phyllis Hirsch, M.Ed.

As a parent of a child with AS and a public school teacher, I know the challenges that students with AS face in getting the right educational support. One area that is sometimes overlooked is that of homework. Homework can be a frustrating experience for students with AS, as well as for parents and teachers. With a student with AS, there are a variety of steps that parents should consider taking to reduce the stress level around homework, while at the same time helping make it more educationally valuable.

Although many of the issues referred to below may be addressed in the IEP, we strongly recommend that the team create a separate document intended for use by classroom teachers on a day-to-day basis. The document should be no more than one page long, and should describe each of the following items:

- The student’s learning style.
- The student’s strengths and interests.
- The student’s challenges, and accommodations s/he needs.
- Signs of stress the student may exhibit (e.g. rocking, flapping, obsessive talking), and strategies that have worked in the past for defusing the situation and helping the student cope.

Meeting with Teachers

Try to meet with each classroom teacher as early as possible in the school year (ideally by the end of September). If your student has a classroom aide, find out if s/he can attend the meeting. It is also helpful if someone from the IEP team attends these meetings.

At the start of the meeting, present the short document to the classroom teacher. Briefly describe its purpose and contents. Next, the group needs to cover the following topics:

- How are homework assignments normally communicated (verbally, blackboard, paper copies, previously distributed course syllabus)? If the teacher’s standard approach is difficult for your student, are alternatives available? If your student has an aide, can s/he make sure the assignments are captured in a notebook?
- What are the teacher’s homework policies and expectations? Is homework assigned daily? Is there a time expectation? Some teachers will accept incomplete homework after a reasonable amount of time and effort has been expended. Does the teacher want to know what help, if any, the parent provided on a particular assignment? Does the teacher have times when s/he is available to help students with homework? Are there other school resources for this purpose?
- Identify the optimal place and time for doing the work. In some cases “homework” may be done more effectively in a study center, or with an aide in school, than at home.
- Identify accommodations the student may need. Possibilities include:
  - Extra time for assignments, or shorter assignments.
  - Alternative assignments, when the assignment is outside of the student’s capabilities.
  - An extra set of textbooks and/or reference material to be kept at home.
- What are the primary goals of homework in this class? Some possible goals are listed below. If all of them apply, ask how you as a parent can determine the primary focus for a particular assignment. This is important to know so that your efforts support class-
room learning, not just mask the student’s disability.

- Promote independent study habits.
- Practice or apply a taught skill.
- Learn research techniques.
- Preview/review content.

- Communications between teachers and parents. Try to establish a regular communications link, preferably weekly: email, written notes, home-school notebook, phone call.
- Request a study-buddy: a student in the same class whom your student may call to clarify assignments or get missing work.

Establishing a Study Routine

The need a student with AS has for order and predictability can work in his/her favor when it comes to forming effective study habits. Together, figure out the time and environment that are optimal for your student, then stick to them. Consider:

- Time of day.
- Length of study time between breaks, length of breaks and acceptable break activities.
- Study room and conditions: own bedroom vs. room near parent; silence vs. low music, etc.

You probably don’t want your student’s passionate interests to be present during study time, as it is hard for most AS students to switch focus back to the less interesting homework.

Get Organized!

- Provide a clutter-free work surface with tools available in labeled containers.
- Post a large daily calendar with space to write assignments for each subject and space to check off work when completed. Breaking down assignments into simple steps can help alleviate anxiety and confusion, and support a sense of progress.
- Provide IN (not done) and OUT (done) baskets.
- Follow the same steps every day, for instance:
  1. Place class notes and handouts in notebooks or folders appropriate to various subjects.
  2. Stack homework to be completed in the IN basket.
  3. Order assignments by priority (such as due date, difficulty level, or preference).
  4. Complete each assignment, transferring it to the OUT basket.
  5. Place completed assignments in a special folder in the notebook to be handed in.

Supporting Your Student

Every student is different. The kinds of help needed will depend on your student’s learning style, interests, experiences and tolerance. In general, students with AS may need help in:

- Understanding the teacher’s expectations for assignment length, level of detail or format.
- Generating, organizing, expanding or explaining ideas.
- Scribing, typing or editing work.
- Planning long-term assignments.
- Differentiating the most important information from the details.
- Understanding figurative language.
• Identifying what he/she doesn’t understand.
• Interpreting diagrams, charts, graphs, or cartoons.

Tips
• Use technology whenever possible. A computer can make writing and research fun as well as easier. Books on tape may be available for lengthy or difficult reading.
• Help your child incorporate his/her special interests into content or presentation. Choose a topic that makes use of your child’s interests and expertise. Showcase his/her artistic, literary or technical talents to present a project.
• If an oral report is required, rehearse non-verbal as well as verbal presentation cues.
• Be realistic; don’t expect high school-level work from an eight-year-old.
• Try to avoid melt-downs. When they occur, let up on the pressure.

Keep your perspective. A single homework assignment will not make or break your child’s education. Maintain your role as your child’s strongest ally. Know when to back off. Remember whose homework it is! Allow your child as much independence as s/he can handle. You may be pleasantly surprised!

Phyllis Hirsch has taught in Massachusetts public schools for over twenty-five years. She has a background in Special Education and has worked with children of all ages. Her son, who was diagnosed with Asperger Syndrome at the age of seven, is now pursuing a degree in Computer Science at Wentworth Institute of Technology in Boston.
Children with Autism Spectrum Disorder (ASD):  
Your Rights to Special Education Services

From Massachusetts Advocates for Children (MAC)  
Autism Special Education Legal Support Center

What is the school district’s obligation to meet the unique needs of your child with ASD?

- School districts must provide special education programs and services that meet all of your child’s educational needs, including academic, social, communication, sensory, behavioral, vocational, daily living skills, organizational.
- School districts must consider the full range of special education services necessary to meet your child’s unique needs resulting from ASD including, if appropriate, intensive services such as ABA, floor time, pragmatics, sensory integration, literacy instruction, etc. The district must provide an individualized program based on your child’s IEP, and cannot operate from a “one size fits all” approach.
- An IEP Team can only consider your child’s unique needs in deciding which services to provide. Make sure the IEP Team considers the full range of services for children with ASD, not just the services that are readily available or currently provided to other students.
- Your child is entitled to the special education services necessary to learn the material covered by MCAS and the general curriculum.
- School districts must design IEPs to develop your child’s individual educational potential.
- Your child should participate with non-disabled children as much as possible. If appropriate for your child, the school district must consider services and accommodations to support placement in regular education all or part of the day.
- It is illegal for school districts to reduce or deny services for your child solely because of costs or because of the change in the special education legal standard (FAPE).
- When determining eligibility for special education, the school district must determine whether your child is unable to make effective progress in regular education because of ASD. The school must consider your child’s social/emotional development as well as academic development when determining eligibility, and must consider the child’s individual potential as well as chronological age and curriculum expectations.

Remember: You are an expert about your child’s needs, which is why parents are legally required participants in decision-making! Talk to parents of children with ASD and work with the school to create a program that is appropriate for your child, and reflects his or her full potential and competency.

For help call the 
MAC AUTISM HOTLINE (617) 357-8431 x233

Massachusetts Advocates for Children (MAC), 100 Boylston Street, Boston, MA 02116  
www.massadvocates.org
What can you do to ensure that your child with ASD receives necessary services?

- Make sure the school district provides a comprehensive evaluation and re-evaluation, with required assessments in all areas related to your child’s autism.
- When you provide consent for the initial or re-evaluation, carefully review the list of different types of assessments and ask whether the evaluators have experience and expertise in ASD. You can request additional assessments in areas other than those proposed by the school district.
- If you disagree with the school district’s evaluation, you can request an independent evaluation.
- Contact your local autism support center and other parents for referrals to make sure that the independent evaluator you select has experience with children with ASD and the kind of service options you are exploring for your child.
- Make sure that the IEP (present levels of performance, goals, and objectives sections) reflects your child’s strengths and potential as well as your child’s needs in all areas.
- These portions of the IEP are important, as appropriate levels and measurable goals reflect the need for intensive, coordinated services required by many children with ASD. The school district must write the number of goals and objectives necessary to meet all of your child’s needs that result from ASD.
- If your child’s behavior impedes learning, make sure the IEP reflects positive behavioral supports and other strategies and services to address his or her behavioral needs.
- Many children with ASD require positive and pro-active behavioral services, as required by federal law. School districts should not wait until a child’s behavior becomes disruptive before providing support.
- Ensure that your child’s IEP includes objectives and services necessary to make effective progress in the general curriculum and meet MCAS standards, and also includes services necessary to meet his or her social, communication, daily living skills, and behavioral needs that result from ASD.
- Your child is entitled to an education that can meet all of the educational needs that result from ASD. Although the emphasis on participation in the general curriculum serves to raise expectations and increase achievement, schools cannot ignore other important learning needs.
- Make sure the IEP determines whether your child needs either specific accommodations or an alternate assessment to participate in MCAS.
- All children with disabilities must participate in MCAS, but the IEP Team must decide whether accommodations or an alternate exam are necessary.
- If your child is not making expected progress in the general curriculum or toward annual IEP goals, insist that the IEP Team revise the IEP and consider additional or different special education services for your child.
- IEP progress reports, report cards, and MCAS scores are some of the measures of your child’s progress. Talk to other parents, contact your local autism support center, and talk with service providers to learn more about possible service options to meet your child’s needs. Consider whether an independent evaluation may be helpful for your child.
- Do not let the Team make decisions based on ideas that children with ASD have limited potential.
● Research shows that with appropriate services, children with ASD can thrive academically, socially, and increase communication skills.

● In cases where you cannot reach an agreement with the school regarding what is appropriate for your child, exercise your due process rights (mediation, advisory opinion, hearing, complaint) to resolve the issue.

● For more information call the MAC hotline, 617-357-8431 x233, your local autism support center, or other advocacy organizations.
Resources for 766 Issues

Note: If you live in Massachusetts, call the Federation for Children with Special Needs at (800) 331-0688, and ask them to please mail you a Parent’s Guide to Special Education.

This excellent book is free. It is a joint publication of the Department of Education (DOE) and the Federation for Children with Special Needs. The clear language and diagrams in the booklet make it much easier to understand the special education law (Chapter 766), and the steps you need to take to ensure that your child gets an appropriate IEP (Individualized Education Plan), to see that the plan is effectively carried out—or what you can do if you are dissatisfied with what your local department of education is providing for your child. This booklet may become unavailable temporarily while it is revised to reflect changes in the law, and then reprinted (we hope). Meanwhile, you may download the text (no cool graphics or diagrams) at: http://www.fcsn.org/parentguide/pgtext.txt. If AANE has copies on hand, we will enclose one with a paid member’s packet.

You may also want to consult the following resources, provided by the Massachusetts Advocates for Children (MAC) Autism Special Education Legal Support Center (617) 357-8431, x 233.

For More Information

Program Quality Assurance at DOE (Department of Education) (781) 338-3700
—To report school violations of laws protecting students or of IEPs not being implemented.

Bureau of Special Education Appeals (781) 338-6400
—When the Team cannot reach consensus about Eligibility, IEP Development, Placement, or Hearings surrounding IEPs.

Legal and Technical Resources

If you think your child’s rights are being violated, or you need basic rights information.

The Federation for Children with Special Needs 1-800-331-0688 or (617) 236-7210 (also TTY)

Worcester: (508) 798-0531
Belchertown: (413) 323-0681 or (866) 323-0681

Website: www.fcsn.org

The Disability Law Center (617) 723-8455
The Children’s Law Center (781) 581-1977
Boston College Legal Assistance Bureau (781) 893-4793
Also try your local legal services office
Be sure to take a look at this wonderful web site:
http://www.nclid.unco.edu/HVoriginals/Advocacy/Popup.popup.html

Although this page was written for children with other diagnoses, many sections of it could be very useful to you in preparing for a school meeting with your child's educational team. On the web page you can click on the text in each box to see good, well-supported responses to each excuse.

I.E.P. Pop-Up

Feeling disenfranchised? Tired of showing up at your child's IEP and leaving dazed, confused, and frustrated? Or feeling like every time you make a suggestion you hit a brick wall? Click on the boxes below to find responses you can use to common "hurdle talk"—words and attitudes that keep the IEP meeting from being successful—as you are advocating for your child's needs. Become empowered, learn the laws and understand your rights to advocate for a communication driven education for your child!

<table>
<thead>
<tr>
<th>1. &quot;Sorry...we don't have the money.&quot;</th>
<th>2. &quot;We're not convinced your child needs that.&quot;</th>
<th>3. &quot;I have 400 other children in this building.&quot;</th>
<th>4. &quot;We assess your child using only teacher observation.&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. &quot;The general education teacher couldn't be here today.&quot;</td>
<td>6. &quot;We're the professionals, we know what's best for your child.&quot;</td>
<td>7. &quot;Let us get back to you on how that might work.&quot;</td>
<td>8. &quot;I don't have the authority to make that decision.&quot;</td>
</tr>
<tr>
<td>9. &quot;Your child is doing great... compared to other deaf/hh kids.&quot;</td>
<td>10. &quot;If you don't teach your child to sign, he'll use it anyway when he grows up. You better do it now.&quot;</td>
<td>11. &quot;If you teach your child to sign, she will never learn to talk.&quot;</td>
<td>12. &quot;We took the liberty of filling out a 'draft' IEP... please sign here.&quot;</td>
</tr>
<tr>
<td>13. &quot;Your child will have to use signed exact English. We don't do ASL here.&quot;</td>
<td>14. &quot;Your child is two years delayed in language...we can't really expect more than that.&quot;</td>
<td>15. &quot;You must be in denial, your expectations are too high for your child.&quot;</td>
<td>16. &quot;We don't need to write that suggestion down in the IEP, we'll do the best we can to get that done.&quot;</td>
</tr>
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HOW TO GET READY FOR A MEETING

Before the Meeting

- **Prepare! Prepare! Prepare!**
  Know exactly what you want to get ahead of time. Find out what services this agency is supposed to offer and what the eligibility requirements are for services. If you are entitled to services, make that clear at the beginning of the meeting. Are there laws that state how and where services are to be provided? Get a copy of the law and READ IT. Most public servants are not familiar with the laws by which they must do business.

- **Talk to Other Parents Who Have Been Down This Road Before**
  They will understand what you are going through and give you the best advice. Look to see who is getting the best services for their family and find out how they got them. Join a support group.

- **Find Out if There is an Advocacy Agency for People Needing This Service**
  There may be someone out there with the knowledge and expertise to help you get what you need. Check the yellow pages or your local community center. Call your public library reference desk. They have heard it all, and may have the answer.

At the Meeting

- **Invite Others to Attend the Meeting With You**
  It is common for parents to feel overwhelmed and alone when confronted with a room full of professionals discussing their problem in a clinical manner. Invite other parents, friends, relatives for moral support. You can provide the same support for other parents at their meeting.

- **The Image You Portray May Affect How Personnel React Toward You**
  You should dress in a professional manner, with clothing that is simple but dignified. Walk into the room with confidence and introduce yourself. Bring your copies of the “Rules and Regulations” and other materials for reference. Remember, the personnel are paid to work FOR you.

- **Do Ask Questions**, especially when you really don’t understand what is being said. You have a right to clear explanations in layperson’s language.

- **Listen With an Open Mind**, taking special note of important points raised at the meeting. Use a tape recorder. If someone expresses resistance, explain that it is good business procedure to tape important meetings, such as this meeting. (However, remember that you must honor any request to stop taping.)

- **Pass Around a Sign-in Sheet at the Beginning of the Meeting**
  You will then have the names of all those present, and be able to address them by name (from their position on the sign-in sheet).

- **When Speaking During a Meeting**, take a deep breath to help project your voice clearly and confidently, and maintain eye contact with all in attendance at all times.

- **Speak Up Early**
  The longer you wait to talk, the more you may feel that what you say has to be profound or brilliant. You can’t concentrate on what is being said while you sit there trying to get up the nerve to speak. Once you have spoken, it is easier to speak again.
• **Be Visible**
A good part of being effective is achieved by becoming visible. Are you trying to take up as little space as possible? Spread out, relax your posture and make sure you aren’t allowing others to encroach on your table space in meetings; spread your papers and other items out, too.

• **Don’t Let All the Decision-Makers “Clump Together”**
Notice where the power sits and integrate the space. Nothing can make you feel like an accused murderer pleading with a judge faster than trying to talk across a wide expanse of mahogany. Move your chair right up next to theirs. You may feel safest schlumping down beside your oldest and dearest friend, but make yourself uncomfortable and sit down next to the powerful and influential instead.

• **No Lurking in the Back of the Room!**
Put yourself in the direct vision of the person you want or need to persuade, impress, or influence. Sit near the chairperson or convener of the meeting.

• **Stop Looking and Feeling Subordinate or Submissive**
You indicate your own lack of power by hanging on their every word. Similarly, remind yourself that those who dominate seldom really look at subordinates, so don’t become flustered when you receive minimal eye contact when you talk.

• **Who’s In Charge Here?**
If you get the creepy feeling that nobody is in charge, assert yourself. Do not sit politely by while the convener allows people to go off on tangents. It may be a ploy.

• **Resist the Pressure to Conform**
You don’t want to leave the meeting thinking, “Why didn’t I speak up and fight for what I wanted?” This is YOUR CHANCE, and may be your *only* chance.

• **Repeat What You Are Asking For As Often As Necessary**
Remember that you are not at the meeting to discuss the limitations of the budget. You are there to determine what your needs are and to get an appropriate response.

**If You Disagree**

• **If you cannot come to an agreement**, are running out of time, or need time to consider the situation, you have the right to request another meeting. Do not feel pressured to make a decision on the spot.
“Accepting your diagnosis may also allow you to forgive yourself for things you might be doing wrong and take away some of the pain, which can only be holding you back.”
Accommodations for a High School Student

By a Parent

My son is a fifteen-year-old boy who just started high school. In middle school, my son had excelled in academics (all A’s) with the IEP accommodations of a full-time aide, who acts as an executive secretary, and modification of homework. He is, however, challenged by the sensory overload at school and by homework. He also has impairments in gross motor coordination, so he chooses not to participate in sports. Outside of school, he prefers to stay at home and usually avoids social situations and crowds. He has only one friend that he sees regularly. He is a loner but enjoys computer technology and games, science fiction, history (particularly World War II), as well as some aspects of physics and outer space science. His three greatest assets are his broad knowledge base, his sense of integrity, and his awesome sense of humor!

Despite efforts by myself and the school system to plan ahead for my son’s transition to high school, ninth grade got off to such a rocky start that I was afraid he might refuse to attend school. We had an IEP meeting scheduled that I knew would provide an opportunity to advocate for my son’s needs and share my knowledge of him with school personnel. To prepare myself, I attended a meeting of AANE’s Parents of Teens Support Group. I was hoping I could get some ideas to improve my son’s situation. Dania (AANE’s Executive Director) and the parents at the meeting gave me a lot of great suggestions.

Going into the meeting, I had one other great asset: my town’s Director of Special Education, who had helped my son succeed in middle school, had promised me her full support. At the IEP annual meeting, she kept her word and supported every accommodation request. She was pivotal in asking the right questions, so that team members understood why the accommodations were necessary and fair in spite of the fact that this is unprecedented at this high school. This is what I requested, and what the school agreed to provide:

- **General Supports and Environmental Modifications**

  Overall goal: School will provide a structured, predictable environment with clearly defined goals, expectations, and consequences. To meet the goal:
  - Quarterly consultation by Asperger's expert.
  - Full-time Aide/Academic Support.
  - Teacher concerns/requests should be addressed with Academic Support, not with the student.
  - Daily communication journal with Aide/Academic Support and mother.
  - “Safe Zone” to retreat to and protocol to assist him in leaving class or another situation should stresses/sensory overload become too great.
  - School will provide a structured, predictable environment with clearly defined goals, expectations and consequences.
  - No unscheduled delays in dismissal from school; if student needs to stay at school late for a club meeting or other event that should be planned in cooperation with his mother.
  - Assistance as needed for passage through hallways and/or no penalty for occasional lateness to class.
• **Modification of General Academic Requirements**
  - They agreed to switch him to another history teacher--one who does *not* yell at the students!
  - Modification of organization of notebooks as appropriate.
  - No foreign language.
  - Permission to use scientific calculator.

• **Accommodations for Written Assignments**
  - Use of computer for extensive writing.
  - When required to write by hand, permission to use pencil instead of pen so that he can erase errors and not feel he has to start over.
  - If handwriting is illegible, teacher to confirm meaning of words before grading.
  - No penalty for spelling errors.
  - Preferential seating.
  - Second set of textbooks to keep at home.
  - Written directions for all independent homework, long-term projects.
  - Note-taking.
  - Photocopy of class notes/outlines provided to help student prepare for tests.
  - Excused from requirement to type/re-type class notes.

• **Homework Modifications**
  - Two academic support periods per day for supervised/mentored homework.
  - Modification of homework to priorities that prepare him for participation in class the next day.
  - In case of absence, only priority work required to be completed.
  - Additional time without grade penalty to complete prioritized homework assignments.

• **Testing Modifications**
  - Additional time as needed to complete tests/quizzes.
  - Provision of enlarged tests/handouts as appropriate.
  - Confirmation if question not completed that he had sufficient time and saw that item.
  - Scribe for standardized testing or for in class tests where writing is extensive.

• **Physical Education Modifications**
  - No change of clothing for physical education or provision of private changing room.
  - No scoring for standardized physical education fitness tests.

**Editor's Note:** Each high school student with AS is different; not all teens would need or want all of the supports listed above, while there are other possibilities not included on this list. Other supports to consider are:

- One skilled central person the student can go to with questions or problems, e.g. a school social worker.
- Permission to arrive early at school and enter the building.
- Extra time between classes.
- Pragmatic social language, social skills group, or friendship groups or peer mentoring program.
- Encouragement to join groups where a skilled adult can “coach” social skills infor-
mally, such as a club in the student's area of interest, e.g. cartooning, chess, school paper, or drama.

- A work/study or volunteer job with a skillful supervisor, e.g. in the school library, computer lab, etc.

For more wonderful ideas and strategies, see these books:


Successes and Struggles of the High School Experience for People with Neuro-differences

By Steph Geheran

Note: This article is the outline of a talk Steph Geheran prepared and delivered at a meeting of the Pathways Parent-Faculty Program at Brookline High School. Their mission is to educate, inform, support, and help students, parents, and faculty to prepare for and make smoother transitions from the K-8 schools to the high school.

Steph also spoke at the 2004 Autism Awareness Day.

Introduction

My name is Steph. My “diagnosis” is Asperger Syndrome. I am nineteen, and I graduated last spring from Wellesley High School. I am currently working part-time while attending classes at Mass Bay Community College.

My aim today is to address the struggles and challenges a student with a neuro-difference may encounter, and ways in which they may be transformed into successes. I can only speak and provide advice/guidelines from my own personal perspective. Please bear in mind there is an extensive variety of neuro-differences and experiences out there, and different methods prove effective for different people. So these are only very loose, general suggestions and concerns that you will hopefully find enlightening or helpful.

Adjusting to High School

High school can have a vast and overwhelming atmosphere; there are few places a student can evade human contact, other than a bathroom stall!

“Home base,” or a safe, isolated space that is accessible for escape at all times, is essential, and should be equipped with a source of calming stimulation such as music, food or candy, and perhaps something akin to “stress balls” if the student has tactile needs.

Certain areas of school and/or times of day may be particularly overwhelming and anxiety-producing. For example:

- The cafeteria is usually a noisy, socially exhausting environment in which one is very exposed. Offer alternatives to the cafeteria; do not force a student to remain there. Asking me to remain in the caf. was the equivalent of requesting that I jump headfirst into a strong, tumultuous current.
- Hallways, Passing Classes: Offer alternatives such as passing classes a few minutes late or early, in order to avoid teeming crowds.

Teachers, Administrators, Special Educators

The most important and helpful attributes of teachers, administrators, and special educators are open-mindedness, compassion and approachability. A non-threatening authority figure will be much more valuable than a looming disciplinarian. Everyone should be prepared to learn as well as teach.

All staff and every teacher should be informed of the student’s differences by a parent or special educator; each should be conscious of specific proclivities and, most importantly, how crucial it is to remain sensitive, patient, and understanding. This will better enable the teacher
to address the student’s needs and create a comfortable learning environment.

Communication among adults is especially vital for students who have difficulty advocating for themselves.

The teachers, of course, aren’t the only ones who need to be enlightened. An effort should be made to promote awareness in the student’s peers. This should be done in a way that doesn’t “single out” any students with neuro-differences or cause them to become self-conscious. Perhaps some type of awareness program can be incorporated into a pre-existing curriculum. The head of the English Department at my high school approached me of her own accord to discuss inserting the extraordinarily realistic and intuitive novel, *The Curious Incident of the Dog in the Nighttime* by Mark Haddon, into the English curriculum. She wanted to make sure children who identified with the protagonist would not feel singled out.

Be open-minded to unconventional learning techniques: When I wasn’t exactly thriving in my academic studies, a truly amazing special educator proposed the innovative idea of my leaving the classroom to pursue more “hands-on” learning experiences. I worked with children who had special functional needs at a therapeutic horseback riding stable, while keeping a journal for scholarly merit. I also worked with a class of children with special cognitive needs. Both were enlightening, luminous, effective, and inspiring experiences, combining my arenas of interest with legitimate academic activity.

**Steph Geheran**, a young adult with AS, attends college, works, and has played a leadership role in many volunteer activities. She has also addressed the Massachusetts Legislature for Autism Awareness Day.
THE DIFFERENCE INSIDE ME
By an Aspie in High School

Throughout my life it has been a struggle every day to find that one point where I could feel comfortable and pleased with myself. Where I would know the functions of the world and who I truly am as person, and be “normal.” Though I have not reached that point yet, I have a lot to show you about the life of someone who has Asperger’s, so you can see the world from a different perspective.

Ever since I was little, I did inappropriate things without realizing what their effect was on other people. I couldn’t think intuitively, but I did what I felt on the tight string of an impulse. I used to hate getting help from therapists. I always thought that I had to be the best at everything. If I didn’t get what I wanted, I would break down. I felt I had nothing wrong with me, except that I wasn’t the best, or couldn’t be. It was frustrating trying to compete with everyone to have the best grades, be the tallest, and most popular. Generally, I would not escape that competitive edge and I was described as thinking that a game wasn’t a game, but my life revolved around it. I hated when teachers corrected what I did. I thought that the assistant teachers were spies, who watched every move I made and wrote notes on even the twitch of my thumb. To avoid them, I used to hide.

In the beginning of middle school, I was told that I had Asperger Syndrome. I thought that was a burger with your butt in the middle and it was very ugly. I hated being referred to by that term. Also around then, I first heard about team meetings. That got me really upset, that I didn’t know everything that went on about me, but my parents did. I also started my grade obsession, competing to have the best grades in the whole class. To this day, I continue to be obsessed with grades, but less severely. In middle school, I got angry if I got anything lower than an A. Since I usually got A’s. I would throw temper tantrums if I got a B+, and sometimes an A-.

People in school ignored me. I felt lonely. I thought everything was fine with me, and I cried that I should have an aide another year. When I got older, I would realize all this fighting with others would be a disadvantage for my future. I avoided saying hi to the guidance counselor, afraid that I was be the only one who had to see her. She mortified me, especially in front of my friends and people I had crushes on.

In seventh grade, I finally realized that I needed to work with my SPED (Special Education) liaison to improve my social skills. I wanted to be accepted by my peers. Every week I would go to her and it would give me great success. This year, not only did I accomplish great things socially, but I also became very mature and I was able to make new friends and finally observe the world and what was going on with my social problems.

That year, however, I had the stress of my upcoming Bat Mitzvah. I also had to take allergy medications, which made me drowsy. And I started becoming obsessively interested in members of the opposite sex. I became infatuated with this trumpet player and I found valve grease or “trumpet oil” near my seat. I fooled around with it at a concert, and it got me in serious trouble. Not only did my friends not want to talk to me, but I also had no one who I could rely on really.

In eighth grade, I took the “boy craziness” to a new level. I began to write poetry about these guys that I would like and think about them every day. I had barely any friends and it was probably one of the hardest years for me. Many kids started dating and I felt left out. I would
obsess why I didn’t have a boyfriend and become very depressed. Even though I did manage to flirt with a couple of guys, my female peers rejected me. I began to realize that some boys I liked were put off by how I pursued them. I got jealous over a girl who had a crush on my long-term crush and best guy friend. She flirted with him and dropped me as a friend. In addition, my parents got divorced, which left a hole inside my happiness.

My first year of high school wasn’t much better. I did make a lot of friends, who had special needs, and other people older than me, but I still was obsessed with guys. I would dress, try to impress, and dream about them TOO MUCH. Unfortunately, I told two people, who were family members of my crushes that year; the guys were very rude to me and scoffed at my existence. Upset by the way peers rejected and bullied me at school, I became abusive to my family. Then I had to go to a social skills group to stop my social regression. Before going to these groups, I thought that the kids in them were social retards; today I laugh at the prejudice I used to have. The group greatly helped me. I developed new friends and new skills.

The thing that helped me the most is that one summer, I worked with a social skills counselor, who has helped prepare me for real life situations. Currently, I am working avidly to improve my social skills. I am trying to listen to my parents’ cues and make contact with my friends. I am learning how to be less self-centered and be part of a family. In addition, I plan to help and advise others with my disability. I am proud that I was able to survive all of this and grow.

I advise that people who have Asperger’s should work hard with their disability. Never give up. Don’t complain about being different: someday you will be a very successful person. It takes a while to develop your social skills, but have patience and then you can succeed. Practice social skills by going to pragmatics groups, therapists, psychologists, or psychiatrists. Try to think positively and find ways to stop anxiety by doing things that work for you, such as listening to music, or doing something else you enjoy. Try to filter what you are saying and see how things affect others; be observant of your world. Listen to others’ suggestions. Help the less fortunate. Advocate for yourself. I hope that all the time and effort you put into working with Asperger’s will pay off and you can become successful later in life.
Introduction

At the Asperger’s Association of New England, we have seen a lot of students with Asperger Syndrome meet with success in getting admitted to a variety of colleges and universities—college, studying, and graduating—and we have also heard about difficulties students have encountered. In this short guide we will share with you what other students, parents, and AANE staff have learned about what steps you can take to maximize your chances of success in college—and in using your college years to create a foundation for a satisfying, independent life after graduation.

As you probably know, people with AS differ widely from one another in their gifts, disabilities, achievements, and interests. Therefore, it is quite possible that not all of our suggestions will be right for you. However, we do believe that many students with AS will find these ideas very useful in avoiding potential problems—or having the means to resolve problems promptly.

Going away to college poses a multiple challenges for every student, not just the student with AS. For example, like any college freshman you will probably find that:

- You will be expected to work more independently, and to take on more sophisticated, in-depth, or complex intellectual challenges.
- You will need to learn the rules of a new social environment. You will face the challenges of meeting a lot of new people, making new friends, and participating in new social activities.
- You will be living more independently and relying less on your parents for practical help with things like laundry, meals, and personal finances.
- Sometime during college, you will need to begin thinking about a career and making some plans for life after graduation.

If you are a student with AS, it is important to plan ahead to ensure that you have the best chance of meeting these big challenges, succeeding in college, and enjoying your college years. There are issues you and your family can think about, decisions you can make, and supports you can put in place that will make things go more smoothly. We recommend that you:

1. Pick a college that’s the best match for you, both academically and socially.
2. Disclose to the college Disabilities Office that you have AS, so that you can obtain helpful supports and accommodations.
3. Establish a support network of people on and off campus who can help you in key areas.
4. Start early with career exploration and planning.

1. **Pick a College that’s the Best Match for You**

When you are researching colleges to decide where to apply, look for colleges that meet
most or all of the criteria in the numbered list below. You can look for the information you need on the Web sites and in the catalogs of individual colleges, in guidebooks that evaluate and compare a lot of colleges, and by talking to your high school guidance counselor. Students now in college are an additional resource.

Later, when you go to visit or interview at colleges that interest you, you should make observations and ask questions to verify that the college does in fact have the characteristics and services you want and need—since the reality may not exactly match the written descriptions.

For most students with AS, we recommend that you look for these characteristics:

1. The college has a relatively small student body. (You are more likely to get the attention and assistance you need to do your best at a smaller school than at a large, impersonal university.)
2. The college has good classes/professors/programs in your area of strongest interest/talent—particularly an area with potential for future employability.
3. The college offers some flexibility with how students fulfill requirements, or will consider waiving some requirements. (Also find out if there are alternative exam arrangements if you need them.)
4. The college has a strong Disability Resource Center or Office of Disability Services, staffed by people who are familiar with AS. The Disability Office may include a learning/tutoring center where you can get help with organizing your work, or extra help if needed it in content-specific areas. They may also offer peer support groups or a one-on-one peer mentoring program.
5. The college accepts students who live off campus or at home, and commute to campus or the college has single rooms for which students with AS are eligible. Living in your own space will protect you from stress that roommates could cause for you because of differences in sleep habits, noisiness, and other kinds of behavior.
6. The college has good systems in place for conflict resolution or problem-solving. For example, a student accused of a disciplinary infraction can have an advocate attend hearings with him/her; decisions are made by experienced college personnel, rather than by committees of undergraduates.
7. The college has the staff and systems in place to monitor the progress and wellbeing of individual students.
8. If the student agrees to it, the college accepts the value of parental involvement, and communicates well with parents.
9. The college has a diverse student body and a positive attitude to individual differences (for example, an art school or a school with a stated philosophy and reputation for valuing diversity and creativity).
10. The college has a good career services office, available both during college and after graduation; the college has internship opportunities to help you prepare for work after graduation. (You might want to visit the career services office before you decide whether or not to apply to this college.)
11. The college has clubs in your interest areas.
12. The college is located not too far from home.
For some students, it makes sense to break the challenge of college up into smaller steps that you can tackle one by one, rather than all at once. For example, consider the option of living at home while attending a nearby community college for one or two years. Later, you can transfer into a four-year institution, either continuing to live at home, or maybe moving into a dorm. Since you will already have experience in meeting the academic demands of college, you will probably be better prepared to tackle the other social, career preparation, and independent living challenges.

*Be realistic. Colleges are educational, not rehabilitative institutions.*

2. Disclosure, Accommodations, and Supports on Campus

By disclosure, we mean telling key people that you have AS. If your disability is likely to get in the way of your academic or social success, or if you will need certain supports in order to graduate, you should strongly consider disclosing to the college during the application process. A college that is willing to admit a student with AS is much more likely to offer an accepting atmosphere and necessary supports and accommodations.

A really effective approach is to give the college personnel an information packet describing what AS is, and what accommodations and supports you might need in order to succeed in college. Some students have also chosen to write about their experiences as people with Asperger Syndrome in the personal essay required on the college application form.

Early disclosure to appropriate college personnel improves your chances for success, and minimizes the chance of misunderstandings or unfortunate incidents. If you have not disclosed during the application process, then we do highly recommend that you give the college information about yourself and about AS after you are admitted and before you begin your first semester.

Asperger Syndrome is legally recognized as a disability under the Americans with Disabilities Act. That means that you are entitled to appropriate supports and accommodations to help you succeed in college. In order to request supports and accommodations from the college, however, you must disclose that you have a disability, and provide the college’s Disabilities Office with a written proof of your diagnosis. It is better to do this before classes start, rather than offering it as an excuse or explanation later on, after you may have run into a problem related to your AS.

Many college disability offices offer special orientation sessions for students before everyone else arrives. A really good orientation will cover all the specifics of the written and unwritten rules of college life. This chance to become familiar with the campus, the people, and the rules can give you a valuable head start on college success. Some students attend a summer course on campus between the end of high school and the beginning of freshman year, in order to have plenty of time to get used to the campus.

Once you give the Disabilities Office staff written permission to disclose material about you, they will be able to let your professors know what supports and accommodations you need, such as time extensions to complete required research papers, extra time or quiet rooms for completing written exams, permission to use a computer in an exam, or other accommodations.

Your Liaison or Case Manager in the disabilities office will also be able to contact other college personnel who need to understand your situation, such as residence directors and assistants, security and judicial affairs officers. He or she might be able to secure a single room for
you in the dorm—by far the best choice for most students with AS. (If you do want a single room, you should certainly talk to the Disabilities Office as far in advance as possible.)

From the very beginning, you, your academic advisors, and your Liaison should look at the college’s academic requirements and decide if any of them are likely to be unduly burdensome for you. If so, you should submit an early request to have those particular requirements waived. For example, if math or foreign languages are very difficult for you to pass, you could negotiate to get these requirements dropped or to be allowed to make substitutions.

Some students with AS find that their best strategy is to take fewer courses each semester. If you choose this route, you can make up the extra credits by taking summer courses and/or by going to college for one or more extra years. Find out before you enroll if the college permits students to use this strategy, and if there is there a lower fee each semester for students taking fewer courses.

3. Establish a Support Network

Set up a system of supports before you start school. Having good systems in place, and nipping problems in the bud, will work much better than waiting for a problem to arise and then scrambling for a solution! In fact, it may make the critical difference between success and failure. Sometimes a problem can become serious very quickly, and by the time you realize you are in trouble it may already be too late to try to arrange for the support you needed.

You should have at least one person at the school (probably a disabilities office staff person or a psychologist) to act as your overall Liaison. Whatever the person’s official title, he or she should be someone who both understands AS and also knows all the people and rules of the college. Your Liaison will be able to act as an advocate, coach and troubleshooter for you. S/he can talk to your professors, your Residence Assistant, or do whatever is necessary to help resolve your issues and make things go more smoothly for you. Your Liaison should:

● Be someone with whom you feel comfortable, so that you can turn to this person if you have any questions, or if you feel overwhelmed or confused either by the academic or social pressures. Be readily available to communicate with you.

● Keep in touch with you on a regular basis (e.g. weekly).

● Notice promptly if you are experiencing stress or running into problems, and help you figure out what’s going on and how to improve the situation before things escalate.

● Bring to your attention the unwritten social rules of classroom, dorm, and campus behavior.

● Be someone who can help you understand the system and help you make the system work for you.

● Help you negotiate the college bureaucracy and comply with the rules governing essentials such as registration, academic advising, meeting requirements for your major area of studies and distribution requirements, graduation requirements, etc.

● Be the person to whom your parents can turn if they have concerns or questions about how you are doing at school. (NOTE: It is not acceptable practice at most colleges for a parent to communicate concerns directly to a professor.)

Either on or off campus, your additional support network might include any or all of the following:

a) A therapist who understands AS and can offer practical suggestions for coping with the demands of your college life.
b) A social skills class to help you with friendships and relationships.

c) Academic support such as: tutoring in a specific subject, organizational help, or study skills.

d) A life coach or someone similar who can help you how to organize different areas of your life, including managing your finances and staying on top of all your papers and documents.

e) A cell phone so you can contact your Liaison or your parents if you run into difficulty and need some emergency assistance or guidance.

Your support network will work best if everyone in it has permission to communicate with the other members. Give them contact information to help them do that. They will also need your written permission to share information with one another.

4. Start Early with Career Exploration and Planning

Having a job you like and perform well can be very important to the quality of your life after you graduate. Earning a college degree is a wonderful accomplishment—but by itself it does not guarantee you a job. New England is filled with unemployed people who earned liberal arts degrees with majors such as video, photography, history, English, communications, or philosophy. A few of these people go on to graduate school and become professors—but that is expensive, time-consuming, and also carries no guarantees. (New England has its share of unemployed Ph.D.s, too!)

You will benefit greatly from setting some professional goals early on in your college career, and choosing courses and other experiences that will ensure that you graduate with some skills, concentrated knowledge, and documented experience that will give you a leg up in the job market.

Your college will have a Career Services or Career Placement office. Visit soon, meet the staff, attend an orientation, and become familiar with what they have to offer. You may want to ask your Liaison to help you find a good person to work with the career office. You might find that they can:

1. Provide testing, such as interest inventories, to help you identify careers that would be rewarding for you, and to which your skills and personality are suited.

2. They may be able to help you find part-time work, volunteer opportunities, or internship experiences. This real life experience is helpful in several ways.

   a. You can discover what kinds of jobs—or what aspects of a job—you enjoy—or hate. (Both kinds of information are useful!)

   b. You can learn about the basic expectations employers have of employees—those unwritten rules that can make or break a career.

   c. You will have items to put on your resume—and people to write recommendations for you. This will put you miles ahead of other college graduates when you start your post-college job search.

   d. Employers tend to hire people they already know. Some graduates get jobs at the very companies or agencies where they interned or volunteered as undergraduates.
3. Help you find the first job you will hold after you graduate. Most will also allow you to use their services to find subsequent jobs.

*Call or e-mail AANE if you have additional questions you would like to discuss, or if you need the names of college consultants or other professionals to help you with finding and applying to an appropriate college, or setting up a good support network.*

*We would like to thank the many parents and college students who have shared their concerns, experiences, and resources with us over the years. We learn from you—and we hope you will continue to let us know what works and what does not, and add to the list of resources we can offer new families.*

*We are also very grateful to the following people for sharing their expertise with us: Leslie Goldberg, Cate Solomon, MSW, Ph.D., Lorraine E. Wolf, Ph.D., Ruth Bork, Sharon de Klerk, and Denise M. Darrigrand.*
College/Independence Readiness Skills

By Susan Erickson

Personal Skills

Practical Living
Driving a car, taking a bus, train, or airplane
Managing a budget and money
Using credit cards, using a checkbook, paying bills
Shopping for food, clothing, toiletries, medications
Doing laundry
Cooking simple meals
Picking up and cleaning up a room or apartment
Self care: showers, dental care, haircuts, appropriate dress

Self-Advocacy and Self-Care
Recognizing confusion and asking for help
Seeking help when struggling with a class or assignment
Recognizing depression, loneliness, anxiety; seeking help
 Asking for extensions, changes of schedule, etc. for classes and exams
Finding and keeping a local coach/therapist/psychologist
Making appointments for a doctor, dentist

Organizational Skills
Keeping track of assignments
Breaking large assignments down into smaller parts with interim deadlines
Keeping an appointment book
Keeping a “to do” list
Scheduling/carrying out re-occurring responsibilities such as bill paying, car maintenance

Academic Skills
Awareness of personal strengths and weaknesses
Awareness of own interests and motivations
Accurate sense of own abilities in various subject areas
Capability of seeking help when choosing classes
Requisite reading, writing, research, computer skills for a particular school/program

Social Skills
Problem solving with roommates: whom to turn to, how to talk through a problem
Recognizing need to reach out; able to join clubs or groups, create or find structured social situations
Ability to make friends, connect with others
Able to join and participate in a conversation at a dining hall table
Questions for the College Disabilities Office

Staffing
● What office at the college offers support to students with disabilities?
● What is the student/staff ratio?
● What is the level of the staff’s training and experience in Asperger Syndrome? Is there on-going staff development in this area?
● Does each eligible student have a single coordinator, or are services offered on a drop-in basis? Does anyone have an overview of how well a student is doing in all of his or her courses and in adjusting socially?
● How familiar/comfortable are professors with students with AS?
● What efforts have been made to educate and support professors?
● Do academic counselors take professor attitude into consideration when recommending courses?

Academic Services and Supports
● What services have been helpful for other students with AS?
● If appropriate, do you arrange for:
  ○ Note-taking support?
  ○ Time management and organizational coaching?
  ○ Advocacy support?
  ○ Study groups or peer tutoring?
  ○ Flexible time for tests and assignments?
  ○ Reduced course load?
  ○ Help with job interviewing and workplace social skills?
  ○ Job coaching while on co-op assignment or internships?
● How often may a student meet with a counselor? Have you ever offered daily phone check-ins?
● Are class notes, syllabi, and assignments available in writing, and/or on-line?
● Is there any communication from your office to the student’s parents? Can the student request such communication?
● Is there an orientation for in-coming students? Is anything done especially for students with disabilities?
● What are the educational issues that have caused students to leave the school?

Social Climate
● How tolerant of different learning and lifestyles is the student body?
● Is there an unwritten dress code?
● How are loners regarded?
● Are commuting students at a disadvantage socially?
● What is the official policy toward hazing, and how does the school respond to occurrences?
● If there is significant conflict between students, who gets involved to resolve the situation?
● What social issues have caused students to leave the school in the past?

Susan Erickson is the parent of a child with AS.
The Dating Scene: Are You Interested?
By Elsa Abele

Let’s look at dating as a pastime for teens, young adults, and adults. Webster says a pastime is “something that amuses and serves to pass time agreeably.” That is dating at its best. Most of us know that it also produces times of high anxiety, anger, sadness, and confusion. Dating, after all, is one kind of relationship, and all relationships vary from satisfying and agreeable to dreadful and confusing. In dating, there is often the added factor of sexual attraction that enlivens but also complicates the mix.

The first paragraph relates to all of us. We are either interested in this pastime, not interested yet, not interested at all, or already participating in this pastime. That is, of course, true as well for persons with Asperger Syndrome. What are the special assets of the AS dating partner, and what are liabilities? I am in the group often called “neurotypicals” so I am sticking my neck out to give my views on some of the particular strengths and weaknesses brought to the dating scene by persons with AS. However, I do know and work with many people with AS so this comes out of my experience and may ring true to you.

The first most important aspect of choosing someone to date is looking for someone who can become a friend. The qualities of being loyal to that person, being willing to listen to his or her concerns and interests, enjoying some of the same activities and ideas, and finding his or her company interesting and fun are all a part of friendship. Friendship is a solid foundation for dating. This means that casual Internet chat friends may or may not turn out to be good dates. It is certainly safer for you to date someone that you have shared activities with than one who has emailed you that he also likes the Civil War, for example.

In fact, my first rule for dating is that you and the date share some common interests. An activity-based friendship has the best chance of developing into a dating relationship that can be agreeable to you both. Stephen Shore, a friend of mine with AS, said in his book, Beyond the Wall, “Any activity where socialization is the primary goal has always been a complete bust for me. For those who are socially cue-challenged and have difficulty communicating in social situations, group activity where the activity is the goal may work.” (p. 81) I think dating works best when people with AS try out a variety of activities that are things they enjoy, meeting people who also enjoy those things.

Persons with AS often have heightened sensations in visual auditory, and kinesthetic modalities which make the sexual feelings that often accompany attraction to another person difficult to manage. If two people date more than one time and become a “couple,” they will have to figure out what feels good to each of them and what does not. Remember that for many persons with AS who have sensory sensitivities, deep pressure (like back rubs) is calming and organizing, while light pressure (running fingers through hair) is often irritating. Personal space, i.e. one’s physical proximity to another person, is a factor in dating. A person will not want his or her date too far away, but will not want to feel physically crowded by him or her either. Persons with AS will need to use all the skills they have learned about reading facial expressions to communicate with a date. They may also need to take cues from the person who can read situational nuances if they often misinterpret in this area. They may fail to consider the context, and so need the other person to cue them as to when loving words and actions are appropriate in social situations and when they are not.
Another hazard in dating is that the person one is attracted to may not be honest; he or she may try to deceive his or her date. It is hard for some persons with AS to recognize when they are being tricked. Another way to put that is that it is sometimes difficult to comprehend the intentions and motivations of others. It may help to ask a friend to say what he or she thinks about the relationship. If one of the people wonders about being tricked, the best policy is to tell the other person about that fear without accusing him or her and to talk it over. This may be hard for the person who has difficulty taking the perspective of the other person (seeing things from his or her point of view), but it is possible as long as the person can keep from getting too worked up or anxious in the process. It may be difficult for some people with AS to determine who is responsible for a given action that can cause a fight over whose fault something is or who gets the credit.

Participating in an activity (e.g. biking, swimming, hiking, computer programming) together takes the focus off the social interaction. One person may be a real expert at fixing a bike, but not be so good at just holding a conversation. That same person may be able to do both together—fix the bike and hold some conversation—better. This may help to focus attention on another person for a longer time, which is important in dating.

What I have outlined is useful for anyone who is dating. If social interactions are difficult for you, and you have had to learn them step-by-step, you will need to learn the rules of dating step-by-step the same way. Remember that no one is a perfect date to begin with; everyone has to learn how to do it. Expressions of affection including sexual expressions are natural, but need to be appropriate to the level of friendship you and your partner have developed over time.

Social interaction may be very hard for you, but you can’t be a good date without some of it. Shared activities are a good foundation on which to attach some social interaction. There is no shortcut to dating that does not include friendship. If you are not interested in dating at this time, then this article is interesting information, but not something you want to try out. That’s fine. If you are interested in dating, hopefully this article will give you some tips to think over as you choose activities that you enjoy that can lead to meeting someone to date.

Elsa Abele is a speech language pathologist with special interest in Pragmatic Language Disorders, particularly as they affect social interaction. Formerly a Clinical Faculty member at Boston University’s Sargent College of Health and Rehabilitation Sciences in the Program of Communication Disorders, she now teaches at Antioch New England Graduate School. She conducts training sessions for public school systems and has co-facilitated social pragmatics groups for young adults. Elsa is a Board member of AANE and its New Hampshire chapter.
AANE has found that teens and young adults with AS have significantly more encounters with first responders than others, especially with the police. Teens may walk a lot, especially at night, and are often challenged by police officers. Some teens may be unaware of their own appearance and look suspicious. Some collect things and are challenged. Some get in trouble with the law when they use alcohol or drugs or buy for “friends” without anticipating the consequences. Sometimes, a child melts down in public or has a verbal outburst. Occasionally, a child runs away from home or wanders off unaware or without thinking.

An encounter with law enforcement or personnel is an anxiety-provoking experience for most of us; it is even more so for individuals with AS. The disclosure card on the facing page offers guidelines to help people with AS interact more effectively with first responders, stay safe, and defuse a tense situation.
An important time for a person with AS to disclose the fact that they have AS is when interacting with a “first responder,” i.e. a police officer, fire fighter, or emergency medical technician. This kind of disclosure may be especially hard, because the situation may be an emergency, or one in which you feel threatened or unsafe. If you are an adult or teen with AS, we suggest that you carry a copy of the card below in your wallet at all times, to use in such difficult situations. Be sure to write on the back of the card the names and telephone numbers of two people who know you, and who explicitly agree to serve as emergency contacts for you if you ever find yourself in a difficult situation with a police officer or other first responder.

Some parents take their children to meet local police and disclose their AS in advance of any possible emergency. Teens and adults could also make it a point to introduce themselves to local police, perhaps taking along a family member or trusted friend to facilitate the meeting. It is far easier to establish a mutually respectful relationship at a time when everyone is calm, than in the midst of an emergency or active law enforcement incident.

The expert on these issues is Dennis Debbaudt, who has kindly spoken at AANE conferences and has trained law enforcement personnel and other first responders in New England on behalf of our community. You can receive his e-mailed “Autism Risk and Safety” newsletter by contacting him at <ddpi@flash.net>. AANE staff members have developed this card based on models created by Dennis, and on his insights and teaching.

It is very important to ask a police officer permission to reach into your pocket to get your wallet and the card yourself, or tell the officer exactly where you are carrying your wallet—purse, left side coat pocket, etc.—and ask the officer to please take out the wallet and look for the card himself or herself. If you reach into your pocket suddenly, the police officer may think you are reaching for a weapon, and react in a way that could endanger you. For example, you could say, “Officer, I have a card in my wallet that explains my disability. May I please show it to you, or would you prefer to reach into my back pocket yourself?”

**Directions**

1. Cut out both the front and back sides of the card.
2. Fill out the front with your name, date of birth, and phone numbers of your two emergency contact people.
3. Cut a piece of card stock to the same size. Put it between the two sides of the card.
4. Laminate with clear contact paper or a lamination kit from a pharmacy, hardware, or stationery store.
5. Put the card into your wallet; carry it with you whenever you leave home.

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**I have Asperger’s Syndrome, a social/communication disability related to autism.**

Because of my Asperger’s Syndrome, I may:

- Panic if yelled at, and lash out if touched or physically restrained.
- Misinterpret things you tell me or ask me to do.
- Not be able to answer your questions.
- Appear rude or say things that sound tactless, especially when anxious or confused.
- Have difficulty making eye contact.
- Speak too loud, too soft, or with unusual intonation.

I would like to cooperate. To help me cooperate, PLEASE:

- Clearly identify yourself as a law enforcement officer/first responder.
- Call one of my emergency contacts. (Please see reverse side of this card.)
- Do not assume that my Asperger’s traits constitute suspicious behavior.
- Avoid touching me or restraining me.
- Speak to me in normal, calm, non-confrontational tones.
- Tell me exactly what I need to do politely, clearly, simply, literally, and step by step.

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**Asperger’s Association of New England**

617-393-3824  www.aane.org
A Hopeful and Flexible Vision for the Future
By Susan Shamus

Recently, as I watched my son drive off on his way back to college, I couldn’t help but marvel at how far we have all come.

When he was first diagnosed with PDD (Pervasive Developmental Delay) at age three--nobody was then referring to Asperger Syndrome--my son was busy skipping, swinging, and “stimming” (engaging in behavior to manage sensory overload) while trying to manage the daily work of kindergarten. Loud noises sent him, with covered ears, away from group encounters, while the world of books and cartoons seemed to be his source of comfort and relief.

Over the years of speech/language and occasional therapy and psychologists’ visits, the need for sensory stimulation disappeared and new concerns arose. We wondered if he would ever be able to cross the street alone or manage his own money? Would driving a car ever be in his future? We worried each day that he headed off to school about the difficulties he would encounter living in his world. Yet he hung there, a real hero, never complaining and always trying his very best despite the many obstacles that were in his way.

Now, seventeen-plus years later, this fiercely independent young man is a real example of what can happen if parents remain hopeful and flexible in their vision for their child’s future. What happened? How did he get to where he is today? We now believe it was a combination of his hard work, all the interventions, normal development, and the willingness to “think out of the box” in developing working strategies to help him manage his world as it changes. It involved learning about AS, and accepting him for his uniqueness and the richness that he brought to the family.

It was, and is, not always easy. It has required that, as parents, we knew when we needed to take time for ourselves and set time aside for other family members, and when to ask for help when we were overwhelmed. It has involved taking care of ourselves and staying balanced so we would have the energy to care for our family.

Today we are still involved in an ongoing process. We and our son have the rest of college, the world of work, and independent living ahead of us. These challenges, too, will require new strategies, lots of conversation, and a healthy respect for the ebb and flow of it all as we try to navigate through.

But now we are confident that while we may not know what the exact outcome will be, we do know we will not limit our visions of what the future holds.

Susan Shamus has a private practice at Special Needs Advocacy and Personal Life coaching. She specializes in helping families with children with AS find a balance between caring for their families and themselves.