Our keynote speakers Dr. Carol Gray and Dr. Tony Attwood kept almost 1,000 AANE members entertained and enthralled for two full days—our largest and longest conference to date. Some comments by conference attendees:

The conference was remarkable. Tony and Carol are top shelf! I have never been to a conference that I enjoyed so much.

Agreed! I was amazed at the level of intimacy the speakers created with the audience. It was a powerful experience to be part of this workshop. Thank you so much to AANE for putting together such a great program!! It was a delight to meet others in the teen group, however briefly.

I must agree it was truly a blessing to be at the conference, to learn so much and especially to meet other parents who are on the front lines.

It was great to put a face with the names, and to see the determination in all your faces and to hear it in your voices. I feel invigorated...recharged, and it helps to know I'm not alone. I am always astounded (though I shouldn't be... Attwood and Gray are incredible) as to how well they understand my kid, and describe my family (Dad -undiagnosed, mom social genius having to forgo/put up with many things selflessly for the Aspie she loved & married). Wow. If she could go back in time knowing what she knows now, life may have been much different for the both of them... well, all of us. For me, the conference helps me on my journey of acceptance and understanding and hope for the future.

See page 17 for Seeing with a Different Eye, the exhibit by AANE adult artists that premiered at the conference.

Cover photo by Karl Kastorf: AANE Adult Social Group picks apples in Ipswich, Massachusetts
FROM AANE BOARD PRESIDENT HANK MILLER

Fall in New England is heralded for its beauty, symbolizing for many a time for change, new beginnings and a sense of renewal. Of course for our community, change can also equal a time of increased anxiety, new routines and changing cycles. Whether you are hoping for a clean slate or continuing to deal with previous issues, this time of year can be difficult for individuals with Asperger’s and their families. New situations often bring a new set of challenges. Calls for help to AANE increase significantly at this time of year.

AANE itself is undergoing transformation as we move to a new facility, increase our programming, and integrate new staff members. Our fall conference just took place, attracting almost 1,000 people to hear Carol Gray and Tony Attwood. It was an educational and social event that served to bring together experts from around the world. Thank you to all who attended, and to our staff. If you haven’t attended an AANE program, I encourage you to join us during the coming year.

My goal as board president is to ensure that resources are available to allow the organization to evolve and meet the demands of a vastly growing, changing Asperger’s world. No individual, parent or family should feel isolated or alone as long as AANE continues to provide doorways for connections and communication.

So if you are struggling in your current situation, know that there is an office full of people ready and willing to help you. There are classes to increase your understanding, and social events where you can meet new friends. The doorway to AANE remains always open—you simply need to step through it.

Melinda and I wish you success, support and good luck in your journey this fall and hope to see you at one of our events.

FROM AANE’S EXECUTIVE DIRECTOR

Dear Friends of AANE,

Welcome to the first issue of the AANE Journal, replacing the AANE News. Now that we can use our Constant Contact e-newsletters to inform and remind you about upcoming AANE events, this twice-yearly publication can focus more exclusively on substantive articles about the many issues relevant to living with Asperger Syndrome, and on showcasing the lives and talents of people on the spectrum. This issue offers articles on topics such as research, sibling issues, college strategies. It also offers visual art by people with AS, poetry, and a prize-winning essay—a fine example of the social activism important to many people with AS.

Thanks to you, our members and donors, AANE continues to grow so we can serve more people and offer more programs. This fall we welcome a new Coordinator of Adult Services, Max Sederer, and a new social work intern, Lindsey Young, both of whom will be working with Jamie Freed, Director of Adult Services, and Gail Kastorf, Director Vocational Support to expand our services to adults with AS. (See pages 28-29.) Brenda Dater is familiar to many of you as the moderator for our on-line support group for parents of young children; Brenda is now also our new Coordinator of Children’s Services, working with Jean Stern, Director of Children’s Services. (See page 25-26.) Laura Beretsky brings a wealth of experience as our new part time grantwriter, freeing Stephanie Loo up to do more in her role as Director of Teen Services.

To accommodate our enlarged staff and increased programming, we will be moving by November 1st to larger offices at 85 Main Street. Keep an eye out for an e-mail invitation to a special house-warming event later this fall.

(Message continues on page 29.)
**BRAIN IMAGING STUDIES IN AUTISM SPECTRUM DISORDERS**
by Helen Tager-Flusberg, Ph.D., Boston University School of Medicine

For the past ten years our research laboratory, now located at the Boston University School of Medicine, has been conducting brain imaging studies on children and adults with autism or Asperger Syndrome (referred to here as ASD) in collaboration with colleagues at Massachusetts General Hospital using magnetic resonance imaging, or MRI. When we began there were very few published studies that had used this technology to investigate the brain structure and function in people with ASD; however in recent years there has been an huge increase in the literature in this area as more research groups take advantage of these exciting methods that allow us to investigate the brain in exquisite detail, in a painless non-invasive way. We have learned a good deal about some of the differences in the ways in which brains develop in children with ASD and how they function when processing different kinds of information. In this article I summarize some of the key findings, including work conducted by our group as well as others in the field.

For us to collect structural images depicting the anatomy of the brain using MRI, a person lies horizontally in the bore of a large “magnet” which produces a strong magnetic field. The procedure can take up to 20 minutes and the person must remain completely still while hearing loud noises generated by the magnet. For these reasons, MRI has more limited use with younger children, or individuals with high levels of anxiety, hyperactivity, or sensitivity to noise. In our lab, we spend considerable time acclimating our participants in a “mock” scanner to help prepare them for the challenges of lying in the magnet. When we collect structural scans, our participants are able to watch and listen to their favorite movies, which help them to pass the time despite the discomfort of the MRI scanner. Functional MRI (fMRI) images are collected in the same way; however the purpose of this method is to identify brain areas that are most ‘active’ when processing specific types of stimuli, such as faces, speech, or motor movements.

We have been collecting structural MRI scans from children and adults with ASD ranging in age from 4 to 24 for quite a number of years now. Much of our work has focused on the key areas of the brain associated with language that are typically located in the left hemisphere. (The outer region of the brain—the cortex—is divided into two halves, or hemispheres, connected by a bundle of nerve fibers called the corpus callosum). This association between the left hemisphere and language leads to asymmetry in the volumes of these “language” regions. One consistent finding from our work, across several different groups of participants, is that we do not find the same asymmetry patterns in ASD. Although there is considerable individual variability, asymmetry is less pronounced in ASD than among typical age-matched controls. The degree of reduced asymmetry is associated with both language skills and with severity of autism symptoms especially in younger children, according to our most recent findings.

In some of our other investigations we have examined the thickness of cortical areas. We found that in the right hemisphere, the areas associated with social functioning and imitation—part of the so-called “mirror neuron system”—have reduced thickness, and that this reduction is also associated with severity of social symptoms in ASD.

There are also some important brain areas associated with social functioning that lie below the cortex, in particular the amygdala. This region shows atypical patterns of development in ASD; by adolescence, the smaller size of the amygdala is also associated with severity of social symptoms.

Across many different research groups, including ours, one of the most replicated findings is that brain volume is often larger than average in individuals with ASD, particularly in children. It is thought that this enlargement takes place during the first few years of life. It is not clear what events lead to this increase in size, but it seems to be primarily in the frontal areas of the cortex, areas that include some of the main regions important for language and social information processing. The white matter of the brain, which is important for making connections across different cells and regions, seems to be responsible for the increase in brain volume. At the same time, the size of the corpus callosum is reduced in ASD. These findings have led to the important theory that in ASD there are differences in how well different areas of the brain are connected: areas that are far apart are not as well connected, which affects how efficiently complex information is processed, especially information that requires integration across visual, spatial, linguistic and cognitive skills.

Our functional MRI studies also focus on language and social processing. In our language studies, we find that even in high functioning verbal children and adults with ASD, there are differences in brain activation patterns. Like typical controls, people with ASD process language in the left hemisphere, in the same key areas of the brain. However, the patterns of activation are distributed differently, suggesting that in ASD the brain works differently, and that the language areas are not as well integrated or connected as they are in neurotypical people; such connections are critical for complex language processing, including higher level discourse.

Many studies have investigated how the brain processes faces, a key social stimulus, in ASD. Early studies found the main area for face processing, called the FFA (face fusiform area), was not activated in ASD. However, in our studies we required our participants to look directly at the center of the face while we collected the brain images. This difference in procedure showed that people with ASD do show typical FFA activation when they are attending to the face. Our collaborators at the University of Wisconsin went one step further, measuring where their participants looked, and which areas of the brain were activated, while they were judging emotional facial expressions. They found a direct relationship between FFA activation and amount of time spent looking at the eye region of the faces in their participants with ASD. Across both...
these studies we also found differences in brain activation in other regions associated with social processing, including the amygdala and the mirror neuron system.

We are continuing to conduct both structural and functional brain imaging studies at our research center at Boston University. To learn more about our work, visit our website www.bu.edu/autism. We are always seeking new children and adults who are interested in participating. Participants are reimbursed for travel and parking costs, and compensated for their time. The future of brain imaging research in the field of ASD holds much promise; yet we still have a great deal to learn about the brain bases of the social, communicative and behavioral patterns associated with autism and Asperger Syndrome. We hope you will join us in the work that we are doing by being a part of our research program!

Ian shares his love for computers with my other brother and me. He finds awesome videos on YouTube and shows them to us. We are always eager to see what he finds next. He shows us videos that I would never think of looking for. Unlike some other people with Asperger’s, Ian thinks about what we would want to see in the videos.

Since I was little, I have been noticing similarities between Ian and myself. We both like to cook. We may not like to cook the same way: I like to make supper over the stove and he likes to bake his bread in the oven. We both also like to make things; for him it’s model cars while I like to knit. We like to laugh at other people’s jokes and listen as other people crack up at ours. It is special to me to know that someone so loved, helpful, and just altogether wonderful can be like me. I am so honored to be thought of as being like Ian, because he is the best older brother someone could have.

This year, Ian is graduating high school and going to college. We are all so proud of him for getting into Northeastern, the first choice on his list. I remember the night when we found out about his acceptance. You could see the excitement and happiness on his face. His hard work really had really paid off, and he knew that too. He thought it would be best to live at home during his first year, and I am very happy about that choice. Without him, things would be altogether too quiet. I understand that he will probably have too much work to spend a lot of time with us, but just having him around is lovely.

A lot of the time, I wish people would notice the characteristics that show so clearly to me. I wish he wouldn’t be thought of as different at school. If people could just look inside Ian and spend time with him as I do, they would see how great he really is. Living with someone who has Asperger’s is not a chore. It is a wonderful thing to have Ian around, and I am so grateful for it.
CONSIDERING THE NEEDS OF SIBLINGS OF INDIVIDUALS WITH ASPERGER SYNDROME

by Carol M. Singer, Ed.D. Psychologist in Private Practice

It is important that families of children with Asperger Syndrome (AS) also consider the special needs of the neurotypical (NT) siblings of these children. The good news is that studies comparing “typical” siblings of children with special needs to matched siblings have found the first group to have no greater chance of having psychological problems than matched sibling groups. In fact, some positive characteristics have been found to be more prevalent in siblings of children with special needs, such as: greater tolerance and understanding of others, more altruistic behavior, increased flexibility and maturity, and a greater likelihood of choosing careers in education and human services. Of course, siblings can be stressed as well as potentially strengthened by having a brother or sister with special needs, and it is more realistic to view the relationship on a mixed continuum of positive effects and special concerns that need to be addressed. There is no simple formula for determining what each sibling’s experience will be. The outcome for a particular sibling is based on an interaction of factors such as: the sibling’s personal characteristics, the nature of the other child’s special needs, and the qualities of the family and community in which they live. Each child is affected differently and the impact changes throughout the lifespan.

The special needs of the NT sibling(s) can be classified into four categories. These individuals need information, need to have their feelings validated, need to have expectations clarified, and, when necessary, need help dealing with peers and community reactions. This article will address these needs as they specifically apply to siblings of individuals with AS.

Providing Information

Whenever possibly, the AS diagnosis should be disclosed to the child with AS before it is explained to siblings. Once the child with AS appears to be comfortable discussing the diagnosis with family members, you can share the label with siblings. Until then, use descriptive language but no label.

It is important to provide siblings with developmentally appropriate information about AS. Children under 8 years old need factual information and concrete explanations. Because children at this stage have difficulty processing more than one piece of information at a time, it is important not to overwhelm the young child with too much information at once. Examples of simple explanations are: “She plays the same thing over and over because she doesn’t think it’s fun to try new things,” or “He’s flapping his hands because it helps him calm down.” Parents should explain that different kids have different needs; what helps the sibling with AS may not help the other sibling and vice versa.

Sometimes children engage in a type of magical thinking where they think that their actions or angry thoughts caused their brother or sister to have AS. It is important to reassure siblings know that having AS is not anyone’s fault; it is something some people are born with. Sometimes children also have to be reassured that AS is not contagious like a cold or the flu!

Neurotypical siblings require a balanced presentation of both the special strengths or talents as well as the challenges of the individual with AS. Siblings usually benefit from having opportunities to meet with service providers (psychologists, social workers, licensed mental health workers, guidance counselors) to learn more about their special sibling’s strengths and challenges, and how these are being addressed. Service providers can also help young children to better understand how their siblings with AS are experiencing their surroundings. For example, a young child might need help understanding what it feels like to be sensitive to touch or sound. Perhaps a demonstration of metal scratching a chalk board could be used to show how sound can be unpleasant to people with AS. Sometimes siblings might need professional help figuring out which of their sibling’s behaviors should and should not be tolerated, or to teach the NT sibling better ways to interact with their brother or sister.

Professionals might meet with the whole family to help them set up a plan of what to do in the event of outbursts or difficult behaviors. Any plans should include clear rules for when the sibling(s) should get help from an adult rather than try to handle the situation by themselves.

Validating Feelings

Young children benefit from opportunities to express their feelings about their sibling’s special needs and behaviors. Useful activities could include reading books about AS, making your own book, or using puppets, dolls, or stuffed animals to facilitate the expression of feelings. It is important to let your child know that it is understandable and all right to feel angry, embarrassed, jealous, neglected, worried or any other feeling they might have about their brother or sister. It should be emphasized that siblings often have these feelings and that they are not “bad” for having them.

Children with AS are often part of their sibling’s community at school and other outside activities. The NT sibling is likely to find him/herself in situations where s/he may need to explain to others unusual behaviors of the sibling with AS. After helping siblings to better understand AS, they can be helped to learn to explain what AS is to others. Parents or professionals can help by providing opportunities for children to rehearse or practice explaining, through puppets or role-play.

Accepting Differences in Parental Rules and Expectations

In addition to providing information, and validating sibling’s feelings, parents often find it is necessary to explain why their rules and expectations may be different for the child with AS. For example, the child with AS may be allowed to spend more time at the computer or to complete homework at school instead of at home. This can appear unfair; it needs to be addressed and explained at a level the NT sibling can understand, for example: “Your brother needs special teachers at school to help him organize his homework,” or “The computer helps your sister calm down when she feels over-stimulated.” These responses may potentially evolve into more extensive discussions about the learning style or sensory issues of the child with AS.
Sibling Groups
Some children may benefit from sibling support groups or sib-shops. This can be particularly useful when the sibling does not know other siblings of children with AS. It can provide an opportunity to find out that they are not alone. Sibling groups can promote an atmosphere in which siblings are more likely to express negative emotions. They may feel safer to do so because they are in the presence of others going through similar experiences, and because they don’t have to worry about hurting or angering their own family members. Siblings can also use the groups to brainstorm ideas about how to handle difficult situations.

Issues in the Middle Childhood Years
Children aged 9 to 12 years need to be encouraged to pursue their own interests. This helps them focus outside the stress that having a member with special needs may have on the family. It also helps them see themselves as more than and-so’s brother or sister. Children at this age often develop an increased understanding of the impact of their sibling’s special needs on their parents. In some cases, NT siblings may feel they need to achieve to make up for the stress caused by their siblings challenges. During middle childhood or later, NT siblings may feel more obligated to take care of the sibling. They may feel restrictions due to care-giving responsibilities, such as financial or time constraints related to being dragged to their sibling’s therapy or other appointments.

This is the time that children become aware that their parents are not perfect! Children may become competitive with or critical of their parents around how to best manage the behavior of their sibling with special needs. It can be helpful to admit that you don’t have all of the answers. This is an opportunity to provide a more realistic picture of parents as people coping, rather than as superheroes whose achievements the youngster can never equal. It is also important not to put the sibling in a parenting role with the child with special needs. Try not to restrict the role of the sibling to that of a caretaker. Let them know that they can help or teach but it is important for them to have different ways to interact that are also fun.

During this stage, children may become more vulnerable to the reactions of peers. They may be embarrassed about bringing friends home to play. They may feel guilt that they have friends and their sibling does not. Sometimes siblings may find themselves in a position of having conflicting loyalties between peers and family. If siblings become protective when a brother or sister is teased, it is important to reassure the child that s/he is not the only protector. That is the parent’s job as well. Try to get help from teachers and school staff for the sibling, as well as for the child with AS, when there is teasing at school.

When siblings witness cruel behavior towards the child with AS, or are the target themselves of school-mates saying insulting things about their brother/sister, it is imperative from the beginning that adults get involved. This includes parents as well as school personnel. Siblings should be encouraged to share this information with trusted adults as soon as it occurs. Parents can use it as a chance to discuss with all the children in the family how to choose friends. The sibling, along with the child with AS, will need to develop strategies with school guidance staff for dealing with teasing or bullying.

Issues in Adolescence
During adolescence siblings are able to reason abstractly and can see the big picture, putting together many facts at once. They can become anxious about a sibling’s future, and to some extent may begin to wonder what their own responsibility should be. Sometimes having a sibling with AS can interfere with establishing a sense of autonomy. The NT sibling can feel guilty as s/he moves forward toward relationships, higher education or jobs, while the brother/sister with AS may be developing more slowly or struggling. Siblings might feel like they are abandoning their parents as well. It is important to reassure your adolescent that things are being taken care of, and that it is important that they keep moving forward in their own individual lives.

Issues in Adulthood
As siblings become young adults, there are three main areas of concern: guardianship, their own family, and continued involvement. Regarding guardianship, questions that might arise are: What will be my financial responsibility in the event that my sibling cannot support him/herself? Will my sibling require a guardian if my parents are not around—and who will that be?

Questions about family might include: Will my spouse accept my sibling? What are the chances that I might have children with AS? How will I balance my responsibilities towards my new family and towards my sibling with AS? How will my children be affected by having an aunt or uncle with AS? Will my sibling live with me?

Questions about continued involvement might include: How often should I visit my sibling? Should I be my sibling’s advocate? It is important to meet together as a family to discuss these issues and get input from everyone, including the sibling with AS. Meetings should be scheduled at regular intervals to revisit the issues.

Summary
In summary, there are many ways that parents and professionals can assist the siblings of individuals with AS. Sibling’s needs change through out the life span. It is important to take into account the sibling’s developmental stage when addressing these needs. The four areas that should be addressed are: providing information, validating feelings, clarifying expectations, and helping with peer and community reactions. A clear distinction should be made between the sibling and parenting roles according to each developmental stage. Lastly, sibling support groups can be beneficial. Considering these factors is of utmost importance since the sibling relationship is often the longest relationship within families.

Carol Singer is a child psychologist in private practice in Newton, MA, and works with both parents and children. She specializes in working with children with AS and related issues, Cognitive Behavior Therapy for anxiety disorders, and sibling issues. She can see NT sibling individually, and periodically offers sibling groups. You may contact her at 617 244-7835.
De acuerdo a lo que nos dicen las familias, la mayoría de los niños con Síndrome de Asperger pueden tener éxito en la escuela en tanto reciban apoyo suficiente y apropiado. Sin embargo, es importante que no solo los maestros, los ayudantes y los especialistas que trabajan en forma directa con el niño, sino también todos en la escuela y en las diferentes jerarquías de la educación especial, estén dispuestos a asumir el desafío de aprender acerca de un tipo de estudiante totalmente nuevo, un estudiante para el cual las técnicas de educación tradicionales pueden no servir en absoluto. Esto requiere una cierta humildad, mucho tiempo y trabajo arduo.

Una vez aceptado el desafío, todo el equipo debe trabajar en conjunto para crear un ambiente en el cual el estudiante pueda tener éxito. El equipo debe ser proactivo en lugar de reaccional. O sea que todos deben trabajar juntos previamente en el desarrollo de un plan educativo que prevenga las crisis, para luego llevar confiablemente a cabo este plan en todos sus detalles. Deberán también estar dispuestos a aprender de la experiencia directa lo que funciona y lo que no con ese estudiante en particular, y ajustar el plan original apropiadamente. Asimismo deberán encontrar el modo de capitalizar los puntos fuertes del estudiante y compensar sus debilidades.

A continuación hay una lista de algunas ayudas que han demostrado ser efectivas. Usted podrá considerar incluir estas medidas en el Plan Educativo Individualizado (IEP, por sus siglas en inglés).

Requisitos básicos:
1. Capacitación sobre el Síndrome de Asperger, incluyendo la ayuda educativa apropiada, apoyos y modificaciones para todos los educadores relacionados con el estudiante.
2. Comunicación efectiva y habitual entre la escuela y el hogar, y entre todos los educadores que trabajan con el estudiante.
3. Los padres deben ser considerados como una parte integral del equipo educativo.

Posibilidades de colocación para el estudiante:
1. Inclusión en clases regulares con apoyos apropiados y modificaciones
2. Clase integrada: cinco o seis niños con necesidades específicas de la escuela normal
3. Clases más pequeñas y separadas para niños inteligentes que tengan necesidades de aprendizaje social o no verbal (las colocaciones inapropiadas incluyen clases para estudiantes con problemas de comportamiento o con discapacidades cognitivas.)
4. Ubicación en otra escuela de la comunidad, en un sistema de colaboración de varios distritos, o en otra comunidad.
5. Colocación fuera del distrito en una escuela de día 766 privada
6. Colocación fuera del distrito en una escuela residencial 766 privada
Nota: Algunas familias han encontrado en la enseñanza en casa (Homeschooling) una opción viable.

Quienes pueden brindar la ayuda necesaria, las modificaciones y el apoyo dentro del entorno escolar:
1. Maestro de clase normal con entrenamiento adicional en Síndrome de Asperger, o educador especial
2. Ayudante dedicado, asistente pedagógico o para-profesional (es decir, dedicado exclusivamente a ese estudiante); prefereentemente con entrenamiento
3. Ayudante de clase para dos o más niños
4. Terapia ocupacional para tratar cuestiones sensoriales
5. Tutor o especialista educativo para tratar necesidades académicas específicas relacionadas con contenido de la asignatura, o habilidades de aprendizaje
6. Terapeuta del lenguaje para apoyo pragmático en cuanto a las habilidades sociales, del lenguaje y de la comunicación.
7. Facilitador de inclusión o consejero de adaptación para cuestiones sociales y emocionales

Apoyo escolar que puede incluirse en el IEP (Plan de Educación Individualizado, por sus siglas en inglés) para ayudar con las habilidades sociales
1. Grupos de trabajo de habilidades sociales (por ejemplo 20 minutos 3 veces por semana)
2. Cuentos sociales (Carol Gray—ver Bibliografía)
3. Conversaciones sobre tareas cónicas
4. Guiones
5. Compañeros de almuerzo u otro grupo de amistad
6. Terapia de la palabra individualizada (lenguaje pragmático social)
7. Clases/actividades de teatro
8. Oportunidades sociales estructuradas durante el receso
9. Actividades estructuradas durante el almuerzo (por ejemplo ayudar en la biblioteca o en la oficina)
10.”Autopsias” sociales
11. Entrenamiento a nivel de la escuela o del distrito escolar sobre la prevención de la intimidación y la burla
12. Divulgación: enseñar a los compañeros de clase acerca del Síndrome de Asperger (escuela primaria)
13. Continua enseñanza de las reglas no escritas de la escuela
14. Compañero de la semana (colegas mentores)
15. Entrenamiento en comunicación social durante la clase

Para ayudar con la parte académica
1. Modificación de la extensión o el enfoque de algunas tareas
2. Tutoría
3. Ayuda para tomar notas (ayudante/compañero que toma notas, computadora, apuntes provistos por el maestro, etc.)
4. Preparación (anticipar el trabajo)
5. Comunicación estructurada y frecuente entre los padres y los maestros acerca de las tareas, las expectativas, las habilidades, el progreso y los problemas.
6. Proyectos y trabajos relacionados con el área de mayor interés para el estudiante
7. Asistencia en la clase de gimnasia
8. Presentar la materia mediante ayudas visuales
9. Presentar el trabajo y la tarea desglosados en pequeños pasos
Para ayudar a bajar la ansiedad:
1. Preparar al estudiante para las transiciones
2. Empezar y terminar el día escolar con una reunión informativa (Home base)
3. Intervención proactiva si el niño muestra signos de estrés
4. Descansos
5. Maestros flexibles que puedan tolerar diferentes maneras de hacer las cosas
6. Rutinas de clase
7. Advertencias previas en caso de cambios en los planes de clase
8. Preparación (anticipo del contenido de la lección)
9. Preparación para nuevas cosas, lugares, estudiantes o maestros
10. Capacitar al maestro en el Síndrome de Asperger
11. Asistencia o actividades alternativas durante los momentos menos estructurados del día tales como el receso, almuerzo, gimnasia, música o arte
12. Modificación, asistencia o preparación de proyectos grupales
13. Manejo del entorno de la clase para prevenir sonidos altos repentinos, movimientos, distracciones, luces
14. Asientos preferenciales lejos de las distracciones

Para ayudar con las funciones ejecutivas
(cuestiones de organización):
1. El asistente en clase puede ayudar al estudiante a ocuparse de las tareas esenciales, priorizarlas, desglosarlas en pasos, entender las expectativas del maestro, anotar la tarea, recordar los trabajos o papeles importantes, etc.
2. Los organizadores gráficos pueden ayudar a los estudiantes a comprender conceptos
3. Proveer dos juegos de libros de texto, uno para la clase y otro para el hogar
4. Comunicar las tareas para el hogar a los padres
5. Anunciar las tareas en una página Web
6. Asignar un/a compañero/a de tareas para el hogar
7. Proporcionar un mapa de la escuela
8. Anunciar el programa de los estudiantes en varios lugares (por ejemplo cuaderno, escritorio, refrigerador, etc.)

Para entender mejor estas recomendaciones pueden consultarse los siguientes libros:

El Síndrome de Asperger: Una Guía para la Familia por Tony Attwood
El síndrome de asperger – Estrategias prácticas para el aula Guía para el profesorado por Leicester City Council

Estrategias Visuales para Mejorar la Comunicación por Linda Hodgdon, M.Ed.,CCC-SLP

Preparación de Ayudas Visuales para uso en el Hogar y la Comunidad: Estrategias para Personas con Autismo y Síndrome de Asperger por Jennifer L. Savner y Brenda Smith Myles

Soluciones Prácticas para Problemas Corrientes de Niños con Síndrome de Asperger por Haley Morgan Myles

Libros para niños

 Esto es el Síndrome de Asperger por Elisa Gagnon y Brenda Smith Myles; Ilustrado por Sachi Tahara
Teens and adults with Asperger Syndrome usually have academic “smarts,” but are much less proficient in “street smarts:” social skills, life skills, and organizational skills. We have found, however, that people with AS can improve in all three areas, and thus become more independent, with the use of a handheld computer (also called a personal digital assistant or PDA) and some special software. This software and the PDA help the people with AS become:

- more aware of their internal states and other peoples’ feelings,
- more organized, and as a consequence,
- more independent.

People with AS like using this tool because it gets authority figures (parents, staff at school, bosses at work) “off their backs,” thus allowing them more independence. Their loved ones like it because they feel reassured that the individual with AS is safer and more tuned in. Educators and employers like it because it allows the individuals with AS to be more independent and aware. One source of such software is a Massachusetts-based company called SymTrend. MGH/YouthCare learned of this software, saw its potential, and contacted SymTrend about using it in our Behind the Scenes teen summer program in 2006.

The software works both on-line and on a PDA. The PDA with its special software serves as a coach, available at all times for guidance about how to handle difficult situations, as a reminder of what to do and what people expect, and as a source of feedback. Three features of the software all contribute to success:

- **Diaries** for self-monitoring
- **Checklists and reminders** about what to do at particular times of day.
- **Guidance screens** presenting strategies for handling challenging situations.

SymTrend has standard screens; schools, individuals and agencies can also create custom screens to meet needs of specific programs or individuals. The latter is what the staff at MGH/YouthCare did. Employers can create custom screens for job task sequences, to aid people who have difficulty with executive functioning, or need to master a new, complex, multi-step task.

**E-Diaries for Self-monitoring**

SymTrend software has self-monitoring diaries that work online and on Palm-based PDAs. These “e-diaries” have rating scales and checklists. Users rate items like anxiety, anger, fatigue, and feelings of control. Some diaries have behavior checks that either remind or check in on a person. For instance: Did you take your meds? complete work? go to all classes? talk with someone? Negative items might include: Did you skip a meal? play video games until way past your bed time? etc. Users can also check if they were derailed by things like arguments with peers, exams, schedule conflicts, or work demands.

Individuals with AS find that daily use of these scales and checklists daily is helpful. One person said, “Tracking my moods is therapeutic. I’m able to put something down so it’s not bottled up. I jot it down, and then it gets out.” Over time, individuals with AS can view a summary of their responses in charts, preferably with a therapist or coach, to look for patterns. (See example below.) The charts make it easier to see consistent relationships between negative moods/behaviors and the stressors that may have contributed to them, so that the user and the human coach can devise better coping strategies.

**Checklists and Reminders**

The software also provides reminders that help a person with AS maintain a schedule and accomplish certain tasks. SymTrend reminders may be checklists to review at particular times of day. Here’s a sample morning checklist:

<table>
<thead>
<tr>
<th>Context: AM Routine</th>
<th>Have you checked these?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pack lunch</td>
</tr>
<tr>
<td></td>
<td>Review today plan</td>
</tr>
<tr>
<td></td>
<td>Pack papers/books</td>
</tr>
<tr>
<td></td>
<td>Notes to teacher</td>
</tr>
<tr>
<td></td>
<td>Schedule/appt bk</td>
</tr>
</tbody>
</table>

An evening checklist might include: Did you pack your backpack for tomorrow?

Users can enter into the date book: repeating appointments, classes, and assignment due dates. A reminder rings at preset times. As one user said, “It really helps you with your awareness of where you are, what you’re doing, and what you need to be doing.”

**Guidance Screens**

People with AS often need help with sequencing tasks, setting priorities, and recognizing others’ responses to their behaviors. E-diaries can include strategies for how to handle a wide variety of challenging situations. For example, a screen can list the steps for what to do when faced with a schedule conflict: keep calm, check available times, see which task has the earlier deadline, compute time needed to prepare.

SymTrend diaries have some pre-set guidance screens. Coaches can also design custom screens. For example, one
person’s screen might recommend: After an argument, do your relaxation exercise. “Testing out the tips, and writing down how it went, has made the reminders stick more than usual,” reports one user.

At MGH/YouthCare we’ve used Symtrend for two years and customized the screens to meet our needs. In our Behind the Scenes teen program, where much of our focus is on self-awareness, social thinking, social skills, and sensory awareness, we decided to use Symtrend to facilitate participants’ learning.

YouthCare staff and teen participants both entered data, so we were able to compare data sets of adults and teens. We collected the data a few times a week during specified periods of the day, and then reviewed it once a week with the teens.

Here are samples of some of our screens’ content:

- Feelings: anxious, relaxed, frustrated etc.
- Self-regulation/sensory: Am I moving around? Am I thinking about what is happening around me? To get my “engine speed” just right I could try stretching, using a fidget, deep breathing, etc.
- Stressors: I didn’t get my way. I have to do something I don’t want to do, etc. Common signs of stress: repetitive thoughts, tense muscles, etc.
- Cognitive flexibility: stuck on thoughts/topic, repeatedly asking the same questions, etc.
- Social pragmatics: Your peer moved away when you were conversing. Were you staying on topic? Did you scan the person’s face/body for information?

During Social Thinking Groups, we discuss their individual data charts/graphs with the teens. Each teen has his/her own charts with both the data entered by teens and by staff. This concrete visual representation proved invaluable for some of our boys. They were able to discuss their data, and recognize the discrepancies between staff perceptions and their own recordings, and make changes in their behavior.

SymTrend is a subscription service available to individuals, schools, or agencies. Once you activate your SymTrend subscription, all you need is need is a Palm-based PDA (a lower end model such as the Zire 22 is adequate). Software customization is available at extra cost. For more information about SymTrend software, including a video demonstration, go to www.symtrend.com or write to Minna at mlevine@symtrend.com. For more information about MGH/YouthCare go to www.mghyouthcare.org or call 617-726-0060.

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**AFTER HIGH SCHOOL: AN ALTERNATE ROUTE**
By Joanne Ludwig

Eric Ludwig has not followed the traditional route for education and work. He was attending public school, where the only special services he received were some pragmatic speech sessions. School was not working for him. It caused a great deal of anxiety and depression. Although he is extremely intelligent, he was not doing well. At the age of sixteen, in the middle of his sophomore year, his parents withdrew him from school. He took his GED immediately and passed it except for the writing section. He took the essay question literally and could not answer it. Then he took that part again with a different question and passed. Eric at 17 is now entering his second year of at Bristol Community College in Fall River, MA, majoring in biology. BCC has not been totally smooth sailing, but he is progressing well in his studies and loves the atmosphere and freedom. His goal is to get a Ph.D. in biology.

Summer arrived, and Eric wanted to get a job instead of taking classes. He looked into working retail at the mall, but decided that was not a good choice. One visit with the intent of applying for jobs was enough for him; the thought of dealing with other teenagers made it a no go. The summer before he had worked a little for his mother in her cleaning business and decided to return. His mother owns an MTOclean franchise and has 12 employees, men and women from 17 to 63 years old, who clean residential homes and commercial buildings. Eric was treated just like any other employee, and had to interact with other cleaners and customers. It was a great opportunity to work on his social skills without much pressure, and with others to back him up. He went through orientation to learn the chemicals and cleaning techniques. He then worked everyday, and the other cleaners asked to work with him. His humor, concentration, and willingness are what they liked the most. Like his colleagues, Eric earned well above minimum wage and got a paycheck each week. His parents told him that he must save half of the money, but he decided since he lives at home, he would save 2/3 of his check. He hopes to buy a car. Eric is very proud of his work, whether he is cleaning a 10,000 square foot mansion with a team, or a three-room empty apartment by himself. Summer of 2007 proved to be a very profitable and good summer for Eric!

(Below: Eric on the job)
We are entering a new era! As the generation of children diagnosed in the late 1990’s comes of age, following the 1994 entry of Asperger’s Syndrome into the DSM-IV, more Aspies than ever are off to college. (“Aspie” is a name coined by adults with AS who are active in the Asperger Pride movement.) Of course we all know there has always been an AS presence on the college campus. (Tony Attwood has joked about going to the physics or the engineering department and trying to find the neurotypicals!) Now more than ever though, Aspies are entering college with a diagnosis. This puts them in a better position to know what kinds of supports might be needed, and where trouble may be encountered, as well as to be eligible for disability services.

While they have this advantage over their undiagnosed predecessors, Aspie college students may still run into difficulty finding the support they need. Given that Aspies constitute a newly identified population on the college campus, students and parents may find themselves in the position of having to educate the disabilities services office about what help Aspies may need and why. In many ways, this generation of college-age Aspies are the trailblazers. As with all trailblazers, obstacles will be encountered, but each one that is overcome makes it that much easier for the next person. So if you are one of the pioneers of the class of 2011 (or even 2010, 2009, 2012 or 2015), here are a few suggestions to keep in mind as you plan, begin, or continue, your college journey.

- **Acquaint yourself with the disabilities services office BUT don't make any assumptions about their knowledge of AS.** As noted before, AS is new territory for many student disability offices. Be prepared to explain some of the characteristics of AS, and be concrete about the help you need. Come prepared with books or articles on AS. If you have a therapist, psychologist or previous teacher who you think could help explain your traits and needs, ask if they would please call the disabilities services office on your behalf. Sometimes that outside, professional perspective can be very persuasive.

- **Consider disclosure, on an as-needed basis.** Many Aspies do not feel the need to disclose their AS to the majority of people they encounter in life. As you become an adult, you will need to begin to assess when disclosure might be in your best interest. For example, in explaining to an English professor why a writing assignment with a focus on taking the emotional perspective of another might prove challenging for you, or to the Resident Assistant in your dorm why you may have to leave floor meetings to avoid a panic attack, it would probably be helpful to explain your AS. Disclosure will be legally necessary to get disabled student accommodations, such as extra time or quiet conditions for testing, or help with note-taking.

- **Find activity-based clubs.** This is sterling advice for Aspies of all ages. Clubs based on activities that you enjoy provide a way to meet people where the focus is the activity, and the social interaction is secondary. There is already a shared interest, and a basis to make conversation with others in the group. Often, you will see signs posted that advertise club meetings, and some college web pages list the on-campus organizations.

- **Smaller is not always better.** In “shopping for” a college, the first instinct of many Aspies, and their parents, is that a smaller college community will be more welcoming and easier to navigate than a larger university. While this is true in some circumstances, it is by no means a universal, mainly for this reason: Going to a college with more people increases the chances of finding people that you fit in with and could become friends with. A larger campus may offer more diversity: a place where some unusual Aspie behaviors may not stand out as much. A larger campus will often offer a larger variety of interest/activity-based groups or clubs, and we already know how important those are!

- **Choose a campus first, then establish your network of support.** It has been said that no matter how much support is available, if the campus community clashes with your own personal style and moral code, your chances for success and happiness there are slim. In other words, if you consider yourself a conservative type, UC Berkeley may not work for you even if they have stellar resources for Aspies!

- **Take care of yourself.** In other words listen to your mother’s advice! While it will be tempting to stay up late or eat greasy dining hall food (and there will be some times when you do this), trying to get adequate sleep, to exercise, and to eat nutritious food will keep your body healthy. You will then be better able to deal with the stress that you will encounter as a college student. It is also a good idea to take time out for stress reducing activities, such as doing yoga or taking a walk.

- **Find someone you trust and can talk to.** This may be a therapist or counselor, a life coach, or campus disability services officer. This person can give you advice on han-
B section:

Another death today, usually there’s two or three trains, shootings, carbon monoxide, skiing incidents I’m lucky if a day passes between tragedies

Later, mom shows me a rap style poem
it’s by a girl just my age
for all I know, she’ll be dead tomorrow
I want to cry, but what’s the use?
Tears are cheap these days.

Everyone’s saying we have to do something
it’s like running in place
nothing ever gets done except speeches and “inspirational events”
I’m not allowed to even publish this poem!
If it goes in the paper, tomorrow I’ll have my head on a pike and maybe my mom’s, for “encouraging” me
besides, to the world, I’m invisible
insulated by my teachers and school
Adults don’t like that
they want to rip your protective covers off
and fling you into the snow of life, saying
"Now go do something."
They don’t even care that you don’t know who you are yet or what the hell you’ll be doing at age 21
the only thing I want is to pull the covers up
and go somewhere where there really is love.

Julia Bloom is a 17 year old junior at Arlington High School. She was influenced to write this poem after she saw an article in the Globe about all the violence in Dorchester and Roxbury, MA. She was diagnosed with Asperger’s Syndrome at age 6.

Thank you for all the support and info. Jean Stern has been wonderful. Her calm, knowledgeable attitude is just what a panicked parent needs!

Dear Stephanie, I can’t think you enough for spending time this afternoon; I felt the information you gave me was more valuable than all the experts for the last few years.

Father of a teen, first-time caller

Carolyn K. Hare (shown right with daughter Ella) is the Director of Achieving in Higher Education with Autism and Developmental Disabilities, a Pittsburgh-based agency that provides coaching, mentoring and advocacy for college students with AS, ADD, High Functioning Autism or Non-verbal Learning Disorder. Reach her at (412) 848-9355 or carol@AHEADD.org; or visit the website, www.aheadd.org

Marie Hicks, LMHC works in the Albany, NY area, providing individualized counseling and support to young adults with Asperger’s Syndrome or High Functioning Autism (HFA), primarily in a college setting. Marie also facilitates a social groups for adults with Asperger’s, and has an Aspie sibling. Reach her at (518) 878-5397 or aspergerNY@hotmail.com.
Getting to Know You: Teens Using Self-Knowledge to “Get a Life”
by Ellen H. Korin, M.Ed., Consultant and Coach

Frequently, despite highly developed cognitive skills, underdeveloped independent living and social/communication skills prevent AS teens and adults from getting the life they desire and deserve—but there are things you can do to improve the situation, and it all starts with getting to know yourself.

In 1994 a young woman came to me for help. Michelle had recently been diagnosed with a previously little known “disorder” called Asperger Syndrome (AS). After graduating from Smith College, she felt adrift and unfulfilled. However, she was also smart, willing to try something new, and determined to “get a life”: friends, meaningful employment, and a significant other. So we went to work. Together we created a model—a way of framing important life issues, and a set of strategies for addressing them. Over the next few years, our use of this model led to the attainment of all Michelle’s goals.

Since then, I have used it to help many more teens and adults with AS meet their own goals. People call me a life coach.

We can call this approach the self-knowledge model, founded on the premise that self-knowledge can lead to improved functioning. That is, the more you know about your profile—the specific ways in which AS affects you and affects the way others see you—the more you will be able to change your approach, and to take control of the AS traits that may be interfering with your achievement of your goals. You will also benefit from identifying other things about yourself—your unique set of interests, abilities, personality traits, gifts and challenges—that may not be directly related to AS.

Using the self-knowledge model, however, you can progress toward your goals and improve your quality of life. The process is simple to understand, although the implementation can sometimes be challenging and take some time.

1. It begins with a commitment to a vision: What do you want in your life? What are your personal goals? Where do you see yourself living, studying, or working after high school graduation? How and with whom do you picture yourself spending your leisure time?

2. Once goals are defined the work can begin:
   - What step do I need to take to achieve my goals? What additional information do I need? What new skills do I need to learn?
   - What might get in the way of achieving my goals? In what ways would I need to change my behavior to remove this obstacle or constraint, or what strategies could I use to overcome it?

It can be hard to articulate our own dreams, and hard to see ourselves as others see us. Throughout the process, it helps to have someone else provide another set of eyes and be a sounding board for our ideas. An experienced, trusted adult such as a life coach can provide essential feedback and support. Using observation and formal and informal assessments, constraints are identified, prioritized and targeted. New attitudes, approaches, and behaviors are tried out. This often requires trying “the un-natural”—which makes sense when “the natural” does not seem to be working! This can be difficult, but with support, and ongoing, collaborative modification of interventions, it can be extremely effective.

The self-knowledge model formed the basis for the recent AANE conference for adults Know Yourself: The Key to a Better Life. We will now present it in workshop for teens on Getting a Life that Fits the Real You. In this workshop you will participate actively and constructively in defining your own goals, identifying strengths and enhancing talents, identifying and removing obstacles, and progressing toward a successful future as a young adult. You will lay the groundwork for the “vision statement” that is a required part of an Individualized Education Plan for teens age 14 and older. (Even if you don’t have an IEP, you can still use this important tool to create the life you want.) By creating a vision statement, and presenting it to your educational team, you will be enlisting the energies of teachers and parents to help you succeed and achieve your dreams.

I also present the self-knowledge model in detail in my two books Asperger Syndrome: An Owner’s Manual (2006, for middle school students) and Asperger Syndrome: An Owner’s Manual Volume 2 for Older Adolescents and Adults (2007). These interactive workbooks guide you through the process of identifying your personal profile in order to develop customized interventions. You can use them on your own, with a coach, or in a group with an experienced facilitator. Those who register for the teen workshop may choose to purchase a workbook when registering. You can also buy a copy from the Autism Asperger Publishing Company through the bookstore page of the AANE website, www.aane.org.

Ellen Korin is a special educator with extensive experience in public and private education and an active consultation and coaching practice. The author of two books on AS, she teaches a graduate course at Antioch University New England and provides professional development for educators, clinicians, and parents. Contact her at ekorin@rcn.com to arrange workshops or professional development for your school, parent group, or clinical staff, or private individual coaching sessions. Ellen is working on a new book, Voices of Autism: People on the Spectrum Speak Out about Survival in the Neurotypical World. If you are a teen or adult on the spectrum interested in telling your story (confidentially) and sharing your survival strategies and your advice for the neurotypical world, please contact Ellen at ekorin@rcn.com.

Save the Date of Sunday afternoon November 11, 2007

Ellen Korin will lead a special workshop for AANE teens 14 and older on creating your own vision statement. The vision statement is the basis of the transition plan in the IEP for high school students 15 and up. This workshop is designed to help teens take an active and constructive part in transition meetings by figuring out what they want their futures to look like, and how best to communicate their vision to parents and educators.

Ellen Korin

AANE Journal    Issue 1    Fall 2007
Getting a teen to join a social/pragmatic skills group is challenging, although it should be the next step after becoming aware of and accepting social difficulties. Many teens who struggle with social pragmatics have already spent a lifetime of feeling different. This is especially true of the bright adolescents who are very aware of others and how they themselves fit in or fail to fit into their social sphere.

Let us assume that your teen is in a place where he or she wants some help developing the skills to navigate their social world. What now? Finding a program that does not make the teen feel even more different can be a challenge. Teens as a whole are a tough audience, and as their identities are forming, finding activities that will appeal to them is tough.

The most important ingredient to having a successful teen group is having a leader or leaders who talk to them as if they are young adults. Teens also need to have some say, within certain limits, in what their group is doing. In general, teens like to talk, be heard, be accepted, be respected, and have fun. Not every moment has to be a skill-focused! In fact, focusing too much on the skill of the day is likely to turn off most teens. The group therapy session offered in my practice generally consist of three parts.

The first part is left to our teens to decide, which is a “sure fire” way of ensuring they like what they are doing. Our job as the leaders is to be quiet participants and learn about our group members and their dynamics through observation.

In the second part of our session, we usually have an agenda item that we either present “as is” or we may use an example from group as a segue to discussing the topic. In the former, we may say, “Here’s a topic, what do you guys think about it, and how can a discussion of it be useful?” Again, we empower them to know something about the topic. In the latter, we may say, “Oh, the other day Jane Doe mentioned something about peer pressure at school, how is that going?” And then we, as group leaders, share certain points about the topic while fostering a useful discussion.

Finally, we do something fun: Drama and Improvisation Acting. Since practicing social skills can feel quite infantilizing to teens, the common practice of role-playing situations has often been replaced with drama and improvisational acting. We have found that many teens love drama. Among those who do not, many enjoy improvisation or that “cool” show “Who’s Line is it Anyway?” Generally well received, improvisation and drama games are powerful tools that teach many skills such as nonverbal language, emotion development, theory of mind, team work, confidence, reading other’s cues, and conversation. Some groups enjoy filming a movie over the course of the year, while others like to play drama games. Again, this is their choice, not ours.

During this process, our job as leaders is to help the teens negotiate for their roles and lines, develop their characters, figure out what information is vital for a scene to work from the perspective of other characters and the audience (theory of mind), and work on relaying a message with the appropriate body language, tone of voice, etc. It is so much safer getting direction as an actor, than receiving direction on your own personal social skills! The teens usually love it, and it is amazing to see their pride and confidence over a drama work they created. Even more magical are their reactions when they see themselves on replays. We often hear things like, “Wow, I didn’t know I sounded that way!” or “Hey, what was I looking at up there?” Not only does the individual finally see him or herself as others may, he or she is now starting to attempt to figure that out without having to see it on the monitor (more theory of mind).

One final piece of advice for making a group palatable for teens: feed them! Growing teens lead busy lives, shuffling from one activity to another, and it is very relaxing to come somewhere to share a snack with your group mates!

**Liana Peña Morgens, Ph.D.** is a Licensed Clinical Psychologist and Clinical Neuropsychologist. Besides her own private practice in Waltham, MA, the Morgens Group, LLC, she is an instructor in the Psychology Training Program at McLean Hospital and an Instructor of Psychology at the Harvard Medical School. In the summer, the Morgens Group offers the Drama-Play Connection, Inc. at Regis College in Weston, MA. You may contact Dr. Morgens at 781-899-1160 or lmorgens@hms.harvard.edu about social skills groups, summer programs, and evaluations (including evaluations done in Spanish).
Over the past eight years, I’ve had the occasion to participate in many school based team meetings for my two sons. Both of them have learning issues, both have been on IEPs and on 504 plans at different points in their education.

I barely remember our first meeting, back when my now 8th grader was in preschool. I do remember walking into it full of fear and expectations, feeling that the team would have answers for us and a plan to help my son function in the classroom. I walked out with more questions and little confidence that the meeting had made any difference.

It had nothing to do with any animosity between us (parents) and the team—in fact, the members of the team were kind, caring, and responsive. The failure of that meeting was due to a mismatch of expectations. I was emotionally vulnerable, trying to adjust to this new universe of having my child diagnosed with a developmental disability. In those early days, I mistakenly assumed that my son was a problem to be fixed, and that the team knew all the tools and tricks to do just that. I don’t know what the educators assumed, but I think they wanted to make me feel better about my son’s issues. Neither of those attitudes were conducive to identifying specific problems, and strategies to overcome them.

By early elementary school, I was better prepared. Because I have been a physical therapist for many years, I have a great deal of experience in participating in and leading rehabilitation team meetings. My new strategy for school team meetings was to prepare as if I was at work. Below are specific techniques that, over the years, have made our team meetings productive and ensured that my children are adequately served at school.

**Team Meeting Survival Tips**

*by Lisa Janice Cohen, MS, PT*

- Sit at the head of the table—physically if you can, metaphorically if you cannot. That means taking control, in a subtle way. For example, welcome the team to the meeting and thank them for attending. This is your meeting, not theirs.
- **Set the agenda, and ensure that everyone is prepared to address your concerns.**
  - At least a week before the meeting, send an email to each team member reminding them about the meeting and indicating your agenda. For example: “I am concerned about Johnny’s social skills in unstructured times, such as gym and lunch. He has been coming home every day with his lunch uneaten and says no one will let him sit with them. Please be prepared to talk about alternate lunch plans.”
  - Also, ask that the team members read one another’s reports before your meeting, so you don’t need to waste time reading them aloud.
  - **Establish specific time frames for follow up.** “Wait and see” will only hold your child back from achieving his or her goals. Yes, children mature and change, but “wait and see” can lead to unacceptable delays in implementing treatment plans. The school is focused on this year, this teacher; you need to keep them looking forward, and hold them accountable for timely feedback. For example:
    - “We know Jane has trouble with transitions. It’s two years until middle school. We need to start now on teaching her how to organize her backpack and her homework.”
    - **Ask for specifics.** “He’s doing better in PE” is not a progress report. What does “better” mean? Focus back on the goal, and the discrepancy between current status and goal. Be persistent and assertive in this redirecting the conversation. The only power we have as parents is to show the school how their implementation of a particular education plan is or isn’t working.
    - **Acknowledge successes and struggles.** Let the team know when something was particularly effective. This is especially helpful in transition from grade to grade. Equally important, if things are not improving for your child—if the gap between current performance and goal is not closing—re-evaluate. Not every school will be able to serve every child. This is not have to be a failure of either child or school, but a mismatch. Even with the best of intentions, educational plans don’t always work. Rather than sticking to something that isn’t helping, focus on alternatives.

It is difficult to put aside your personal hopes and fears, but if you are to be an effective advocate for your child, you must work to be as objective as possible. Approaching my sons’ team meetings as if they were part of my work tasks has been a successful strategy to keep me focused on those specific problems and goals that the school can and should address. As the parent/guardian of your child, you know that child better than anyone at school. You are your child’s expert. It is your job to be a proactive advocate for your child’s best future.

Lisa Janice Cohen is a physical therapist. She is the parent of a child with AS and a child with NLD.
SEEING WITH A DIFFERENT EYE:
ART BY ADULTS WITH ASPERGER SYNDROME

In January 2008 works from this show will be on display at the Cambridge Multicultural Arts Center and in May 2008 at the Honan Allston Branch of the Boston Public Library. See www.aane.org for more information.

Congratulations and thanks to the members of the art show committee: Kathy Clark, Chair and Curator, Kathleen Pigott, Sheila Berry, Susan Maxfield, & Bill Maxfield. Special thanks due to Bill and Susan Maxfield for donating their labor to frame the artwork. Thanks to art show funders the Hershey Family Foundation and Kraft Foods.
Seeing with a Different Eye: Art by Adults with Asperger Syndrome

Statement by Curator Kathy Clark

This exhibition, which features the work of more than 30 adult artists with AS, is the first such event in the history of AANE. Our purpose is to provide an opportunity for these artists to show an often-dismissive world that they have abilities of great value. Since people with AS are neurologically different from the general population, their lives can be extremely difficult. Yet these very differences allow them to perceive the world in a unique way, often expressing their vision in brilliant works of art. They are seeing with a different eye. Occasionally their work may look conventional, but more often it is unfettered by typical expectations, and therein lies its great appeal. A startling freshness and excitement jumps out from their work. Sometimes it shows an obsessive quality, and at other times it expresses the pain AS artists feel because of being different and socially unaccepted. Yet most often their art is just brilliantly inventive and amazing, taking the viewer into a world so fascinating that it leaves us breathless with its imagination. “What kind of mind ever thought of this?” we ask. The answer is: the mind of an artist with Asperger Syndrome.

Artist Statement by John M. Williams

I am an artist with Asperger’s Syndrome. Living with this disability is like having a TV turned on in your head with the channel changer broken. Thoughts and images swirl around endlessly, making it difficult to stay calm and focused. Art has helped me find a way to calm down and to channel my energy into my work. It is a refuge from the fast-paced chaos of the world around me.

I began creating artwork with clay when I was about four years old. I liked the feeling of the soft clay and I could withdraw into my own world to create my fantasies, usually dinosaurs or other fanciful creatures from my imagination. Today I work in several media, including print-making and collage, as well as clay sculpting. I enjoy combining different materials in my work and use lots of color. My work is energetic and animated.

Art helps me live with my disability. I can escape from the world and channel my nervous energy into creations. I am a visual learner and see the world with a different eye which adds originality to my work. Asperger’s people typically have very specific interests. My passions are history and science fiction and many of my works reflect these areas.

Another characteristic of Asperger’s is the inability to read emotions in other people, making it hard to pick up visual cues in social situations. I find it easier to reflect emotions in my artwork than in real life. In my “face” collages, I try to show the emotion that I imagine the person represented would be feeling. All in all, art lets me expand my horizons and feel part of something great.
Above: John Robison with his photography on display at the AANE art show.
Below: Artist Deborah Sklar with three of her paintings.

John Robison signs a copy of his book *Look Me in the Eye* for Yvonne Christian at the Brookline Booksmith on the evening before the AANE fall conference. AANE co-sponsored the reading. (See book jacket below.)

*Photo: Jamie Freed*
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SO IT’S A MONTH INTO SCHOOL AND…..

by Jean Stern, M.S., Director of Children’s Services

By October, the quiet honeymoon time of getting acquainted and slower academic demands is ending, and everything gets ratcheted up. By now, new and “quirky” behaviors may be seen as annoying, teachers start to feel that it’s time to get going making their academic deadlines, and our children show more signs of stress. Reviewing a new book, Asperger Syndrome in the Inclusive Classroom: Advice and Strategies for Teachers by Stacey W. Betts et al., reminded me of a few pointers that I’ll pass along to you for a smoother fall.

Did you provide your child’s teachers with a brief introduction or description of what makes a successful day for your child? Chatting in person is best way to start, but be sure also to hand him/her something in print for the teacher to refer to afterwards. We know teachers should have the IEP at hand, but your concise paragraph and conversation might get the critical points across more effectively. By October the teacher may really see the need for your advice, and be willing to try your proven strategies.

Teachers know that a good home/school communication system is going to help them, but they will probably be swamped at school start-up. You can facilitate the process if you work with your child’s educational team to create a simple communication system, preferably a one-page form. Provide space for messages going both ways, and clear sections for what you need to know (homework assignments and details, upcoming requirements or events to prepare your child for); it will help get the system going quickly. If the teacher has not had the time to provide this for you, s/he may really appreciate your support and will remember this kindness later.

The sections you provide in the form also let the teacher know those areas that will need the most communication in order for things to run smoothly. You can shape the focus of the exchanges. Any of the following might be some areas to work on together. Only do what you can, and in your child’s priority order.

Other ways to help your child:

• Provide down-time when your child comes home.
• Get an additional set of text books to keep at home.
• Each evening, review the next day’s schedule.
• Practice the locker combination, or provide a lock with a key for school. (N.B.: Look for new alphabetic combination locks!)
• Ask for a homework materials list for your child, so you know what to get out at home, and for a homework checklist for the child to check off items when done; talk with the teacher ahead of time about which assignment it’s o.k. to drop on a difficult night.
• Assist in starting homework and prioritizing assignments.
• Talk to the team about limiting the amount of writing teachers expect.
• Ask for notice of tests, so you can review content with your child.
• Rehearse and desensitize your child to the worst sensory school moments.
• Work on hygiene issues.
• Practice school-provided, popular, age-appropriate social topics to talk about.
• Be sure your child has time each night for a joyous, relaxing activity.

Parenting a child with AS is about being organized but also about being reassuring, being kind to yourself, spraying yourself with “Guilt Away,” and keeping your sense of humor—nurturing yourself so you can nurture your child. 
Advanced Workshop Series for Educators and Professionals

AANE’s Educator Advisory Group recommended that this year, since Tony Attwood and Carol Gray would be presenting such a good foundation at the AANE fall conference—and since many New England educators have already taken courses on the basics of AS, AANE’s educator training should focus on advanced topics presented by top specialists. They also urged us to diversify geographically. We hope you will join us for one or more of the following educator conferences. Of course, parents are educators, too, so you are also welcome to come learn with these wonderful presenters.

The 2007-08 AANE Awards for Excellence in Teaching Students with Asperger Syndrome will be presented at these conferences, where award winners and nominators will be guests of AANE. Winners are selected by the Educator Advisory Group—some of whom won this award in previous years. Winners will also be recognized at the Massachusetts State House in the spring.

Self-Sufficiency for AS Students by Improving Executive Function Skills
Sarah Ward, M.S., CCC/SLP
October 17, 2007 in Plymouth, MA

Classroom Accommodations for Elementary AS Students
Alex Michaels
November 28, 2007 in Worcester, MA

Social Thinking Live! Teaching Social Skills in Elementary Classes
Lori Hodgins Brazell
January 23, 2008 in Marlborough, MA

Advanced Strategies for Teaching Social Skills in Your Existing Groups for AS Students
Pamela Ely Martins, MS CCC-SLP
March 5, 2008 in Brockton, MA

Registration forms and more details are available at www.aane.org.

Congratulations to the 2007-2008 Winners of the AANE Awards for Excellence in Teaching Students with Asperger Syndrome

Michelle Dextraze, School Aide, Norfolk, MA
Laurie DiBella, Teaching Assistant, Needham, MA
Midge Foley, Kindergarten Teacher, Roslindale, MA
Maura Forcier, Kindergarten Teacher, Brookline, MA
Patrice Glancy, SpEd Teacher/Inclusion Specialist, Allston, MA
Amy Gordon, ASD Consultant, Marshfield, MA

Marissa Gumas, 7th Grade Math Teacher, Medfield, MA
Barbara Newkirk, High School SpEd Teacher, Lexington, MA
Jaclyn Quesnel, Guidance Counselor, Shirley, MA
Arlene Shainker, Assistant Director of Student Support K-8, Northborough, MA

On-line Support Group

We’ve had a wonderful response to our on-line support group for parents of children with AS from all over New England, now over 160 members strong. Below are two typical comments from parents on the value of the group:

“This support group has helped me so much!! I have always felt so alone and overwhelmed, but since hearing and “talking” to the others in the group, I know I have the support I need. I have learned so much from others’ experiences, and it is very nice to get advice from someone who has been there.”

“For us, this group has been like a lifeline. We do not have any support groups where we live, so this is the first time that we have been able to talk with parents in similar situations. It is so wonderful to know that we are not alone, and that our son's issues are very similar to those of other children with Aspergers. We have learned valuable tips, and have learned about important resources.”

How wonderful to have a community where parents feel understood, appreciated and safe! Parents ask questions, share experiences and information, and offer emotional support to each other. Please consider joining us if you have a child in elementary or middle school with AS or a related diagnosis. First, please check that your AANE membership is up to date. (Scholarships are available in case of hardship.) Then just e-mail me at Brenda.dater@aane.org.
AANE STAFF PORTRAITS: STEPHANIE LOO, M.ED., DIRECTOR OF TEEN SERVICES

by Debra Cash

The melodic, reassuring voice that parents of teens hear when they call the AANE belongs to Stephanie Loo, AANE’s Director of Teen Services. As the mother of a 20-year-old college student with AS, Stephanie herself has navigated many of the same perplexing roads as other AANE parents.

When Stephanie began working at AANE three days a week in 2001, her primary responsibility was writing grants proposals, but fielding calls from parents became part of her job description early on. Stephanie found she loved talking to people whose experiences she had shared, and whose frustrations and devotion to their kids she knew intimately. Working closely with Dania Jekel and a panel of AANE parents and adults with AS, Stephanie also helped develop improved versions of AANE’s information packets. On this project, Dania says, Stephanie’s writing skills and insight as a parent were invaluable.

“A few years ago, Dania recognized that AANE needed to start a new support group for parents of adults, to deal with issues like independence, housing, and employment,” Stephanie remembers. “So I took on facilitating AANE’s group for parents of high school students.” Kids who are stable in elementary school often find themselves at a loss when they undergo the multi-faceted changes of adolescence, and enter the larger, more impersonal world of high school. The social pressures of high school life that often make even neurotypical students anxious, can drive students with AS to depression or even hospitalization.

“High school can be a vulnerable time for any teenager,” Stephanie says “but kids with Asperger’s sometimes enter high school and are suddenly aware of how socially marginal they are.”

The solution? AANE’s efforts are as varied as the families it serves. One of the privileges of AANE membership is access to an on-line forum where parents of teens from throughout New England can exchange resources and strategies. This fall, AANE is experimentally offering monthly teen social events to build community: a pizza and game night, indoor rock climbing, and a visit to a laser tag arcade, where teens accompanied by a parent can enjoy themselves under the guidance of Kathryn Jantz, a graduate student at the BU School of Social Work. A few AANE parents have volunteered to host teen house parties, and Stephanie has helped developed an event “planning kit” to smooth the arrangements.

More formal information is being shared too, at events like AANE’s recent college panel presentation. Soon Terri McLaughlin from the Federation of Children with Special Needs will give a two part transition planning workshop to help parents make sure their teens use their high school years to prepare for adulthood. Ellen Korin will give a workshop for teens on planning for adulthood. Also, Attorney Barbara Jackins, author of Legal Planning for Special Needs in Massachusetts, and psychologist Kate Collins-Wooley will be explaining legal issues around SSI for teens turning eighteen.

“AANE is a nice hybrid of a grassroots organization of parents, and a professional organization that is led by trained social workers and educators,” says Stephanie, who earned her M.Ed. in at the Eliot-Pearson Department of Child Study at Tufts, but feels that her most important qualification for her work at AANE is a “life experience MSW.” “Every one of us at AANE has a real respect for the parents who call. When parents call, it’s important that they get a person who really understands, emotionally, how hard it is. At the same time, they’re not just getting information based on our gut feelings. We are constantly learning from the top professionals in the field.”

“We don’t have all the answers,” Stephanie says. “I often remind parents that we’re a pioneering generation. Although public awareness is growing, to a large extent Asperger Syndrome is still an invisible disability. Often, parents of kids with Asperger’s still have to take the lead in educating the teachers and the doctors.”

Recently, AS has been in the news in more positive ways that increase public awareness and understanding. Mark Haddon’s novel The Curious Incident of the Dog in the Night-Time stayed on the best-seller list for months, and John Robison’s new memoir, Look Me in the Eye promises to further educate the public. People with Asperger’s have been featured on the front page of the New York Times and in lengthy features in the Boston Globe. Recently, noted music critic Tim Page penned a thoughtful, rueful autobiographical essay in the New Yorker magazine that discussed his experiences as a child and adult with Asperger’s.

“More people with Asperger’s are speaking for themselves,” Stephanie says. “Our staff learns from adults in our community and we’ve learned about the “Aspie Pride” movement. The very real accomplishments of adults with Asperger’s give parents of younger children and teens a sense of hope.”

Debra Cash is a longtime Boston arts reporter, user-centered design consultant, and friend of AANE. Contact Stephanie at 617-393-3824 x 6 or Stephanie.Loo@aane.org.
ADULT SERVICES UPDATES

Know Yourself: The Key to a Better Life Successful Adult Conference in July ‘07

On July 7th at Bentley College, AANE hosted its first conference exclusively for adults with AS and related issues. 130 adults attended from all of the New England states, New York, Maryland and even Oklahoma. The conference was well received and provided an opportunity for adults with AS to see the broader community, to find others who shared common interests and to listen, learn from, and interact with our keynote speakers: Stephen Shore, speaking on Self-Advocacy for AS Adults, and Zosia Zaks on Managing your Physical and Mental Health.

Prior to the conference, participants were asked to choose a couple of interest areas, and were seated at tables with others sharing the same interests. The room was soon abuzz with discussions about movies, outdoors and nature, anime, computers (we now know that technology and gaming need to be separated!), aging with AS, recent diagnosis and psychology. (Next year we will put on each table some questions or conversation starters related to the topics of interest.)

After the morning keynotes and lunch, everyone attended one workshop. Choices were: Dating and Relationships with Zosia Zaks, Managing the “Multi”, a workshop on Executive Functioning with Sarah Ward, and Know Your Brand of Asperger’s with Gail Kastorf and Jamie Freed. We ended the day with an optional ice cream social.

Some snapshots of the conference include:

- Many attending the conference were seen to squeezing the fidget balls we provided at registration.
- “I got to meet some really cool people” said one conference participant. Two people who had been communicating by email for years and who lived a great distance from one another but never met who were sitting at the same table. Two adults who had worked in the same city in the same field 15 years apart were able to meet and compare notes.

Overall the conference was a great success, and evaluations resoundingly requested another conference next year or even sooner. We hope to make our next conference even better, utilizing the feedback this year’s attendees provided.

This conference could not have taken place without the support of the entire AANE staff and especially the organizational skills and energy of 2006-2007, BU social work intern and summer fellow Kathryn Jantz. We are fortunate that Kathryn will continue to assist AANE by continuing to facilitate a monthly women’s group and will assist at teen events.

Other News

We were extremely fortunate this summer to have on staff, Stephen Nadel, a dual degree graduate student at BU School of Social Work and BU School of Education. With Stephen’s participation we were able to offer weekly pizza and game nights, an extremely popular activity, in addition to our regular monthly activity based get-togethers. The regularity of the event meant that people attending were really able to get to know and feel comfortable with others in the community. It also meant that the numbers of people attending each P & G night were less than typical than when they are only held every few months. Thank you, Stephen, and we look forward to maintaining our connection with you as you begin our new South Shore based discussion/activity group.

We plan to keep these more frequent activities available with the hiring of a new full-time adult services assistant, Max Sederer. Max has a Master’s in Education and has worked with ASD teens in a school setting. He’s looking forward to facilitating adult activities, running groups and fielding phone calls and emails. (See opposite page.)

We also welcome Lindsey Young, our new social work intern from Boston University. Lindsey will be beginning her clinical training with AANE focusing on individuals and groups.

AANE VOCATIONAL SUPPORT UPDATE

by Gail Kastorf, Director of Vocational Support

Since our last newsletter, my job title has changed from “Employment Specialist” to “Director of Vocational Support.” We made this change to emphasize that finding and keeping a job is an ongoing process. It may begin in high school and continue throughout adulthood. The process begins with identifying one’s talents and interests, researching appropriate jobs using those talents and, for people with AS, developing an understanding of how AS affects one’s ability to perform certain jobs, and what potential work environment will be most suitable. You also need to learn how to advocate for yourself, to follow the written and unwritten rules of the workplace, and to relate to supervisors and co-workers. Eight young adults have begun this process by participating in our pilot course, WORK!? What Do I Need to Know? Susan Shamus and I developed the course and co-lead it.

We continue to spread the word about Asperger Syndrome and employment issues to Massachusetts Rehabilitation Commission (MRC) rehab counselors and provider agency personnel. In June, Bekan Knox and I presented at Autism Spectrum Disorders: Pathways to Employment, a conference for the vocational rehabilitation field at the College of the Holy Cross, Worcester. Jamie Freed and I offered a workshop on AS and work at AANE’s adult conference in July.

The AANE Employment Advisory Committee is still seeking “Asperger friendly” employers. If you know of an employer who has job openings, or is willing to learn more about AS, please fill out the questionnaire at www.aane.org or give me a call.

We are always happy to have new members join the Committee. If you can’t attend the meetings but would be willing to speak to a local Chamber of Commerce about AS, please let me know.

AANE Journal    Issue 1    Fall 2007
Meet Max Sederer, M.A.T.  
AANE’s Adult Services Coordinator

Greetings! I am delighted to introduce myself as a new team member of the Asperger’s Association of New England. My name is Max Sederer, and I have joined as a full-time Adult Services Coordinator. I come to AANE with a comprehensive background in psychological research, with both the American Psychiatric Association and McLean Hospital. I have also had several years work experience with an AS adolescent population while a Teacher at Pathways Academy in Belmont. Additionally, I bring many years of experience running social functions from my time working in the restaurant industry. I hope to bring new ideas and enthusiasm to an already outstanding AANE staff.

Working together, Jamie Freed, Gail Kastorf and I hope to expand both social and support services available to you, our adult members. Some of the events to be held in November and December include: a tour of artists’ studios in Allston/Brighton, a Film Series, a Book Club, a Craft night, Pizza and Game nights nearly every week and more!

I encourage you to contact me at max.sederer@aane.org with any suggestions, questions, comments, or concerns you may have. The more involvement you our members have in planning AANE activities, the more you will enjoy them!

Lastly I want to encourage all our members to attend our upcoming Halloween Party! It will also double as a going-away party for our office at 182 Main Street; in November Please come and join us for food, fun, music and more on Tuesday, October 30 from 7:00-9:00 p.m.

I look forward to meeting you!

(Message from Dania continues here.)

AANE staff members have been heartened in recent months at the number of articles about AS (e.g. Time Magazine), and the emergence of additional positive role models increasing public awareness of Asperger Syndrome. Many people in our community have followed with interest the fortunes of Heather, the first contestant with AS on America’s Next Top Model. Music critic Tim Paige wrote a moving essay in the New Yorker Magazine, describing the impact of AS on his life. We enjoyed meeting author and photographer John Robison. On the evening before our Asperger Connections 2007 conference, several of us had dinner with him and attended his reading at the Brookline Booksmith from his wonderful new memoir Look Me in the Eye. (See page 19.)

Nevertheless, there is still a lot of work left to be done. Tony Attwood told us that an estimated 50% of people with AS are still undiagnosed. This means that here in New England a huge number of children, teens, and adults with AS are still at risk, lacking an essential key to self-understanding, and to the acceptance and appropriate support of family and community. With your support, AANE intends to keep educating the public and reaching out to more and more individuals and families. Thank you for participating in our community as companions, as learners, as teachers, and as donors. We hope to be in touch in many ways over the months to come.

Sincerely,

Dania Freed

Please let AANE know if you change your e-mail address!

Please join AANE staff and adults from our community for food, fun, music & more on HALLOWEEN PARTY!

Tuesday, October 30
from 7:00-9:00 p.m. at
182 Main Street
Watertown, MA
RSVP to Max.Sederer@aane.org

Gorillas
by Jamie Maxfield
"Our society will be defined not only by what we create, but what we refuse to destroy."  

John C. Sawhill

Global warming has gone too far. Polar bears find their dens filled with water; on the other side of the warming earth, penguins float helplessly to sea on thinning ice. What can we do, as the beings changing the earth, to stop global warming? We’ll only know if we try. The chimpanzees won’t help, but we can. If we don’t, floods, famine, sickness and homelessness could overtake the lives of every being on this earth.

Many people don’t understand the fate global warming may bring to our precious planet. They seem to think of the world as their home and how they live it. But is that the world? The world is the state of every thing in the earth’s atmosphere (and much more). The state of the world involves global warming; something so horrible many people refuse to believe it when just outside themselves it is still there, truer then ever. Some humans seem to think (such an awfully human thought) and question to themselves, “Why should I help to stop global warming by doing this – it won’t make much of a difference.” The truth is, it does make a difference.

There are many ways to conserve energy, fossils fuels, and much more with little effort (although it is even better to give much effort to stop global warming). One of the best contributions is educating people about global warming: inspiring others to help conserve. Composting can save large amounts of trash like food and wood shavings from being buried in landfills. Another superb way of conserving energy is using compact fluorescent light bulbs. There are cars that can run on vegetable oil, and an electric car out that runs a whopping 90 miles per charge. One small difference made by one small person can avert earth’s grim destiny.

Have you ever wondered where the oxygen is going? There are two main causes for the decline in oxygen: a significant rise in human population, and the demolition of the Amazon rainforest. Humans take in oxygen and produce carbon dioxide; every day, the human population grows by 219,000 people, which has a large impact on global warming.

Sunlight hits the earth, giving it warmth and energy. Then carbon dioxide within the atmosphere keeps some of the heat, therefore keeping it at a good temperature. However, with too much carbon dioxide, more than enough heat stays in the atmosphere and the world gets warmer. Meanwhile, in the depth of the lush vegetation of the Amazon, monstrous bulldozers and tree-cutting machines devour hungrily the towering trees, while trucks carry the dry timber to other parts of the world. Generally the Amazon rainforest produces 25% of the earth’s oxygen and with 20% cut down (and a predicted 40% in two decades) oxygen levels are declining constantly. Once farmed, the soil of the Amazon rainforest is drained of nutrients and becomes stretches of barren desert that will not change for thousands of years. In addition, the Amazon produces half of its own rainfall from the moisture it releases into the atmosphere; with less rainforest, drought, famine, and wild fires are destroying the Amazon as well. In 2005 (the hottest year on record), drought caused the Amazon River to drop 40 feet! Vanishing with the trees are habitats valued by South American animals including over 2,400 species of poison dart frogs, jaguars, birds, and much more. What will happen without the plants, the animals, and the oxygen that the earth needs to continue its everlasting cycle of life?

With the warming world, ice caps are melting, endangering not only penguins and polar bears, but causing floods. If the ice keeps melting at the rate it is going, coastland could be flooded, forcing evacuation of human populations, killing crops and destroying valuable animal habitats. Boston, Sydney, and the entire string of Hawaiian Islands could slip under water. The heat would also cause crops to die all around the world, causing an epidemic of hunger. Without our intervention, even forests, grassland, and all the earth’s vegetation could disappear.

Though global warming is a shadow hovering threateningly over our heads and enveloping our earth in its festering haze, we still have hope. Vehicles are being changed to reduce emissions of bad gases and reduce the use of fossil fuels. Recycling programs are being put together. Buildings are being constructed that use less energy. Laws have been passed to conserve energy and protect the earth, although many people want more. Brazil is trying desperately to protect the Amazon. Recently people have become more aware of global warming, and they want to banish pollution from the Earth. There is at least some hope for our heating Earth.

One of my main goals in life is to educate the world about the horrifying state of our earth. When I was eight (2003), I decided I wanted to do something more for the world than just being in it. My birthday was coming up, and I was tired of getting presents that I did not think I needed. In the days that followed, I got the simple idea of a fundraiser: my birthday. Instead of presents, I collected donations for the Snow Leopard Trust. I have done it since then and have found ways of fundraising with my artistic talents too. In total, I have donated over $1,400 to animal organizations, such as the Kiwi Recovery Project, the Darrel Wildlife Conservation Trust, and African Wild Dog Conservation (AWRC). I am participating in environmental actions, such as Step It Up 2007 and The Mass Audubon’s Statewide Volunteer Day. I wish to continue my efforts to change the world and to work with others.

Many things have happened on our Earth, but how many could destroy it? The impact of global warming could destroy what may have once been a place full of life, inhabited by its own killers – yet trying to sustain itself with a power ebbing from its living inhabitants. Imagine a world without life; without trees, grass and, animals; without anything to know what it would be like without life on earth. It is up to us; we have changed this planet so we can change it again – saving our planet until it is no longer enveloped in global warming.

Melissa Sullivan now attends Corwin Russell School. With this essay, while a student at the Bigelow, she won 1st Prize (Middle School) in the 1st Annual Student Energy Conservation Contest, sponsored by the Green Decade, the Newton Schools Foundation and GreenEnergyNewton, with prizes provided by NSTAR.

Many people with AS share Melissa’s concern for the environment.

Heliconia, from the Amazon, Peru

Photo by: Dr. Rick Gillis
AANE Chapters Across New England

At www.aane.org, check the chapter web page for your state to connect with other parents near you; find out about support groups and conferences; communicate your needs, contribute ideas, and volunteer. AANE chapters are staffed by dedicated volunteers; so anyone in need of information, support, or referrals should generally start by contacting the AANE “parent” office in Watertown, MA.

AANE New Hampshire Chapter

Hope everyone is relaxed after summer! Things for AANE-NH are picking up for fall. We invite all interested persons to attend our monthly Chapter Meetings. We meet to plan for NH events, find out what’s happening in the state that’s relevant to AANE-NH, and to find out how we can work together to support families and individuals. We meet the 3rd Thursday of every month at 6:30pm in Concord, e.g. October 18th and November 15th. We hope people will take this opportunity to become part of a great group that is working hard to support families and individuals with AS.

Our Open Membership Meetings are held around the state to help promote the AANE membership opportunities and to bring guest speakers to different areas. Our next one is Sunday October 28th on the seacoast at 1:30 -3:30pm. It will be held at Wentworth Douglas Hospital in Dover NH in auditoriums #2 & #3. Traci Gilman OTR will be the guest speaker. Another Open Membership Meeting will be held on Sunday Dec. 2nd in the Nashua area and the guest speaker will be Teresa Bolick. Pre-registration is requested, more information to be announced, check out our NH website link at www.aane.org.

It is with great sadness that we said goodbye to three board members this summer. They are Carol Clark, Jean Rich, and Wendy Watts. They have worked hard to support individuals with AS, and their time on the board has been greatly appreciated. They will be missed! Wendy will still be handling our website and other internet business—thanks, Wendy.

Finally we welcome Robin Lurie-Meyerkopf as the new Information Specialist for AANE. She is on board to help families and individuals who need information in the New Hampshire area, but is also available to look into issues for people in Vermont and Maine. She is a graduate of the ASD program at Antioch New England and has worked with children and families for over twenty years. She can be reached at robin.lurie-meyerkopf@aane.org or 603-520-4780. Please call or e-mail Robin with questions or to register for the Open Membership Meetings.

Directions to monthly AANE-NH Chapter meetings: Exit 2 off of Rte. 393 in Concord. Turn right onto East Side Drive, travel about 1 mile; look for Havenwood Heritage Heights on the left. Pull into parking area and we meet in the large recreation building. It is 33 Christian Drive which is off of East Side Drive, between Loudon Rd. and Hazen Drive.

AANE Maine Chapter

Adult Activity/Parent Support Group

meets at
National Semiconductor - 5 Foden Rd, South Portland
1st Thursdays, 7:00pm - 9:00pm
Marc.Landry@nsc.com or 207-671-7180

Group for Adults with AS

meets at
YWCA - 25 Campus Drive, New Gloucester
1st Saturdays, 1:00pm - 3:15pm
Lena Hann: lenahann@yahoo.com or 207-783-1411
Bette Johnson: bjohns4@maine.rr.com or 207-939-5310

AANE Rhode Island Chapter

For all activities, contact Chapter Director Barbara Whalen at 401-333-1705.

Group for Parents of Adults

Second Mondays of the month, 7:30-9pm
Bradley Hospital, Providence, RI

Group for Adults with AS

Second Mondays of the month, 7:30-9pm
Bradley Hospital, Providence, RI

Support Group for Parents of School-aged Children

Last Mondays of the month, 7:00pm
Meets at the Autism Project, 51 Sockanosset Cross Road Cranston, RI; 401-785-2666
Facilitator: Barbara Whalen, B.A.

Adult Pizza Night, last Fridays of the month, 7:30-9pm
Neurodevelopment Center
260 West Exchange Street, Providence, RI
Cost: $3 per person, pay at door.
New members must contact Barbara Whalen to attend!
A HEARTFELT THANK YOU TO ALL OUR GENEROUS DONORS

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Please let us know if we have inadvertently omitted or misspelled your name, so we can print a correction.

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In Memory of Joe Tompkins, beloved husband and father. My deepest condolences.
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Message from
Kristen Z. White, M.Ed.
Director of Development

I have been a part of the team at AANE for over a year now and have greatly enjoyed getting to know many of our members, donors and Gala committee volunteers. We are currently recruiting individuals for the development committee, now co-chaired by AANE board members Bonnie Betters-Reed and Bill Flaherty. Also, this fall, networking receptions for AANE supporters are planned at four volunteers’ homes in the Boston area with Elsa Abele as the featured speaker.

If you would like to become active in one of our committees, or share ways you would like to support AANE or refer us to other prospective donors, please contact me. Also, watch your mail for our fiscal year 2008 Annual Appeal, and please be as generous as you can. Your support is critical in sustaining and expanding AANE’s services and all that we do in support of the Asperger’s community.

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AANE Administrator Lisa Grafeo (right) and Administrative Assistant Carynn Meyers, Bekan Knox, who works with Ann Holzman, Charles Donald, Edith Burns, and Marcella Baird to see that hundreds of information packets are mailed out. Lynn Flaherty, our Family Grants Administrator; Leonard Rizy, Ann Woodbury, and Hannah Yelin who have been working with Mary Ann Medlar to update our referral database. Jodi Scaltrete, for thank you letters; Erin Flaherty, special projects. Phyllis Hirsch for her work revising our adult book.

Kathy Clark, Bob Clark, Al Clark, Kathleen Pigott, John Williams, and Nomi Kaim for setting up and staffing an AANE booth at the Cambridge River Festival.

Asperger Connections conference volunteers Cindy Bondi, Edith Burns, Joan Geist, Jennifer Goldman, Martha Heassler, Nomi Kaim, Bekan Knox, Ryan Lewis, Steve & Nancy & Ben Meshon, Gina Minks, Nancy Mulloy, Robin Parker, Roberta & Michael Scanlon, Nancy Schwartz, Miriam Scrivener, Ingerid White, & Ann Woodbury

College Panelists Hannah Yelin, Jamie Williams, Jim Williams, Tricia Feldman, Korinne Hertz, Marie Hicks Gala film crew Kaz Gamble, Director; Andrea Ajemian, Producer; Jesse Albro, Intern Parent support group and adult group leaders Gina Beaney, Ellen Boudreau, Susan Brooks, Lorraine Cavallaro, Peggy Chapman, Christine Connolly, Stephanie Gammons, Lisa Grant, Phyllis Greene, Joan Hoffman, Martha Hartnett, Tricia Huff, Barbara Ives, Carol Keating, Lucie LaJeunesse, Dolores Lopes, Grace Myhill, Suzanne Phillips, Anne Reel, and Niki Wilson.


Jane Mildred for her years of service as an AANE Board Member. Jane drove to Watertown every month for board meetings. She will remain involved in developing AANE’s Western Massachusetts Chapter.

BEST WISHES FOR HEALING TO:

Steve Lewis
Tom McQuoid

OUR CONDOLENCES TO:

Phil and Susan Schwarz, whose generous donation we forgot to list on the donors’ page of our spring 2007 issue.
Beginning college is a big step for most kids, and can be even tougher for young people with Asperger’s. If you choose to live on-campus, it means leaving your family and your home and moving into a dorm room with one or more total strangers. College students don’t have to take nearly as many classes as high school students, but the work load is still pretty heavy. Even so, if you play your cards right, college can be fun.

The most serious problem I had starting college was dealing with my roommates. During my first semester, my three roommates thought I was a total weirdo because of my strong interest in the Lord of the Rings. I guess they just couldn’t get it into their heads that we don’t all have to be preppy, stuck-up fashionistas. I couldn’t stand that they left the lights on when I was trying to sleep, or that they had boys in the room almost all the time. And not just regular boys; their guy friends were really immature. You probably know the type.

Luckily, I had already dealt with childish boys before, and I knew that immature guys should just be ignored, unless their irresponsible behavior turns to harassment. If anything they do makes you feel awkward and uncomfortable, you should report it to someone with authority, like a teacher or, in a college situation, the hall staff. Also, remember that there are still nice boys out there, and that even jerks can get more mature as they get older.

I didn’t disclose my AS to my roommates; I figured it wasn’t worth it to swap being stereotyped as a weirdo for being stereotyped as a SPED kid. When another girl who liked to hang out with my roommates asked me if I wanted to switch rooms with her, I jumped at the chance. For the rest of the year, I lived in a dorm room with a girl whose home was really close to the campus, so she was out of our room a lot. That suited me fine because I like to have a little alone time. I didn’t disclose to her either because she and I just didn’t talk much. We let each other do our own thing.

Making friends on campus can take time, but it’s totally worth it. If you want to make friends, I think the best thing to do is join a school club. I joined my college’s Christian Fellowship early in the year, and I’ve made quite a few friends through that. I also got to know a few people by being involved in a play that the school’s theatre department put on. Clubs are good friend-making places for people with Asperger’s because everyone there shares a common interest, and because the club meets regularly at a specific time and place.

Learning strategies for making friends and socializing is key for anyone with AS, but being supported by your surroundings is really important also. School special education programs are good if you need a little extra help, but family is also an excellent support. The best thing parents can do for their kid with AS is to learn about AS by reading books about it or attending presentations like this one. I was diagnosed with AS when I was seven, and once the people around me started learning about my differences, my life became a lot easier.

When the time came to start looking at colleges, I made sure to put some schools with good special education programs on my list, which is why I ended up going to Westfield State College. The most important advice I can give to kids about choosing a college is: pick a favorite school, but remember that almost nobody ends up going to his or her first choice for a college. If you know a kid who ended up disappointed by the school search, the best thing you can do is give sympathy rather than give advice.

Transitioning to college has its ups and downs, just like everything else. Even if you end up with the Roommate from the Black Lagoon, or if one of your professor’s lectures put you to sleep faster than knockout drops, there’s always a way to smooth over the rough spots and enjoy your time at school. And I certainly couldn’t have made that transition without the years of experience that led up to it. Almost a year ago, at my college orientation, some professor told me that my four years of college were going to be the best years of my life. I still have three years to figure out if she was right or not. Now I’m going to tell you something similar–the years of your life that you’re in now are going to be among the best. You have the opportunity now to discover who you are. Enjoy it.

Caitlin Medlar presented this talk for AANE’s Teen Girls’ and Moms’ Afternoon Out in the spring of 2007. She is currently working at Disney World through a program connected with her college, and will return to the Westfield State College campus for the spring semester.

Note from AANE Staff: Parents should be aware that even if a college has AS-savvy disability officers, you should not assume that your student will access their services. College students are expected to take the initiative to seek out the help they need. You may need to expend energy and ingenuity to persuade your young adult son or daughter to go to the disabilities office, academic advisor, or other support staff.
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