Front cover: AANE Board members Dave Harmon (left) and Michael Wilcox (right) holding copies of the recently released Massachusetts Autism Commission report. AANE Executive Director Dania Jekel also served on the Commission.

Left: Dr. Tony Attwood (in jacket), the speaker at the AANE fall 2012 Asperger Connections conference, speaking with an AANE member. If you missed hearing Tony this year, you can view videos of his talk on the AANE member page.

Above: Jonathan Rintels, author of “Lifemobile.”

You may purchase books by Tony Attwood, Jonathan Rintels, and David Finch through bookstore at the AANE web site.

Above: Chris Mulligan, LCSW, keynote speaker at AANE’s spring conference on “Asperger Syndrome and Technology: Pitfalls and Potentials.”

David and Kristen Finch signing books after speaking for AANE. David is the author of “The Journal of Best Practices: A Memoir of Marriage, Asperger Syndrome, and One Man’s Quest to be a Better Husband.”

For more perspectives on Asperger marriages, please see pages 4-9.
Dear Friends of AANE,

Research is now showing that nearly 1 in 50 children have a diagnosis of autism and, although the diagnostic label for Asperger Syndrome may be changing with the upcoming publication of a new diagnostic manual, the daily realities do not change. We all know the anxiety that we and our loved ones feel as they face a new homework task, or a new social situation, or as they stand on the threshold of college or a new job. No matter what name is given to the constellation of factors that affects people with Asperger Syndrome, what it means—for individuals and for the people who love them—remains the same.

In this issue of the AANE Journal, we acknowledge the struggles, but also celebrate the journeys of individuals and families living with Asperger Syndrome and similar conditions. We applaud the ingenuity and quiet heroism they exercise every day in order to survive and even thrive. We salute the dedication of those educators and professionals who strive to understand and to help. We pause to savor the joys that come with small but meaningful successes.

Since 1996, AANE has been here to support individuals and families through the lows and celebrate the highs. We have always served the individual, not the diagnosis, and we will continue to do so, with more urgency than ever. In the last year we have redoubled our efforts to ensure that people with AS get the services they need, implementing our strategic vision to:

• Expand adult services, offering more support in key areas such as college, employment, daily living skills, housing, and relationships.
• Expand family services and promote family connections through on-site education and support, and webinars that allow families to learn regardless of their location.

• Broaden our trainings and workshops to reach a wide range of service providers.
• Become the leading voice in the state legislature on issues affecting individuals with Asperger Syndrome and related conditions.

With your participation and support, we will continue to pursue our mission, working with individuals, families, and professionals to help people with Asperger Syndrome build meaningful, connected lives. Together, we will ensure that people with AS and their families are heard, and that their needs are met.

We thank you for your generous support. We invite you to continue this challenging, often surprising, and deeply rewarding journey together, as part of the AANE community. We wish you a wonderful spring and summer, and look forward to seeing you at the AANE Laugh Out Loud Gala on May 18th, and on October 4th and 5th at Asperger Connections 2013.

With gratitude,

Dania Jekel   Shannah Varón
Executive Director  President, Board of Directors

Enjoying the AANE 2012 family summer picnic!
Marriage, Asperger Syndrome, and Emotional Streaming

by Amanda J.

It was two and half years ago, at the age of thirty-three, when I was first presented with the possibility that I have Asperger Syndrome (AS). After the shock wore off, I quickly came to realize how helpful the AS diagnosis could be in helping me sort through the mysterious and recurring sets of difficulties I had experienced in most aspects of my life. The fact was that I had already spent half my life dealing with mental health issues: in particular, recurring bouts of depression, some being very deep and very resistant to medication.

At the same time, I had accomplished many of my life goals. I had completed my education after spending eight years at a Boston area university getting my bachelor’s degree, law degree, and MBA. Eleven years earlier I also had met my husband, T, in college, and we’d been married for five years.

As I examined the impact that AS had made on my life, I also considered how my marriage was affected. I was fortunate to find it had remained relatively untouched by my AS (at least compared to the rest of my life). That said, I truly believe I am extremely blessed in my choice of spouse.

My husband is firmly in the realm of the neurotypical (NT) world, but his own unique set of traits seems to help bridge the divide between NT and Aspie (person with AS, also used as an adjective). He is an incredibly empathetic person who hates to cause me any pain. He’s an introvert, which probably helps a lot since I need plenty of down time. He is also a geek who enjoys, among other geeky interests, role-playing games, Star Wars, and medieval weapons. And like many geeks, he long ago moved beyond the need to be judged as “cool.”

I know T appreciates a few of my AS characteristics a lot. I cannot play emotional games: I must be direct and honest. If I have a problem, I want to deal with it directly. While this made junior high a living hell for me, it has served us well as a couple. T is not left guessing what I really mean or want.

The most important lesson I’ve learned about making our marriage work, however, I learned the hard way. Like many Aspies, I tend to have a relatively poor understanding of my inner emotional state. Frustrations and irritations (of which there seem to be so many) build up over time until the compressed emotions, now ripened into rage and angst, cannot be ignored any longer. At that point, I have one choice and that’s to let the emotions out: I have a meltdown.

About a year into my last major depression, after a medication change and the ensuing set of miserable side effects, I had a major meltdown where I launched into a full scale attack on T. My frustrations with my mood, and with the lack of progress from the many rounds of medications, plus the stress of a recent trip to a family funeral, had all been compressed and commingled and fermented into pure rage, and it all came pouring out of me in torrents of emotions.

In this meltdown, I apparently went through “everything T ever did wrong since the day we met” and then some. When it was over, he made it clear that what had happened was unacceptable; he didn’t deserve to be (emotionally) attacked to facilitate my meltdown.

It was then that I committed myself to the following: I will not direct emotions at T that are not about T. I may vent emotions in T’s presence, but emotions arising from my interactions with the world—be it work, my health, my AS, my family, his family, the house, the cars, whatever—MUST NOT be intermingled with emotions about T, our marriage, and our home life.

In other words, do not cross emotional streams.

T is my spouse, partner, friend, lover, supporter, and confidante. He is a person I respect immensely, and I have chosen him to be in my life. He is not my whipping boy or my punching bag, in any way, literally or figuratively. He is on my side, supporting me; so he deserves more from me than to be the target of my angst and annoyance about unrelated people and things.

For us, this separation of emotional streams can be as simple as starting a vent with “I need to vent—just listen.” And while I need to be just mindful enough to stick with the stream of emotions unrelated to T, a good rant about only those topics is cathartic and can go a long, long way toward providing me with emotional relief.

If I err, T does forgive me, and quickly, but that forgiveness doesn’t mean I have permission to berate him in my pursuit of emotional catharsis. In fact, my revelation from the aftermath of my meltdown was that T’s love for me and his role in my life meant I must do what I can to prevent him from being in the cross-fire of my emotional outbursts.

Yes, I have to be mindful of this as I manage my mental and emotional resources, something that, ironically enough, takes up mental and emotional resources. However, on balance it’s worth it, because T deserves that effort, and I know T’s support of me, as I try to live the life I want and become the best partner I can be, helps make that journey possible.

Amanda J. is an adult-diagnosed Aspie living and working in the MetroWest Boston area. She and her husband have been married almost 8 years. Amanda sometimes imagines that her streams of emotions look like the streams of energy created by the proton packs in the movie “Ghostbusters.” According to the wisdom of the great Dr. Egon Spengler, “Don’t cross the streams... It would be bad.”
The Asperger’s Association of New England (AANE) has been offering Partner/Spouse Support Groups and Couples’ Support Groups for about ten years. Since most of the couples we see consist of a neurotypical woman married to or partnered with a man with Asperger Syndrome (AS), in this article I will often speak of “the wife” (understood to be neurotypical or NT, i.e. not having AS) and “the husband” (understood to have AS). The principles below will apply whether or not the couple is married, whether the wife or the husband is the partner with AS, and in same-sex couples. (Similar dynamics may also obtain in couples where both partners have AS.) I may also refer to the couple as “neuro-diverse.”

In our groups and couple’s counseling sessions, we have observed recurring issues or challenges, and common strategies for addressing them, which I am calling here the fourteen practical strategies for facilitating an AS marriage, namely:

1. Pursuing a diagnosis.
2. Accepting the diagnosis.
3. Staying motivated.
4. Understanding how AS impacts the individual.
5. Managing depression, anxiety, OCD, & ADHD.
7. Creating a Relationship Schedule.
8. Meeting each other’s sexual needs.
10. Coping with sensory overload and meltdowns.
12. Improving communication.
14. Managing expectations; suspending judgment.

1. Pursuing a diagnosis

Diagnosis is an important step in starting to work through issues in an AS marriage. Even if the diagnosis isn’t formal, it can help lessen the blame, frustration, shame, depression, pain, and isolation one or both partners may be feeling, if they can acknowledge that the characteristics and traits of AS might be causing or contributing to the marital discord. In some cases, even if the husband refuses to get an evaluation, the wife may be able to use her understanding of his probable AS as a tool to reframe her understanding of her husband and change how she relates to him.

A diagnosis of AS can be obtained from a clinician who is experienced in identifying AS in adults, whether a clinical social worker/LICSW, licensed mental health counselor/LMHC, a psychiatrist/MD, or a psychologist/neuropsychologist/PhD or PsyD. It is especially helpful if the clinician’s procedure includes interviewing the spouse or partner and/or other family members.

Diagnosis can also help with finding an appropriate couple’s counselor who can work within the AS framework. Many couples report that working with a couple’s counselor who is not experienced in working with adults with AS can often harm rather than help an AS marriage.

2. Accepting the AS diagnosis

While re-evaluating the relationship in light of the new diagnosis, and striving to achieve acceptance, it is helpful for both partners to continue to seek information about AS, see a clinician experienced with adult AS, and/or join support groups focused on AS marriages or relationships. A detailed understanding of AS—both the challenging and also the positive traits—is important. Individuals with AS can have such highly desirable traits as loyalty, honesty, intelligence, strong values, flexibility with gender roles, the ability to work hard, generosity, innocence, humor, and good looks. Enumerating all the positive and challenging traits of both partners can give the couple a more balanced picture of their marriage.

3. Staying motivated

Both partners need to be motivated to address the issues in their marriage and to commit to its long-term success. Otherwise, any attempts to improve the marriage will probably be short-lived.

In some cases, the NT partner may be so depressed, angry, lonely and/or disconnected from her AS partner, that salvaging the marriage is not an option. In such a situation, the couple can work with a couple’s counselor or mediator towards a more amicable divorce (and resolution of co-parenting issues if they have children).

4. Understanding how AS impacts the individual

Psycho-education is an important part of sorting out the challenges in AS marriages. Reading books on AS marriage written by other NT partners can help the wife by validating her experience and feelings within the marriage. Some narratives paint a painfully negative picture; while it may still be helpful to read these accounts, remember that every marriage and relationship is unique.

Because AS is so complex, and AS traits and behaviors change over time, psycho-education can be a lifelong process. Similarly, neurotypical traits and behaviors are mysterious and surprising to the partner with AS, and merit continued study and attention. It helps to keep learning about one’s partner throughout the lifespan; there is always more to discover about one another.

5. Managing depression, anxiety, OCD, and ADHD

People with AS are at increased risk for depression, anxiety, Obsessive Compulsive Disorder (OCD), or Attention Deficit Disorder/Attention Deficit Hyperactivity disorder (ADD/ADHD). Undiagnosed, untreated anxiety is a major problem for individuals with AS, and can fuel negative AS traits like impulsivity, melt-downs, rage, and withdrawal, all negatively impacting the marriage. It is vital to diagnose and treat depression, anxiety, OCD, or ADD/ADHD with medications or/and therapy.

A life coach who specializes in AS (such as an AANE LifeMAP coach) can also be helpful. Coaches can help the husband resolve practical problems that are draining him emotionally, or causing friction with his wife, such as employment issues, or difficulty with time management, staying organized, or social skills.

Many NT spouses experience their own mental health issues such as anxiety or depression, perhaps partly as a result of being in a long-term relationship with an undiagnosed or untreated partner with AS. In these cases, the NT partner should also receive treatment.  

(Article continues on next page.)
6. Self-exploration and self-awareness

In many AS marriages, the NT partner may be an exceptionally strong manager and organizer, who entered the relationship motivated by a desire to help and nurture the partner with AS. Understanding why she chose her partner with AS is an important step toward becoming self-aware and making some necessary changes in her own behavior. Many of the women in AANE’s spouse groups report having at least one parent with AS. A woman’s experiences in her family of origin may have led her to seek out a spouse with AS because he felt familiar. Some of the NT partners also say that, when they were going through a vulnerable time in their lives, the presence of a strong, quiet, gentle, highly intelligent, and loyal man with AS provided a sense of emotional security.

The NT spouse needs to rebuild her self-esteem and reintroduce into her life some of the activities and interests she may have given up while shouldering the majority of the responsibility for maintaining the household. The NT spouse may also need to look for sources of emotional support outside the marriage, so that she does not rely solely on her husband for emotional fulfillment—as that may not be a realistic expectation.

7. Creating a Relationship Schedule

Even NT-NT couples can greatly benefit from creating a Relationship Schedule: an online and/or paper calendar showing important weekly, monthly, and yearly events such as holidays, birthdays, anniversaries, plus family visits, doctors’ appointments, etc. In an AS marriage, a relationship schedule is an essential tool for keeping the partners connected. It is also very beneficial to add to the calendar times for such things as solitude, conversation, sex, shared leisure activities, exercise, and meditation/prayer.

Holding daily conversations between the spouses at a scheduled time can serve to keep the couple in-sync with each other, amidst the many challenges and activities of everyday life. In addition to scheduling conversations, it can be beneficial to schedule sex in order to meet the needs of both partners.

8. Meeting each other’s sexual needs

Having a discussion about which days and times to have sex eliminates the guess-work for both partners. However, putting sex on the Relationship Schedule isn’t enough. Neurological differences apart, partners may have major individual differences in how they want to be intimate with their partners, not only how often. It is helpful for both partners to communicate their sexual needs verbally, in a clear and detailed manner.

Adults with AS may either want a lot of sexual activity or very little. Some individuals with AS don’t enjoy sex due to their sensory issues and/or low sex drive. For some people with AS, a light caress of the skin can feel like burning fire. In some cases, an individual with AS can be very robotic; he may be technically perfect in bed, but not pay attention to his partner’s need for foreplay before intercourse and for making an emotional connection.

It is important for the husband to understand that his partner’s sexual needs are different from his own, and vice versa. Both partners also need to work at the keeping their emotional connection going on a daily basis, both inside and outside the bedroom. Learning about each other’s “love language,” as described by Gary Chapman in his book “The Five Love Languages,” might help the couple meet both partner’s individual emotional and sexual needs.

9. Bridging parallel play

Many couples tell us that sharing common interests and activities is what first brought them together: long walks, boat rides, hikes, picnics, dancing, exercise classes, or travel. After getting married, however, life obligations tend to crowd many of these joint activities off the couple’s schedule. Many couples tend to engage in what is known as “parallel play,” where one partner engages in a preferred activity or hobby alone, rather than seeking out his or her partner so they can enjoy the activity together. Because individuals with AS struggle with social communication, initiation, and reciprocity, a husband with AS can literally go days, weeks, or even months without spending quality time with his NT partner, leaving the wife feeling abandoned, isolated and terribly lonely.

Research shows that couples who play together stay together. Playing together—participating in joint leisure activities—can help bridge the physical/emotional distance between the partners. Integrating each other back into the activities that both partners enjoy helps the couple create new memories and experiences of closeness and togetherness.

10. Coping with sensory overload and meltdowns

Individuals with AS often have sensory issues; i.e., one or more of the person’s five senses may be either hyper-sensitive (overly sensitive) or hyposensitive (with low or diminished sensitivity). For some adults with AS, fluorescent lighting may induce an immediate migraine. The noise at a train station, or too many people talking at once at a party, can feel like the loud hammering of metal on metal. Smells at the grocery store can cause nausea. On the other hand, a person with AS may barely feel a hard prick by a needle, go coatless on a winter’s day, or have a weak sense of smell or taste.

A self-aware and motivated adult with AS can reduce or prevent meltdowns by learning to avoid sensory triggers, recognize the early manifestations or warning signs of stress and sensory overload, and develop strategies to short-circuit an oncoming meltdown.

The wife can assist her spouse on his journey to self-awareness. For example, the NT partner may be able to bring attention to the husband’s rising stress level, and suggest that each of them take some time alone to alleviate the overstimulation.

11. Expanding Theory of Mind

Individuals with AS tend to have weak Theory of Mind, meaning a relatively limited ability to “read” another person’s thoughts, feelings, or intentions. While relating to another person, NTs are able to hypothesize with some accuracy what that other person is thinking or feeling, based on a mental map of their own emotions and an intuitive sense of the feelings of other people. Those with AS find it harder to hypothesize about another person’s mental or emotional state. Weak Theory of Mind often leads individuals with AS to say and do things that appear insensitive or are unintentionally hurtful. Over time, the wife’s hurt feelings, pain, and suffering tend to cause some serious tears or lacerations in the marriage.

It is important that both spouses become curious, and learn about each other’s thinking processes, inner worlds, and life experiences, rather than making assumptions or judgments about how the other partner thinks and feels. Open mids allow meaningful conversation and dialogue to occur. Verbalizing details about their inner and outer worlds, in a non-judgmental atmosphere, gives partners an opportunity to understand each other better and to bond.
12. Improving communication

Improving communication is an ongoing task most relationships. Within an AS marriage, the importance of communication cannot be stressed enough, since AS is in part characterized as a social-communication deficit.

Studies show that over 90% of human interaction is based on non-verbal communication. Individuals with AS, who have difficulty picking up and interpreting facial cues, vocal intonations, and body language, miss out on a significant amount of communication.

In some cases, the disconnect in an AS marriage is due to the fact that the partner with AS has great difficulty initiating conversations and keeping them flowing, leaving the NT spouse feeling abandoned and isolated. The NT spouse needs to communicate in clear words everything she would like her AS spouse to know or do on a daily basis, since the AS spouse will not be able to read his partner’s mind, due to his somewhat limited Theory of Mind and inability to read non-verbal cues. For both partners, verbalizing one’s emotional, mental, physical, sexual, spiritual, and social needs in the relationship is the only way to ensure that those needs will be met.

The partner with AS is often willing to meet the needs of his partner once he understands exactly what he needs to do. Merely knowing what the NT partner’s needs are is not sufficient for him to know how to meet those needs. He can, however, learn what to do if he is given a list of concrete, step-by-step actions through which he can offer loving support to his NT partner. For example, some spouses may say, “I’m unhappy because we don’t talk anymore.” It would be more helpful to something like: “I would like for us to have a conversation for about an hour tonight after we put the kids to bed. I’ll put the tea kettle on, and then I’d like to tell you about how rough my week at work has been. I don’t want you to solve my work problems. I just want you to listen, agree, and validate me by saying things like, ‘I’m sorry that those things happened. You’re brilliant at your job and your company is lucky to have you.’” The more specific the instructions are, the better the husband will be able to meet his partner’s needs, and the more satisfied the wife will feel.

13. Co-Parenting Strategies

Individuals with AS can be very good parents when it comes to concrete tasks such as helping the children with their homework, teaching them new skills, playing with them, and taking them on outdoor adventures. When it comes to meeting the children’s emotional needs, husbands might need some coaching and cues from their wives. The mother can help facilitate opportunities for the child to bond with the father. She might have to help the father give the child a compliment, or use the family calendar to schedule daily and weekly one-on-one quality time with each child.

Given the complexity and extra challenges of an AS marriage, and the unremitting pressures of child-rearing, neuro-diverse couples who do not yet have children may want to think care-fully before deciding to become parents. They should realistically assess the strength of their joint economic, physical, and emotional resources, and of their support networks (extended family, accessible people or services in the wider community). In many neuro-diverse couples, the majority of the work of caring for and raising children may well fall on the NT spouse, as the husband with AS may have enough on his plate just managing his other responsibilities, such as holding down a job and keeping himself on an even keel.

14. Managing expectations; suspending judgment

Adjusting one’s expectations to accommodate one’s partner is important for both husband and wife. Understanding the fundamental neurological differences between NTs and individuals with AS is important for partners trying to manage their expectations of each other.

For motivated couples, working to improve the marriage with the various tools listed here can bring about real change and make the marriage more comfortable and rewarding for both. However, working toward marital change and growth can be a slow and painful process for any couple. For any marriage to succeed and thrive in the long-term, both partners have to make a daily effort to do things differently than they have done before. Growth and change may happen unpredictably. Maintaining a high quality, happy marriage is a lifelong commitment.

Couple’s counseling for an AS marriage

All of the steps and strategies described in this article can be addressed in couple’s counseling. With a skilled counselor, experienced in AS, both spouses in the AS marriage are more likely to be able to gain awareness of their own individual patterns of behavior, and learn how they can make both attitudinal and behavioral adjustments to get more out of their relationship. A counselor can facilitate conversations, and help both partners learn better communication skills. The counselor can also help the couple brainstorm, strategize, connect emotionally, and problem-solve around sensory integration issues, melt-downs, and co-morbid conditions such as anxiety and depression.

“If you’ve met one person with AS, you’ve met one person with AS.”

Stephen M. Shore, Ed.D.

While many of the issues and challenges that couples in an AS marriage face can seem similar, it is important to remember that every individual with AS is different, and each marriage unique.

Not all strategies will be equally effective for every couple. Each couple has to brainstorm and trouble-shoot their marriage based on what works for their unique situation and needs. As in any marriage, the key practices for anyone seeking a happy and loving relationship are awareness, understanding, compassion, connection, respect, passion, and trust.

Eva Mendes, M.A. leads Spouse, Couples, and Women’s Support Groups at AANE. She is also a Disability Support Counselor at UMass Lowell. She is presently in the midst of a Post-Graduate Practicum at AANE for her License in Mental Health Counseling (LMHC). As part of her Practicum, she has been seeing individuals (adults with AS and/or their family members) and couples (where one or both have AS) for counseling. Eva received her Master of Arts in Clinical Mental Health Counseling at Union Institute and University in Vermont and her Bachelors of Arts in Psychology from Vermont College. Her master’s thesis was called, “Bridging Parallel Play in AS Marriage.” She may be reached at 617-669-3040 or eva.mendes@aane.org. You may read an expanded version of this article, including a list of references, at www.evmendes.com or on the AANE member page.

To learn more about AANE’s programs and services for spouses and couples, please contact Jamie Freed at 617-393-3824 x 24.
One of my biggest challenges as a psychiatrist treating children and adults with Asperger Syndrome (AS) and related Autism Spectrum Disorders is diagnosing and treating depression. It is important to address this challenge, as people with AS may be at increased risk for depression compared to neurotypicals (NTs, i.e. people without AS). Exploring how negative moods can be woven into their lives—and figuring out how to alleviate those moods—is vital to the overall health and function of many people with AS.

Why might people with AS be at risk for depression? Try to imagine what it must be like to get through a day where it requires constant effort to navigate the natural flow of events in a social environment. I think that many NTs take for granted how naturally and spontaneously they can read social cues, engage in conversations on both familiar and novel topics, and understand how to begin and end social interactions. It is often a system on auto-pilot for NTs, who can meet the average day with a relative calm that comes from knowing they can handle most social situations.

For those with AS, however, the average day can be exhausting, due to the amount of mental effort required to perform tasks such as requesting help, making “small talk,” or buying items in a store. How does the social world appear to someone with AS, or how might the person feel confronting social challenges? Here is what two of my patients have reported:

• One woman with AS described how, for her, social situations seem like a series of decision trees where she has to choose the appropriate response to other people’s questions. She feels she must prepare for social interactions, studying the possible options in advance, so that she can respond in a more natural manner. This adds a tremendous amount of stress to her life, which can lead to social withdrawal, feelings of inadequacy, and overall mental exhaustion, which all combine to provide fertile ground for the development of depression.

• An adolescent girl with AS once told me that she felt as if all of her classmates were speaking a coded language that she could not understand. Some adults in her life were worried that she was paranoid or hallucinating, but in fact her description clearly conveyed her sense of alienation and helplessness. These feelings of isolation occur on a daily basis and can quickly lead to a depressed mood.

Whether you feel that you have to memorize complicated conversation algorithms, or decode a secret language, I can see how facing such monumental tasks can cause or contribute to depression. It is very easy for someone to feel worn down and saddened by these continual efforts, especially if progress is slow. If we add other depressive symptoms such as insomnia, decreased energy, and feelings of hopelessness to the mix, it can become even more difficult to function. I find that treating co-occurring depression, along with other psychiatric disorders, is a major way to improve the overall quality of life for those with AS. However, there are some diagnostic and treatment challenges that need to be addressed as one moves forward in working with someone with AS and a suspicion of depression.

The first challenge I find is helping people with AS connect with and communicate their “internal states.” These “states” may be feelings, perspectives, or self-appraisals which we depend upon to help identify difficulties such as depression in ourselves and others. Even most NTs have difficulty describing exactly how they feel to others. Whether it be imposing upon someone what it feels to be in love, describing the passing of a family member, or expressing the exhilaration of obtaining a reward that was long awaited, we are all often at a loss to put things into words. This difficulty is magnified in those with AS, such that “big picture” feeling states are very hard to describe.

It may also be hard for someone with AS to think of depression as a process tied to a persistent feeling of sadness. The person may state that he or she feels sad when sad things happen, but have difficulty describing whether depression is more subtly, but significantly, affecting his or her day-to-day life. Many adolescents I see with AS, when I ask how they feel, will report “I’m fine!” Their parents may later find out that their teen with AS got into a fight over a social misunderstanding and may not be “fine” at all!

Describing one’s feelings is a social endeavor that allows NTs to find connection with others. For someone with AS, however, telling someone about how you feel can be a social challenge causing significant discomfort. The fear of this discomfort may keep many people with AS from engaging in an evaluation or treatment for their depression. In fact, the therapy may seem or even become more uncomfortable than the original depression!

Another challenge I face in diagnosing and treating depression in someone with AS is collecting helpful and accurate information from others about how that person is functioning. If a person with AS is having difficulty describing how depression feels to him or her, I need to rely on the observations of family members, colleagues, or friends to recognize that something is “off.” However, this is difficult, since the signs of depression in someone with AS may be subtle, such as quietly losing interest in hobbies, decreased energy, and insomnia. Other behavioral difficulties, such as hyperactivity, tantrums, and panic attacks are often easy for people to recognize in others. Someone with AS and depression may be able to keep him or herself together while having ruminative and sad thoughts that could subtly affect the person’s functioning at home, school, or work. Thus, if the person with AS and depression is having difficulty recognizing how s/he feels, and those around the person have difficulty recognizing it, then we are probably missing many people with AS in need of psychiatric care.

The exploration of depression in AS requires patience and perseverance from the person experiencing the depression as well as from the person treating it. Allowing a therapeutic relationship to develop is often the key to successful diagnosis and treatment. Treatment will likely take non-traditional routes, which bring
texture to the experience. While difficult, it is an extremely valuable endeavor. I have the greatest respect for those in the AS community who embrace this often arduous task—whether as therapists or as patients—to try to relieve the painful burden of depression.

**Dr. Todd Levine** is an Assistant Professor in the Department of Psychiatry & Human Behavior at the Warren Alpert Medical School of Brown University. He is a staff psychiatrist at the Brown Center for Children and Families, Women & Infants Hospital, in Providence, RI, where he evaluates and treats children and adults with Autism Spectrum Disorders and behavioral difficulties. Dr. Levine was a speaker at AANE’s Asperger’s & Anxiety Conference in March of 2010. He lectures/consults often on the recognition and management of psychiatric difficulties in those with AS. Dr. Levine can be reached readily via email at tlevine@wihri.org.

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**Yes, Elementary School Students with Asperger Syndrome Can Learn Math!**

by Judy Storeygard

“If you’ve seen one student with Asperger Syndrome, you’ve seen one student with Asperger Syndrome.” This statement about the diversity of children with Asperger Syndrome (AS), tends to be ignored where mathematics education is concerned. Like all other students, children with AS have many strengths that can be applied to their mathematics education. However, because these students are also inclined to struggle with abstract thinking, the focus of their math instruction tends to be on learning procedures and facts. While this approach can be useful, it is insufficient if students are going to understand the kind of mathematics needed to succeed in high school math and beyond.

Parents of students with AS frequently leave parent-teacher conferences discouraged. Too much time is apt to be spent on their children’s deficits. While most parents are well aware of their children’s needs, they are also very knowledgeable about their students’ strengths. For example, one parent knew that her child has an amazing memory for directions, completes complex puzzles easily, and can follow instructions to build models; yet the expectations for him in math class were low. She rightly asked, “How can my child’s skills be used to build math knowledge?” However, parent teacher conferences do not usually include this kind of conversation.

How can that parent’s question be addressed? While it is challenging for teachers to support these students who need help grasping abstract concepts and developing solution methods that can be applied in more than one situation, some teachers have developed strategies that foster students’ understanding. What these teachers have in common is that they do not focus on the students’ diagnostic labels, but assess their strengths and learning needs, and provide a structure and scaffolding that builds their mathematical understanding. They realize that each student is unique, especially when it comes to individual strengths and interests. For example, one teacher had several students with AS in her class. One student had musical talent, and the teacher encouraged him to apply his skill with patterns to the mathematical arena. Another was able to interpret and solve a word problem, but could not explain how he did it. With this student, the teacher focused her instruction on helping him with his explanations. Another student had strong visual/spatial thinking. His teacher utilized his success with models and representations in geometry to help him understand numerical reasoning. These teachers also made it clear to the students that they had high but reasonable expectations for them to make sense of mathematics, rather than merely relying on procedures.

When teachers plan supports to help their students with AS learn mathematics, they think carefully about the language they use. Ms. Santiago asked her student, “How many numbers are between 20 and 30 on the number line?” When the student didn’t answer, Ms. Santiago thought about her wording and changed the question to be more concrete: “How many black marks are there between 20 and 30?” Once the student answered this question, she was able to see the connection between the black marks and the numbers.

These teachers do not expect the students to discover mathematical concepts on their own. They are purposeful in how they introduce concepts and plan interventions. From the beginning of the school year, these teachers work to understand how the student best approaches problems, and to use the student’s preferred style as the basis of mathematical strategies that the student can learn and then use over and over again. The following are some of the strategies that teachers have used successfully with their students who have AS.

**Introducing the Problem: Making Things Explicit**

The teachers in the examples below developed structures and routines utilizing explicit language to support their students’ learning. The support begins as soon as a problem is introduced to the class. The teachers know which of their students might have difficulty following directions that would typically be given to the whole class. The teachers might demonstrate or act out the action of a problem, or ask students to restate what the problem is asking. For example, with the problem, “Ms. Thompson bought books for the class. She bought 27 biographies and 23 novels. How many books did she buy all together?” is a question a teacher might ask. Ms. Thompson asked one of her students, Michael, to restate a word problem without using the numbers at first, to determine if he understood what the problem was asking. For example, with the problem, “Ms. Thompson bought books for the class. She bought 27 biographies and 23 novels. How many books did she buy all together?” She began by introducing the problem without the “27” and “23”. She knew that Michael could usually understand the plot of a story in literature, so she applied the idea of “plot” to mathematics. Once he established what the problem was asking, Ms. Thompson asked Michael to solve the problems with the numbers “27” and “23”. She repeated this process many times until Michael was often able to work independently. When working on a story problem, Ms. Neal introduces it by acting it out, or by using objects to demonstrate the action of the story or situation. This multi-modal

(Article continues on next page.)
strategy benefits her students with AS—and probably some other students, too (universal design). She then has her students write and solve an equation that matches the action of the problem.

Ms. Neal knew that one of her students had mastered his math facts, but did not always know when to apply them to word problems because the language in the problem could be hard for him to interpret. She gave him a set of choices for an equation because she knew it would be hard for him to solve a word problem on his own. She had to work with him to review what “choose one” means, or else he would solve all of the equations. For example with the problem, “I have 7 apples and I need 11; how many more do I need?” she might ask him to choose among: 7+11=?, 7+?=11, and 7-11=?, listening to his thinking as he went through the choices. After using this structure repeatedly with the teacher’s guidance, the student began to work independently.

Using Representations to Model Abstract Concepts

In the examples below, teachers use models, representations, and large motor experiences to get across mathematical concepts, instead of relying on language alone. They also realize that the interventions they develop need to be repeated for the student to integrate the concept.

Beginning with concrete models can be an effective way to help students with AS become familiar with abstract number concepts. With young children especially, actually touching objects can help foster understanding. When Ms. Hall noticed that Shauna was distracted during a conversation about comparing two towers of cubes, she held the towers directly in front of Shauna and moved her hands along each tower to indicate the quantities. She then asked Shauna to touch each cube and count. Shauna was then able to say which tower had more cubes. This teacher often uses gestures and exaggerated body language to make her points.

When Ms. Owens realized that Manuel was not understanding multiplication, she asked him to represent 7 x 2 with tiles. Manuel took out 2 groups of 7 and then 2 groups of 2. Ms. Owens asked him, “How many 7’s are we talking about?” Manuel replied, “7 + 7.” Ms. Owens followed up, “So how times do you multiply 7?” Manuel replied, “2.” He was then able to see that the 2 groups of 2 were not correct and removed them, leaving just the 2 groups of 7. Ms. Owens then added rows of 7 and each time Manuel was able to state the number sentence, “7 x 3, 7 x 4,” etc. She realized she would have to repeat similar sequences over time to help Manuel grasp the concept of multiplication.

Not only do number concepts need to be made accessible, but geometric concepts need to be introduced in a variety of ways as well. For example, Ms. Hall takes her students on a “shape walk” to solidify their understanding of geometry. She found that this strategy particularly helped one of her students with AS who tended to focus on only one aspect of the shape at a time, limiting his ability to identify the shapes. When he went on the walk, he was able to take in the whole figure and remember the shape.

Developing Computation Strategies that Make Sense

Developing reliable ways to do computation can be challenging for some students with AS. The traditional approach to the operations (addition, subtraction, multiplication, and division) has been to offer a procedure such as the traditional algorithm by which many of today’s parents and teachers were taught. While memorizing facts and sets of problem-solving steps has a place in mathematics education, this approach does not build number sense. While many students with AS can memorize these procedures, they may not be able to apply them to problem-solving situations, and when they forget a step, they have nothing to fall back on.

While Michael, in Ms. Thompson’s class, had a good memory in some areas, he had difficulty remembering the steps of the multiplication procedure and became extremely frustrated. He had no idea if his answer was reasonable. When observing Michael do multiplication, Ms. Thompson became aware that he had developed an ability to understand the operation of multiplication, had a sense of estimating and place value, and could use good number sense as shown in his work for the problem 233 x 5. He broke up the problem as follows: 200 x 5, 30 x 5, 3 x 5. He was able to multiply these small parts and add up the answers to each part in order to solve the whole problem. Ms. Thompson’s goal was to help Michael see that this method could be used with other numbers.

After rehearsing with him many times, Ms. Thompson would also call on Michael to explain his thinking to the class, clearly writing his number sentences on a whiteboard to help him organize his thinking. She prompted him with questions: “How did you know that?” and “Did you double-check your work?” explicitly naming his steps and strategy: “So, you used 30 times 5 and 200 times 5 to help you; “So, you double-checked by adding 233 up 5 times and you got the same answer.” As the year progressed and the numbers got harder, Michael was able to use this same strategy of breaking up a problem into smaller problems that he knew how to solve. If he made an error he was able to adjust, because he understood what he was doing. Having a reliable strategy gave him a starting place to build further understanding. As with the previous examples, it is clear that Ms. Thompson used specific language and routines with Michael over time to build his number sense.

Incorporating Technology

Another tool for making mathematical concepts accessible to students with AS is technology. Schools are increasingly using technology, and students and teachers often find these resources an appealing option. However, like any other kind of tool, technology can be used effectively to promote mathematical learning, or it can be used as just another form of drill and practice that fails to build a foundation of understanding.

There are many valid uses of technology for students with AS. For example, tablet computers that have a digital pen can be a valuable resource for students. There are many websites that offer useful resources. NCTM’s Illuminations (http://illuminations.nctm.org/), the BBC website (http://www.bbc.co.uk/schools/websites/4_11/site/numeracy.shtml), and PBS (http://pbskids.org/) offer a variety of games and activities that can help students with AS understand mathematical concepts. CAST, an organization that has been instrumental in developing Universal Design for Learning (UDL) principles, also offers a variety of free multi-media learning tools (http://www.cast.org).
Working with Partners

Much of math class today involves small group or partner work, situations that can be challenging for students with AS. Teachers can try to highlight these students’ strengths, as well as show their own attitude of acceptance. Ms. Thompson has conversations with her students about how to help classmates if they get upset. She also talks directly with potential partners on specific ways to help.

Ms. Neal found that Joe, one of her students with AS, was skillful at teaching the class a strategy that he learned. When she knows that he understands a strategy, she asks him to explain it to the class. Although he doesn’t ask students if they have questions, his explanations make sense, and Ms. Neal might jump in to add to students’ remarks or suggest that he take questions. This practice helps Joe’s classmates see him in a positive light, and they are therefore more likely to work with him in small groups.

Ms. Neal also chooses partners for her students and keeps them in these dyads for a month. Students can then get comfortable with each other and find ways to work together. She finds that one of her students performs better in a group of three, because the other students are not solely dependent on him, and he is able to listen to them. With a group of two, one of her other students with AS sometimes becomes distressed when trying his partner’s method of solving the math problem. Ms. Neal encourages him to take responsibility by giving him words to say: “I’m sorry I couldn’t work with you. I just got stuck.” She also gives the neurotypical partners language to handle the situation. She suggests, for example, that they consider something like, “Sam is doing an unexpected behavior. My strategy is to ignore it and yours should be the same.”

With younger children, Ms. Hall finds that students who are assertive but patient can be good partners for the students who need support with cognitive flexibility, because they can keep the student on task. Sometimes a student who perseverates can actually be a good partner for a child who struggles with expressive language, because the repetition is useful. Pairing or grouping these students who struggle with flexibility is easier when they are playing a game that has a “specific dialogue.” For example, with a card game like War or Compare, the directions and wording are clear: “Turn over your card,” “I have more,” and so forth.

Summary

Let’s return to the parent’s question posed at the beginning of the article, “How can my child’s skills be used to build math knowledge?” The purposeful planning of the teachers described above begins to address the parent’s concerns. These teachers carefully consider each student’s strengths and learning needs. They make sure that each child has an understanding of what is expected during each session, and offer support as needed. Paying attention to how each child learns is a crucial part of their intervention. They take into account the child’s strengths, such as whether a child has good comprehension, memory for details, or good visual-spatial skills.

When parents of children with AS have conferences with the teacher, they might ask, “What do you see as his strengths in math?” and “What are some activities we might try at home?” They also might contribute what they know about their child’s strengths and interests that relate to mathematics. For example, does your child enjoy puzzles, art, music? Does your child follow directions from reading rather than listening, or from symbols and pictures rather than words? Does your child have a good memory for patterns, details, or travel directions? By establishing a dialogue with teachers about what their child CAN do, parents can help enact the statement: If you’ve seen one student with Asperger Syndrome, you’ve seen one student with Asperger Syndrome.

For over 20 years, Judy Storeygard has been a senior researcher at TERC, a not-for-profit organization specializing in research, development, and professional development for STEM (Science Technology, Engineering, and Math) education programs. Much of her work has focused on the learning of students with special needs. Her latest book, written in collaboration with classroom teachers, Count Me In! K-5: Including Learners With Special Needs in Mathematics Classrooms (Corwin Press 2012), uses research-based and field-tested methodology to describe proven approaches to fostering the mathematics learning of students with special needs. The examples in this article are drawn from the classrooms of the talented teachers who contributed to Count Me In. Her previous book is My Kids Can: Making Math accessible to All Learners, K-5 (Heinemann 2009).
How Did You Feel When Your Child Received an Asperger’s Diagnosis?

AANE Parents Speak

At thirteen and a half years old, my son was officially given a diagnosis of Asperger Syndrome (AS). When he was ten, I was told he met the DSM-criteria, but they didn’t trust the evaluation because his anxiety level was too high. I didn’t fully appreciate the diagnosis; I just thought AS meant “bright, literal, quirky kid.” I knew my son was also kind, witty, and compassionate. It was just a part of who he is. He was an easy target for bullying. Then, on another day in a long string of days that he came home from school angry and frustrated, I was trying to get him to tell me what happened at school, and that only made him more angry and upset. There was another woman with me and she just said, “Teens with AS can’t access and identify their emotions the way others can.” She suggested that I contact AANE the next day, I called you. Since then, I have learned so much about AS! I will be forever grateful.

It’s good to think on these things, if for nothing else then to see how far we’ve come. I am the parent of two children on the autism spectrum. When my daughter was first diagnosed with AS at the age of seven, in 1995, I briefly went through the classic stages of denial, anger, etc. I’ve been in and out of minor depressions depending on what the schools’ response or lack of response has been. Mainly, I remember inhaling and devouring anything and everything written about Asperger Syndrome—and there wasn’t much written material at all back then. Boy, was it a relief to discover AANE! When my son was first diagnosed with AS and ADHD at the age of seven in 2000, I felt so validated and empowered, I could have shouted with happiness: “Finally, the schools will have to listen to us about my son and his needs, instead of pointing their blaming fingers at us!” That’s it in a nutshell: :) 

When my daughter was first diagnosed it was a combination of relief (“Ohhh, so that’s what’s wrong”), and an attempt to “circle the wagons” (by this I mean: learn as much as I could and get going on helping her). I never, ever looked back. I joined AANE, took classes, read, talked with others, learned more about her specific needs, and found support for her. I figured we had a certain amount of time to get going on support, remediation, and therapy, and “damn it” I wasn’t going to miss any of it. I was never, ever, ever sad. Not for one day. My sole focus was on trying to understand more deeply who she was and how I could support her, being who she is. I still do this.

My older son was cared for by a nanny, in my home, for the first three and a half years of his life, and then part-time by the nanny and in an institutional day care for neurotypical kids a few hours a day, until he started all-day kindergarten. I chose this arrangement because I work from home, and I loved having him around to breastfeed in the first year, and to see what he was up to/help out the nanny, throughout. It was almost like being a stay-at-home mom, only with a salary! At home and for a few hours a day in day care, my son never had any major issues, and hit all his developmental markers on time (or, more typically, early) with the exception of drawing human figures. My thought was “Hey, he does not like to draw, so no surprise he can’t do it so well,” so I never suspected any problems.

Then he started all-day kindergarten. For some reason, despite his academic readiness and past experience with a group situation in daycare, this elicited inappropriate behavior (including undressing, spitting, and violence against other students for which he was suspended twice, as well as odd behaviors the school reported but I had never seen at home, like spinning, rocking, and banging his head). This from a kid who, at home, was gregarious and friendly to all. And, despite the school’s opinion that he was really bright, he underperformed in writing (illegible) and reading. Half-way through the year, at a parent-teacher conference, the school’s counselor showed up unexpectedly to talk to me along with his classroom teacher, and shared that the school believed he was autistic, but that if they were right, this was not a diagnosis for them to make, but for medical professionals. While concerned about the above problems, I thought they were nuts, but did agree to raise the question of his school behavior with our pediatrician, who referred him to a developmental specialist. Six months later the process produced a diagnosis. We had the results of a full neuropsych evaluation. It was indeed autism, as the school had suspected: specifically, Asperger Syndrome.

By the time the diagnosis was official, I was happy to have it. It was a relief to have a clear, actionable explanation for what was going on with my son. So I never had the grief phase some parents describe after getting a diagnosis; it was onward to IEP planning to ensure school would no longer stress my little guy out beyond recognition.

We moved schools after kindergarten (for reasons unrelated to the diagnosis). The new school and having an IEP based on an autism diagnosis has completely turned things around. There are still things that are a struggle, from writing, to arguing with teachers, to awkward handling of social problems that come up, but the unreasoning, sudden, excessive reactions to others are gone. I am convinced that in his case they happened during meltdowns caused by stress, and he does not get that stressed by school anymore. He is given ways to take himself out of stressful situations before they escalate too much, and receives supports for “problem” subjects like gym and writing, which allow him to participate and learn without stressing him out unbearably.
I will never forget hearing my son’s initial diagnosis of PDD-NOS. He was nine, in 4th grade, and was being evaluated due to some peer interaction issues. He had always been considered a little quirky and intense, but never missed any milestones or had any other triggers that might have alerted us to a spectrum disorder. Another specialist had diagnosed him as gifted when he was seven, so we weren’t too worried.

So there we are: my husband and myself, my son’s teacher, the special educator, and the psychologist hired by the district, sitting in his classroom, waiting for the results of his testing. With a perfectly straight face, the psychologist told my husband and me that our son, who we always imagined would go to an Ivy League school and accomplish great things, would never go to college and would likely never live on his own. He droned on, and my first thought was, “He’s less empathetic than my son.” Then the grief came in. We sat there shell-shocked, and after his spiel we had to listen to the special educator tell us that he wouldn’t be getting any services through the school because of the lack of academic effect. “But don’t worry” said the psychologist, “he won’t be able to keep up in middle school, and when he fails then you can get services.”

Three years later, we are doing fine. We ended up homeschooling after more terrible experiences with our school district. My son’s diagnosis is less of an issue now, and I fret less about his future. But, I will never forget the crushing feeling of sitting in that home room, listening to strangers casually condemn my son to a bleak future.

* * * * *

When my daughter was four, the director of her preschool bluntly told us that there was something “wrong” with her. My daughter was a wonderful child. She was precocious and exceeded all milestones set out in the various parenting books we read. Already, she could read, do simple math, and was kind and outgoing. She charmed adults. She was even coordinated and athletic. So the preschool director’s insistence that there was something wrong with our daughter caught us off guard. We took her to a psychologist. After several meetings, the psychologist pronounced my daughter to be very intelligent, secure, and wonderful; perhaps an ADD diagnosis might be coming later in life but it was nothing to worry about now.

In kindergarten, the teacher noticed that my daughter was delayed in the way she interacted with peers. She told us the school would also watch her development. It was in second grade that everything fell apart. My daughter became extremely anxious, often crying and leaving the classroom. She could not transition with the class and could not produce the work necessary although she was more than intellectually capable of doing so. As a mother, I think I feel the pain my children feel but even more acutely. I spent many nights crying over her anxieties and fear, and many days searching the internet and asking friends for answers. The school offered an evaluation and I jumped at the offer of help in understanding my daughter, whose actions were so inexplicable. When the evaluation team met, the school psychologist so very gently delivered the diagnosis: autism, either Asperger’s or high-functioning autism. It was an enormous relief and a searing pain. It has taken me years to fully understand what those words mean for my daughter, myself, and my family.

The good part of receiving the diagnosis was that my daughter now had an IEP and an educational team. The team was very helpful in educating me and putting supports in place to help my daughter. I was immediately empowered with a word—Asperger’s—and I set out to learn everything I could about it. What I didn’t understand until much later was that the word Asperger’s also meant loss. It meant the loss of some of the hopes I had for my daughter. It meant she would have many more hurdles to deal with than typical children. It meant loss for me, too, because my life would also have more challenges.

Over the years I have mourned those losses, but I have also learned to treasure and revel in each small step my daughter has taken, and not to take for granted all of the blessings we do have. This change in mindset was a journey for me. I found tremendously supportive people along the way. There are the moms in the waiting room at the social skills class, or other parents whose children have special needs. Parents of special needs children are truly some of the most compassionate and kindest people I know.

I’ve also encountered many mean, selfish people who don’t hesitate to stare or make mean comments about my daughter. I’ve learned to hold my head high and to be proud of my daughter 100% of the time. She always tries to do her best, and she puts in more effort in one day than some people put in over a year.

My daughter is now 16. She attends an alternative school. We expect her to get a driver’s license, go to college, and eventually get a job where she can support herself. Many people don’t know she has Asperger’s and she has overcome many challenges she faced as a child. She has grown into a kind, smart, and gentle young woman. She has learned to ask for help when she needs to, and is comfortable some of the time with her diagnosis—although she will be the first to tell you that Asperger’s is only a small facet of who she is. She is a learner, animal-lover, friend, daughter, skier, soccer player, spends-too-much-time-on-Facebook teen who also happens to have Asperger’s!

If I could go back eight years and talk to myself on the day of her diagnosis, I would tell myself that everything WILL be okay. It may not be the life that I had pictured for my daughter, but those were my dreams, not hers (but it’s still ok to cry sometimes). She has her own wonderful journey ahead of her. There will be plenty of bumps along the way but she will find peace and happiness. She will still get a driver’s license, go to college, get a job, and even get married some day.

I’ve spent the last eight years providing support for my daughter with many classes, camps and various other supports. But loving her and accepting her for who she is was the most powerful thing I could do for her and for myself.
Rethinking College

Which colleges work well for kids with AS? How do I help my child transition successfully to college? These are the questions most parents ask as a child with AS nears high school graduation. As the mom of a recent high school graduate, I wanted to share my recently developed perspective on college with other parents as they consider what the right path might be for their children post high school.

While my son was making his way through the school system, I, probably like most parents, tended to think from year to year, from IEP to IEP. Each year had its own quite sufficient challenges. The school also thought from year to year and their focus, like mine, was getting my son to college. He was a B+ student at a 766-approved school: a hard worker, very motivated to succeed, and intensely interested in being social. He took charge of his entire college application process and got accepted to four private colleges with scholarship offers. However, because our son has ADHD, slow processing, and language fluency as well as pragmatics difficulties, my husband and I felt that a step by step approach to college would be better than instant immersion. We insisted he do a gap year to work on his language issues, while taking a couple of courses at a community college to get a feel for college work. Against his wishes, we deferred two of the colleges he got accepted to, expecting that he would go the following fall. To appease his desire to start college, he attended Landmark College’s Transition summer program. There he got a chance to experience dorm life, and learned how to discuss his disability and advocate for accommodations.

The gap year was a very smart decision, as my son himself acknowledged during our Thanksgiving dinner. The gap year gave all of us a realistic understanding of where our son stood in relation to the real world, without the expense of paying a full year’s tuition or the emotional trauma of finding he was unable to manage.

The community college courses proved more difficult than anticipated. Most of the material was new; so he did not have any previous knowledge to spiral back to. The tests required applying the learned concepts to new situations. Many accommodations that our kids are accustomed to from public school were not available in college. And despite the accommodations that were available (note-taker, extended time, separate test environment) he struggled and needed significant tutoring help. Given how much time my son had to devote to each course, it became clear to me that he would need a reduced course load, so that college would likely take five or six years instead of four. At around $50,000 per year, that would add significantly to the total cost of college.

My son was seeing a speech language therapist who specialized in working with adults with AS. She told me that she frequently sees adults with AS who have college degrees but cannot get or maintain jobs because they lack the soft skills needed. She had a client who earned an engineering degree, graduating with honors, yet went on fifty job interviews without getting hired. Another client, who graduated with honors in accounting, could not manage the busy pace of an office environment. I heard stories from other adults with AS, or parents, saying the same thing: getting a degree does not level the playing field. Many adults with AS, after earning college degrees, are living at home, unemployed and with college loans to pay back.

I started to rethink college. My son has solid intelligence, determination, and drive. With great effort he could get a degree, especially if he attended one of several colleges that market themselves to students like him, providing more accommodations, usually for an additional fee. Many parents pay that fee, because they want their kids to be successful in college. However, such supports are not available in the work place and the workplace is ultimately where I want my son to be successful. Employers may make some accommodations, but only make extensive accommodations for employees who are extraordinary. In my previous careers at a Wall Street investment firm and a Madison Avenue advertising agency, I encountered two individuals so talented that the firms assigned other people the responsibility of making sure things worked for these favored superstars. If your child with AS is unusually talented, perhaps the workplace will accommodate his or her needs. Parents who have children with more typical abilities, or children with learning challenges like my son’s, have to consider our options very carefully. In college, success is based on coursework and grades, but in the workplace our kids will be measured against their typical peers along multiple dimensions. For my son to be successful in a profession, we need to consider everything about the profession: the typical work environment for that profession the kind of supervisors and co-workers, and those soft skills: the abilities other than knowledge that the profession may require, such as extensive person to person contact versus email contact.

When I went to college, I chose my own courses and decided upon my major. I wanted to let my son do the same. However, he has less understanding of the job market than his typical peers; so he needs more guidance. Since he does not have a special interest, I needed to be more direct in our search, because our son has more criteria for the right profession than most kids do. Fortunately, we found an incredible website, www.onetonline.org, that gives abundant information about the requirements of a multitude of professions, including soft skills needed.

Given the uncertainties of future employment, we have decided that paying private college tuition would not be a good use of our financial resources. We want to keep as much in reserve as we can for our son’s future needs. Community college is a much less expensive way of seeing whether he can succeed at the college level with the supports available. If he can, he still has the opportunity to continue on to a four year state college, where tuition is much less than at a private college. If he can’t succeed in community college, he could do a certificate program that would give him a specific skill set, possibly one more marketable than the skills represented by a liberal arts degree—particularly in this economy, where even many neurotypical college graduates are struggling to get jobs.

Of course college is about more than getting jobs. It’s about my son’s self-esteem and my own desire as a college-educated parent to have a college-educated child. We walk a fine line between what we want and what is realistic. I need time to teach my son that his self-worth need not be measured by whether or not he earns an academic degree. I also need time to reconcile myself to this next stage of life as the parent of an AS adult.

But then again, my son may surprise us. He is just 19, and change happens.
My Hoop it Up Championship
by Anthony Rossacio

The 2012 Hoop it Up World Championships took place on August 18th-19th at Citi Field located in Flushing. Flushing is in the New York City borough of Queens. I participated in a free throw shooting contest at the tournament. It was a best of 10 free throws and I beat two other opponents with a score of 7-6. I made 7 free throws out of 10 and my two opponents made 6 for 10, so I won by one. This Hoop it Up World Championship is my 2nd in a row and my 3rd in 5 years. I clinched the title on Aug. 19, 2012.

I trained extremely hard for this world championship. On the basketball court, I take about 200-500 free throws each practice and I shoot roughly 50-100 3-point shots. I lift weights at the World Gym in Milford, Massachusetts, and I do a spin class twice a week. I have a personal trainer named Janice Barden. Janice also teaches Zumba, and is a weight and nutrition coach. I first met Janice in 2005, and begin training with her in 2012. As a trainer, Janice has qualities that cannot be taught. She had the ability to bring me to a level both in life and as an athlete which I could not have reached by myself. She has an unique way of motivating athletes to enhance their performance and to excel in the game of life. Through my work with her, I felt that I became much stronger physically, mentally, emotionally, and spiritually. Janice is the most highly self-motivated personal trainer I ever got to know. She will always hold a special place in my heart that no person or thing in the world can replace. I will always look up to her as a role model, and a friend. As I compete in future Hoop it Up World Championship tournaments, I would love to have her train me and go for another ride to the summit with me, because she and I both have the will to win, the will to live, the eye of the tiger, and the heart of a champion. If there ever was an MVP trophy for this world championship, I would call Janice the MVP of my 2012 Hoop it Up World Championship!
AANE Artists Collaborative & Gallery

AANE’s 2012 fall conference featured a juried exhibit of work by New England artists and poets 18 years of age and older, who have Asperger Syndrome.

Thanks to Susan, Bill, and Jamie Maxfield, Andrew Novis, and Anastasia O’Melveney, a greatly expanded display of work by our artists graces the walls of the AANE Gallery in our Watertown office.

Please join us for the AANE Gallery Opening

on Sunday, June 9th, from 1:30-4:00pm

Or come in now to look--and perhaps buy!

You can see more artwork at http://www.aane.org/artists/
The site, created by Karen Boyd and Abram Kelly, is still under construction.

Visual artists and poets interested in joining the AANE Artist Collaborative, a group of adult artists who meet monthly to exchange ideas and promote their artwork.

To learn more about participating, please contact Jamie Freed at ext. 24, or Jamie.Freed@aane.org.

Prism by Abram Kelly

Each poet or visual artist holds copyright to his or her own work.
Misty Day with Vines by *Gary Hudson*

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Diversity by *Brian Rusconi*

*Artist Jackie McCann at the AANE fall conference art exhibit.*
Listen

Embraced by a redefining memory
And a reviving sense of healing,
I am slowly rebuilding my inner voice
So that you may hear me--
Let me be.
Let me breathe.
Let me speak.
Just stand beside me and hold my hand
Let us lead instead of follow--
Let us teach the world to understand
What may seem different
Or may seem broken
Is simply a misperception of who I am.
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Beyond the Storm

Dark clouds loom before me.
I bow my head to keep me warm--
And hold on tight to the light within me,
To see beyond the storm.
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Starting Over

Isolation and angst
Solids and shapes
Which one am I?
These ambiguous states.
Reaching out to be heard
Feeling alone and sad,
Keeping the faith to go on
Is all I have
Creating memories to hold
Not floating or flying,
A flight against teh negative
Twilight conscience streaming
Into morning dew and daylight
Once, twice, three times
To begin again, starting
Over and trying to achieve
Familiar shapes and solids
Treading lightly on
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AANE Journal: April 2012–13 Issue 11
An Approach to Transition Assessment and Planning


Generally speaking, transition is defined as the movement from one set of activities to another, but for the families of adolescents and young adults with special needs it has a more specific meaning. In this context, “transition” refers to the complex process of moving from one life stage to another: from adolescence to adulthood. For most teens, this means moving beyond high school into some form of post-secondary education or training, the workplace, and a fully or partially independent adult life. Transition encompasses the teen cultivating self-awareness, and developing a vision and goals for his or her future, while the teen’s family, educators, and sometimes other professionals guide and support the teen’s growth into adult independence.

This major shift from high school into college/vocational training, employment, and independent living is challenging for every student, but even more so for those with disabilities. It can be an exciting process, but also a daunting and emotionally demanding experience for everyone involved. However, careful planning and preparation can mitigate the stress. Furthermore, research indicates that students who have actively participated in defining their own vision of their future, and planning and taking action to achieve it, will experience greater success and satisfaction in their lives as adults.

Transition in State and Federal Laws

The law on transition is clear. IDEA (the federal Individuals with Disabilities Education Act) reads, “the term ‘transition services’ means a coordinated set of activities for a child with a disability (beginning at age 16) that:

• Is designed to be within a results-oriented process focused on improving the academic and functional achievement of the child with a disability; to facilitate the child’s movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment); continuing and adult education, adult services, independent living, or community participation;

• Is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and,

• Includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation.” 34 CFR 300.43 (a) [20 U.S.C. 1401(34)]

The Massachusetts special education statute (P.L. 108-446, Sec 603 (34) goes further, mandating that, “…no later than the first IEP developed when the eligible student is 14, the Team considers the student’s need for transition services and documents this discussion. The IEPs of students should include a post school vision statement as well as identify the transition services necessary to support the vision.” The statute continues: “If appropriate, the IEP includes a statement of needed transition services. The school district understands that it must maintain documentation of a full discussion of the student’s transition needs, whether or not such discussion identifies needed transition services for the IEP. Such documentation must be reviewed and updated annually thereafter. Students must be invited to all educational meetings and allowed to participate actively when transition planning is discussed.”

In short, both state and federal law require that transition planning be a fully participatory process, taking into consideration not only the student’s needs or limitations, but also his or her interests, strengths, and aspirations. Ideally, the transition process will be continuous and constantly evolving, recognizing that the student will be a very different person at its end, having acquired new skills and, likely as not, different interests. At every step along the way, the educational team (parents plus educators) should be asking: Where are you now? Where do you want to go? How can we help to get you there, safely and successfully?

The Genesis of NESCA’s Transition Model

NESCA is a private pediatric neuropsychology group practice in Newton, Massachusetts. NESCA staff embraced this student-centered, process-oriented approach early on, becoming pioneers in the development of coordinated transition assessment, planning, and case management services.

We believe that our transition protocol is an effective model for the identification of needs, and for the targeted, effective delivery of services. We provide an experienced team of clinical specialists working collaboratively over time with the teen, his or her family, the school district, and other professionals.

NESCA’s original model was developed by Transition Specialist Sandy Storer, LICSW, who joined the NESCA staff in 2010. For twelve years previously, Storer had been School Social Worker at the Clarke Middle School in Lexington, MA, where she specialized in helping students with autism spectrum and related disorders. Storer had also spent a semester as a disability specialist at Northeastern University in Boston, where she saw first-hand that some students fared quite well, while others struggled. It became her mission to find the key to improving the outcomes for students transitioning to adulthood. “I asked what could have made the difference for those who struggled. I wanted to reverse engineer the process,” she says.

In 2008-2009, Storer completed a LEND (Leadership Education in Neurodevelopmental and Related Disabilities) Fellowship at the Eunice Kennedy Shriver Center of the University of Massachusetts Medical School. She conducted an in-depth investigation of transitional issues impacting students with Asperger Syndrome (AS). She determined that the most successful transitions result when:

• There is full participation of a student’s educational team, and coordinated case management over time.

• The process is guided by a person-centered, individualized plan.
• There is a set of services maintained throughout high school, and in some cases beyond high school completion.

This seems obvious in retrospect. At the time, however, most people viewed transition not as a process but as an event: high school graduation. The law notwithstanding, too little attention was paid, and often too late, to equipping special-needs students with the life skills they would need in order to cope with the increasingly complex demands—personal, social, and academic—of life beyond high school: continuing education, employment, and everyday independent living.

The climate changed with the landmark 2008 Dracut case, in which a federal district court, upholding a decision by the Massachusetts Board of Special Education Appeals, found that a student had been denied the free and appropriate public education (FAPE) to which he was legally entitled. The court ruled that the school district “failed to provide training ‘reasonably calculated to enable Student to develop vocational skills . . . after High School.’” The Court found that the services provided had been inadequate because they did not expose the student to the “full range of situations involving interaction with the public and peers, with the result that Student did not experience all of the communication and social skills typically found with a job in the community.” The district was ordered to provide significant compensatory educational services even though the student had already graduated from high school. (Usually special education services end when a student graduates, but in this case the court ordered the compensatory services because the student had not received them during the period in which he was eligible.)

Sandy Storer left NESCA early in 2013, leaving in place a well-established protocol and a highly-experienced team. Because of her long tenure in a public school setting, she understood that everyone benefits when students, families, and outside professionals work closely with educators, and that such teamwork is the most effective and efficient way to design and deliver transition services. Some of her keys to success:

• Start early.
• Conduct realistic, in-depth assessments.
• Build a solid team.
• Provide follow-up support.

Start Early

When to begin formal transition planning is a highly personal decision for each family, and there is no age too early or too late. In fact, says Kelley Challen, M.Ed., Director of Transition Services at NESCA, “Every family has already started in some way. Each time a skill is taught to increase a child’s independence—sleeping through the night, holding a bottle, choosing one’s own clothes—it’s a part of the process.” Learning to cross the street, attend a sleep-over, buy one’s own ice cream cone, or make a bed—all of these can be part of the process.

When families and professionals help individuals with learning differences develop new skills, it is important to prioritize goals and skills rather than trying to tackle everything at once, allowing plenty of time for skills to be acquired, and for the teaching to be repeated in multiple settings and contexts.” The more a student can truly master essential skills before making the transition to adulthood, the easier it will be for everyone. In whatever novel situations follow high school, the more automatic a skill is, the more easily it will transfer to a new routine or a new setting.

Getting an early start prepares a student and the student’s family to enter into conversation with the rest of the educational team, with a better-defined vision to guide their work together. It also enables the family to incorporate the long-term vision into their lifestyle and parenting decisions (since some skills are learned not at school, but at home or out in the broader community).

Assessment, Teamwork, and Case Management

Assessment is the essential first step in the planning process. Assessment is an ongoing process that is necessarily highly individualized, because it must consider each adolescent’s personal strengths and challenges, the nature and complexity of the person’s aspirations, and the pace at which he or she learns. The skills necessary for living a fulfilling and independent life go well beyond those linked to academic success in high school; so a meaningful assessment must be comprehensive, and look at many other factors and areas. A assessment must consider not just intellectual potential, but also functional life skills: the ability to interact socially, make change, ask directions, use public transportation, care for one’s health, maintain hygiene, and stay safe.

At NESCA, an assessment generally begins with a thorough document review, and an intake interview with both the student and his/her parents. A clinician will determine whether or not additional testing is required and, if so, what kind. In many cases, neuropsychological evaluation will serve as a starting point from which the need for additional formal and/or informal assessment will be identified. There might also be a recommendation for assessments via community-based observation. (See transition tips on page 26.)

NESCA clinicians perform neuropsychological testing and community-based assessments as needed, provide parent consultation and training and, in many instances, individual counseling for students. They then work closely with the student and the educational team to develop the vision statement and personal goals to be identified on the Massachusetts Transition Planning Form (TPF), and recommend for inclusion in the student’s IEP those services necessary to achieve the goals.

The clinicians involved in these assessments will then support the family as it seeks to have these recommendations included in the student’s IEP, and periodically monitor progress as services are implemented by the school and other professionals. To that end, NESCA personnel routinely observe students in their classrooms and in the community, and participate in meetings of the educational team.

Transition Tips

• When families and professionals help individuals with learning differences develop new skills, it is important to (Article continues on next page.)
consider whether the help being provided will translate into true independence or dependence on a caregiver. For example, notice the difference between teaching a morning routine that starts with a parent waking the individual up and prompting several times throughout the morning, vs. teaching a routine that starts with an alarm clock and is followed up by additional digital or visual prompts from the environment.

- When creating IEP accommodations, it is important to consider how supports will be faded out if they cannot be translated into post-secondary and employment settings. If there is no way to fade an accommodation or teach an individual to self-accommodate, than other supports should be considered.

- Transition planning should be informed by assessment data, and assessment should be ongoing, individualized, and include community-based observation and testing when possible. Good, individualized assessment allows for identification of strengths and challenges that may otherwise be unseen or unknown. For students who plan to take part in post-secondary education, a critical component of NESCA’s assessment process is taking those students to a college campus and observing whether they are able to independently complete tasks like navigating a campus map, finding the disability support office, and appropriately ordering and paying for food in the campus coffee shop.

- Transition planning starts with the individual, and should be vision-driven and person-centered. Sometimes, adults assume that the individual is too young to have thought about what his or her future will look like. However, by asking good questions and taking into account the strengths and interests of the individual, it is possible to begin forming a vision statement. For example, many teens have strong opinions about their living situation as adults. One would love to live in his parents’ basement, while another wants to live on her own in another state. In each case, there are ways to create goals that will support skill development and take the individual’s current vision into account. For an individual interested in living at home, it may be a good time to start including the teen in the budgeting, bill paying, and even working to support the household. And as the individual changes and develops additional self-awareness, the transition-related IEP goals should also change.

- The student and the parent are part of the IEP team. Transition planning and skill development is not just something that happens at school; it is important for the family to share ownership of the process. Therefore, the student and parent should walk away from each team meeting with homework, and be accountable for working on measurable goals, just as the educators are.

- Self-awareness is a critical component of a successful transition to adult life. Self-awareness is not necessarily knowing that you have a specific diagnostic label (although that will be important at some points in time), but it is knowing what your strengths and challenges are. It also includes understanding your needs based on your challenges.

- Self-awareness is essential to being able to advocate appropriately for oneself. That is, because individuals with learning differences are in the minority, they need to be able to explain to members of the majority (a professor, a roommate, a boss) what their needs are, and what supports will help to get those needs met. Teaching self-awareness and self-advocacy is an ongoing process, and one that should begin as early as possible.

Kelley Challen, M.Ed., C.A.S. is the Director of Transition Services at NESCA. She has been facilitating group programs for children and adolescents with autism spectrum disorders since 2004. She received her Master’s Degree and Certificate of Advanced Graduate Study in Risk and Prevention Counseling from the Harvard Graduate School of Education. Before joining NESCA this year, she was Program Director for the Northeast Arc’s Spotlight Program, where she oversaw drama-based programs for youth ages 6-22 with Social-Cognitive Deficits. Challen also spent four years at Massachusetts General Hospital’s Aspire Program (formerly called YouthCare) where she founded an array of life skills and career skills programs for teens and young adults with Asperger Syndrome and related challenges.

For a dozen years, Jason McCormick, Psy.D., has specialized in working with adolescents and young adults on the autism spectrum, and has developed a particular interest and expertise in the challenges involved in the transition from high school to college. As part of his work with older students, Dr. McCormick became very familiar with the documentation requirements of standardized testing boards, including those overseeing the SAT, GMAT, LSAT and GRE. He also holds an advisory and consultative role with a prestigious local university, assisting in the provision of appropriate academic accommodations to their students with learning disabilities and other issues complicating their education.

Kate Dellaporta, Psy.D., trained at the Center for Autism Spectrum Disorders of Children’s National Medical Center near Washington, D.C., where she was a member of a multi-disciplinary team conducting comprehensive diagnostic evaluations of children aged 5 - 21 suspected of having autism spectrum disorders. She also completed a two-year post-doctoral fellowship in pediatric neuropsychology at NESCA. She provides cognitive-behavioral therapy (CBT) to adolescents, and performs the transition team’s community-based observations and functional life skills assessments.
Transitioning From High School to Adulthood

Making the transition from high school to adulthood can be both enormously exciting and stressful for any student. The stress may be magnified for students with Asperger Syndrome (AS) as their maturation level, ability to tolerate or accept help, and their social skills/perspective-taking, executive functioning, and meta-cognitive abilities (i.e., reflecting upon thinking, introspection) may lag behind their peers’. The same factors may also have an impact upon choices or decisions a student with AS makes. Conversely, people entering adulthood with AS also bring many gifts, and have the potential to be extremely successful with the right transitional supports. Fortunately, Massachusetts is beginning to understand what a critically important time this is for our students, and is now dedicating resources to this transitional period. In addition, many colleges now offer academic and social services specifically for students with AS. By contrast, employment settings often remain competitive and not as disability-friendly as would be ideal. For now our students must learn to live and thrive within society’s current norms, while we continue working toward the day when society will view people with disabilities as a very capable population.

Milestones Day School’s Transition Program

Milestones Day School enrolls all students in our Transition to Adulthood Program (TAP) starting at age 14. Here, students learn transitional skills required to succeed in life post-high school, working toward goals developed in collaboration with their families. Along with their traditional academic subjects, students take classes specifically focused on transitioning to adulthood, and try out different careers by participating in internships in a safe environment at meaningful employment sites. They also have the opportunity to enroll in our college-partner program where, with the support of our staff, students take classes at both college and high school starting in 12th grade. They also participate in classes where they learn special study skills needed for success in college classes. By allowing them to practice employment and college skills prior to leaving high school, Milestones staff can help students determine any additional skills they will need to address, or avoid any pitfalls that may not be apparent in a high school environment alone. Having these types of experiences while still enrolled in high school can greatly boost post-high school success.

Backwards Design

The success Milestones has with students is due to our backwards design methodology. Backwards design asks students to answer the questions: “What do I want for my future? Where do I want to be after I finish high school?” Then we plan backwards to ensure that all necessary steps are in place to achieve the student’s transition goals. To “begin with the end in mind means to start with a clear understanding of your destination... It means to know where you are going so that you better understand where you are now so that the steps you take are always in the right direction” (Stephen Covey, “The Seven Habits of Highly Effective People”). This model can be employed with any student in any school system.

Important Questions that Need to be Answered

When using a backwards design model, the following questions may be used as a guide for planning the remainder of high school and setting the student up to achieve his/her goals. Many of the questions below are the same questions all high school students must ponder; for students with disabilities, planning for success may take more intentionality and guidance.

• What will I need to do after high school are graduateing in order to achieve the career and lifestyle I want to have? Immediately after high school, do I want to take a gap year, attend college or a trade school, or enter the workforce? It is important to have a focus, although for many students (with or without a disability) the focus may change from year to year.
• What are my strengths and personality type? Does my profile match the career and lifestyle that I desire?
• What are my career interests and aptitude, and do they match? One may have a strong interest in a specific career, but little aptitude. Conversely, one may have a strong aptitude but little interest. (Interest can foster aptitude, but rarely does aptitude foster interest.) Do I know the socially appropriate behaviors needed for of getting a job and keeping, e.g.: what to say/not to say during an interview, following up, accepting or declining a job offer, reluting to a boss and co-workers, etc.?
• What type of living arrangements do I desire: live at home, shared apartment, living alone, etc.? If I want to live independently or with minimal support, what types of skills will I need that I may not have now?
• How good is my knowledge and application of safety skills, e.g.: medication management, medical issues, understanding of strangers and danger, how not to be taken advantage of, and consumer skills?
• What life skills do I need to learn, e.g.: banking, mail systems, time management, following directions, knowing what to do if I make a mistake, waiting and patience, phone skills, nutrition, cooking, operating home appliances, filling out medical forms, transportation, and hygiene?
• How will I get to work or school? Will I need training in travel skills and/or adaptive driver’s education?
• Do I know how to structure free time and have safe, healthy activities that I enjoy doing and can initiate independently? Do I desire and have a balance between solitary activities and activities with friends?
• Do I have appropriate social judgment?
• Do I want to experience dating and sexuality? Do I understand the nuances of dating, such as: how to tell when someone is expressing interest in me, appropriate ways to express interest in others, what is expected behavior on a date, appropriate ways to handle rejection, knowing what is appropriate behavior when talking about sex and dating, and understanding STDs and pregnancy prevention?
• How well do I understand my diagnosis? Do I know when and how with whom to share this information about my diagnosis? How can I advocate for my needs?(Article continues on next page.)
What type of access to government or private support services do I need, if any, and what would I be eligible for?

Sample Timeline for Transition Planning and Services

Keep in mind that different students might be on different time-tables.

Step one (8th grade): When students turn 14 within the IEP year, a transition plan should be created by the student, his/her family, and the school staff. The educational team should begin to look at the student’s post-high school goals using the questions above, and then use the backwards design model to outline the specific steps s/he will need to take in order to achieve the goals. Based upon these goals, an initial transition plan is created. Keep in mind that many 14-year-olds do not have answers to the above questions, so the transition goals in a 14-year-old’s IEP should be broad.

Step two (between 8-9th grades): A comprehensive transition assessment is conducted. This assessment should look at the above skills for example: functional academic assessment, workplace social judgment assessment, vocational interest assessment, vocational aptitude assessment, functional life skills assessment, etc. All of these skills should be assessed through formal testing, observations, interviews, and/or questionnaires that the student, parents, and teachers fill out, as it is important to have all three perspectives. It may also be time for an updated neuropsychological evaluation. In addition, it’s important to start to identify what the family’s needs are for transition. Many of these tests should be repeated in 3 years. If students are not proficient at the safety and independent living skills outlined above, students should also begin taking courses on functional living skills, with peers who have similar challenges and strengths.

Step three (starting between grades 10-11): Students should begin work experiences either in the form of a part-time job or internship. The Team needs to determine the level of support the student’s first work experience should have. Some students benefit from a 1:1 job coach whereas others need minimal or no support. In addition, if the student would like to attend college or trade school, investigations should occur now to see what type of disability support the college/trade school has to offer.

Step Four (between ages 18-22): Many students with AS and related conditions need one or more extra years to complete their high school academic requirements, pass MCAS (or alternatives), and receive needed transition services. If the student is continuing on in high school, classes should focus on functional, independent living skills; the majority of the day should be spent either in dual enrollment (at college) and/or in a work-place setting, learning and practicing real world employment skills.

Resources

For more information about the Milestones Transition to Adulthood Program, transitions goals, parents as the child’s quarterback, and a sample transition plan, please visit www.AdvancingMilestones.com.

Mass Government: When you Turn 18 in Massachusetts: http://www.mass.gov/ago/consumer-resources/your-rights/18/


National Center on Secondary Education and Transition: http://www.ncset.org/

MDESE: http://www.doe.mass.edu/sped/links/transition.html

Office for Civil Rights: Preparing for postsecondary education: http://www2.ed.gov/about/offices/list/ocr/transition.html

NICHCY: Transition goals in the IEP http://nichcy.org/schoolage/transitionadult/goals

National Collaborative on Workforce and Disability: guide for individual learning plans: http://www.ncset.org
Strategies To Support Siblings
by Emily Rubin, Director of Sibling Support
Eunice Kennedy Shriver Center, University of Massachusetts Medical School

1. Talk openly with siblings. The most effective intervention for siblings is for parents/guardians to talk openly with them in age-appropriate language, acknowledging the challenging family life, and the fact that one child’s disability impacts every member of the household.

2. Validate the sibling experience. Listen actively to the sibling, and validate his/her complaints: “I understand you get angry when your brother/sister does such-and-such.” This will let the sibling know that his or her concerns are important, and that you understand what the child is going through.

3. Avoid blame. Try not to blame the child with the disability, and remind siblings that we all something we struggle with.

4. Help siblings figure out what to say. It can feel uncomfortable for siblings to answer questions about the brother’s/sister’s disability, or to try to explain to friends, relatives, or strangers why the brother/sister is acting differently. Give them language to use that is appropriate to the situation.

5. Encourage siblings to attend sibling support groups. Sibling support groups with adult facilitators provide a safe and welcoming environment for siblings to talk with other sibs who appreciate what they’re going through. Just as parents benefit from talking with other parents of similar children, it can feel both comforting and liberating for siblings to meet others who share their experiences.

6. Try individual or family therapy. Individual and/or family therapy with a trained clinician can be extremely beneficial for siblings, especially for those sibs who don’t want to attend sibling support groups. Siblings shouldn’t have to harbor secrets about their home life.

7. Encourage siblings to have their own lives. Encourage siblings to develop interests and hobbies of their own. This will build their confidence and give them outlets to express themselves outside of the family.

8. Separate siblings frequently. Separating siblings gives them a much-needed break from one another. Spending time apart can be refreshing for siblings and can lead to more positive interactions when they come back together.

9. Help siblings identify “safe buddies.” Safe buddies are understanding friends or relatives they can turn to when home life becomes challenging.

10. Spend one-on-one time. Try to spend one-on-one time with siblings, even if it’s a simple activity like watching television together or walking around the neighborhood. Focusing attention on the sibling conveys the message that the sibling is important, and that you value your time together.

11. Connect with other parents. Parents who struggle with similar issues can provide valuable resources, in addition to advice and support. Attend AANE Parent Topic Nights, and share your concerns and experiences with parents on the AANE online support groups (Google groups) for parents of children, parents of teens, or parents of adults.

Emily Rubin is President and co-founder of the Massachusetts Sibling Support Network. She is also the Director of Sibling Support at the Eunice Kennedy Shriver Center of UMass Medical School. She is currently conducting a research study about how best to support siblings of children who are admitted for psychiatric hospitalization.

For more information, visit www.masiblingsupport.org or email info@masiblingsupport.org.
Message from Ilia Walsh, M.S. Ed., MBA, Director of Training and Consultation  
617-393-3824, ext. 11, Ilia.Walsh@aane.org

Hello! I’m Ilia Walsh, AANE’s new Director of Training and Consultation. I am happy to be at AANE, and look forward to providing a variety of learning opportunities for our community.

Like many of AANE’s staff members, I have a child with AS; so I understand what it is like to live with, coach, parent, and teach a child with neurological differences. I also have an MBA in Organizational Development, a Master’s in Elementary Education, and extensive experience as an educator and as a corporate trainer. I feel very fortunate to be able to use my skill set to provide training in an area that is important to me both personally and professionally.

At AANE, I will be working on AANE’s Cape Cod Summer Conference in August and the Summer Institute in July. I also manage the training and consultations AANE delivers to schools, colleges, hospitals, clinics and other outside organizations. Please contact me if you are looking to bring high quality training or consultation to your organization, or to an organization in your community.

I have also started an online training initiative at AANE. We recently delivered our first set of classes via the web and they were highly successful. We had attendees from all over Massachusetts, from other states, and even from outside the U.S.! Throughout the year we will be expanding our distance learning so that we may provide a variety of topics and access to experts for those who cannot attend programs in Watertown or the Greater Boston area.

I am excited to be a part of AANE and look forward to meeting you at a conference or workshop. I would love to hear what topics you are interested in learning about. Please email or call me and let me know what ideas you may have for workshops, conferences, trainings, webinars, and other forms of online learning.

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Message from Ethan Eisendorfer, Coordinator of Adult Services  
617-393-3824, ext. 44, Ethan.Eisendorfer@aane.org

I grew up in New Jersey, majored in psychology at the College of William and Mary, and came to Boston University to earn my master’s degree in Mental Health and Behavioral Medicine. I got married in April of 2012. My wife is a film-maker. She and I live in Waltham and own two cats.

It was in my second job after grad school, in the day treatment programs of the Jewish Family and Children’s Service, where I first encountered adults with Asperger Syndrome (AS); I lead a men’s group, and later on supervised Lurie House, their small transitional housing program. Having learned about AS, I looked back and realized that a close friend I grew up with has it. Although he’s now doing well overall, I wish I had known earlier the source of some of his struggles; both of us would have benefitted!

When I spotted the listing for the job of Coordinator of Adult Services at AANE, one thing that appealed to me was the mention of pizza and game night. I myself am a huge fan of games, from board games to games played on a computer, smart phone, or iPad! I enjoy hosting AANE’s game nights and holiday parties, and seeing the members of our adult community happily connecting with one another, discussing special interests, playing games, or just schmoozing! I also plan and publicize recreational and cultural events such as our ever-popular summer outings to Fenway Park. Since I also like documentaries and sci-fi films, I am delighted to be working with AANE board member Phil Schwarz to coordinate AANE’s long-running film viewing and discussion series, originated by Phil—an inspired idea!

Like my colleagues in Adult Services, Director Jamie Freed and Coordinator Michelle Alkon, I answer phone calls from adults or their family members (parents, spouses/partners, siblings, or adult children) in need of information, support, or referrals. I also meet with adults or family members new to the AANE community, to welcome them and explain our programs and services.

In Watertown, I lead a young men’s support group and a new Cognitive Behavioral Therapy group. I also coordinate and work on expanding our network of social groups meeting in other locations: Canton, Danvers, Worcester, Framingham, with plans for a group in Amherst. Another aspect of my job is training other professionals: dispelling myths about AS, and addressing clinical issues.

If we have not yet met, I invite you to call or email me and set up an appointment. My door is open, and I look forward to meeting you. Or just come say hello at the next pizza and game night!
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Meet Karen Doran
Receptionist/Registrar
617-393-3824 x10,
karen.doran@aane.org

I was born and raised in Norwood, and have lived in Massachusetts most of my life. I became a stay-at-home mother with the birth of my first child in 1991; my second son was born in 1995. Both of my sons were diagnosed on the autism spectrum in early 1999. From 1998-2002, I provided hands-on support to my children at home, with direct instruction from the various professionals and therapists working with my children. Now, at ages 17 and 21, my boys are becoming more and more independent, and my roles as a soccer mum, taxi driver, cheerleader, and home therapist are fading in regularity. Last summer, when I found myself with some spare time, I called AANE to ask about volunteering, little knowing that I would start working at AANE full time in September of 2012.

I find I am very comfortable sitting at the reception desk and working as Registrar. My education in Paralegal Studies and my work as a paralegal provided me with numerous skills beneficial to my new position: attention to detail, organization, the ability to multi-task, and communication skills. I also bring to this job the knowledge and understanding gained in raising my sons, and my strong belief in work that AANE does.

I look forward to meeting you, to answering your questions (or directing you to someone who can), and to providing any assistance you may need in registering for/attending AANE workshops and conferences.

We are so fortunate to have AANE, such an incredible and unique organization in our corner of the world. I am very excited to be part of it!
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Please submit ads, articles or ideas, stories or poems, drawings or photos for the AANE Journal to the Editor at Stephanie.Loo@aane.org.
Meet Jessica Butler, Development Coordinator

I grew up in Cambridge, Massachusetts. I played basketball in high school and at Canisius College in Buffalo New York. Every summer I came back to Massachusetts to coach and mentor youth. One summer, I did an internship with the Center for the Study of Sport in Society, whose philosophy is to use sports as a platform for education, advocacy, and social change.

After college, I played international basketball professionally for six years. Next, I worked in development for a local business. Just prior to joining the staff at AANE, I helped care for a child on the autism spectrum, and saw the obstacles this child and his family faced every day.

As Development Coordinator, it is my honor to represent AANE: an organization that provides education and support to thousands of individuals and families. I love helping AANE build new partnerships with Boston businesses and corporations, and closer connections with our sustaining donors. I will also be working on third-party fundraisers throughout the year, to help set AANE on a firm financial foundation.

I look forward to meeting many of you at the Laugh Out Loud Gala on May 18th. Planning for the Gala is well underway. This event usually sells out, so buy your tickets today at www.aane.org/make_difference/gala/. And please keep AANE and the Gala in mind when speaking with your employer, friends, or family. We are currently seeking additional individual and corporate sponsors for the event.

Thank you, everyone who donated so generously to our Annual Appeal. Additional gifts are still welcome!

Please feel free to contact me. I would love to hear your ideas about how we can work together to strengthen AANE and help it become a permanent community resource.

Meet Michelle Sudit, Laugh Out Loud Gala Event Coordinator

I was raised in Buffalo, NY, the city of lake-effect snow. I am a Michigan State University alumnus with a B.A. in Human Development and Family Studies. Currently I am a graduate student in Non-Profit Management at Northeastern University, and will be graduating with my master’s degree in September of 2013.

I have worked with children with Autism/Asperger’s for six years, so I realize how important it is to raise awareness and unite the Asperger’s community. Working at AANE has made me realize how many people need the support of others, and how important it is to raise the funds necessary for carrying out AANE’s mission. I cannot express how amazing everyone at AANE is, and how honored I am to be working here! Thank you to everyone who has made this experience so unforgettable!
The Asperger’s Association of New England: Helping people with Asperger Syndrome build meaningful, connected lives