



TIPS FOR PARENTS OF TEENS WITH ASPERGER SYNDROME

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I am no expert on parenting a teen with AS—and every teen is different. Still, I'd like to offer other parents the gist of what I've learned from being a parent myself, from my colleagues at AANE, and from the many other parents I have spoken with by phone, via e-mail, or at the monthly support group meetings I facilitate. Please consider this article just another contribution to our community dialogue; feedback is welcome!

Keep doing the things that work.

- Be patient. Remember that children and teens with AS are relatively immature, socially and emotionally, compared to neurotypical children of the same chronological age. Imagine sending a 10 year old off to high school (even if she has a chronological age of 14), or putting a 14 year old boy behind the wheel of car (even if he has a chronological age of 18)—or sending that 14 year old off to college or the army. We need to adjust our expectations for teens with AS—and make sure they still have appropriate supports. Don't pull the "ramp" out from under the "wheelchair"!
- Kids still need structure, down time, soothing activities, and preparation for transitions.
- Go with the flow of your child's nature. Simplify schedules and routines, streamline possessions and furnishings. If your teen only likes plain T shirts without collars or buttons, buy plain T shirts. If your kid likes familiar foods, or has a favorite restaurant, indulge her.
- Have realistic, modest goals for what the teen or the family can accomplish in a give time period. You may need to postpone some plans for career goals, trips, culture or recreation.
- Communication
 - Tell your teen just what s/he needs to know, one message at a time, concisely.
 - Impersonal, written communication is easier for the teen to absorb: lists of routines and rules, notes, charts, or calendars. E-mail may become a new option.
 - Side by side conversations (walking, in the car) may be more comfortable for the teen than talking face to face.
 - In so far as you can, keep your cool—they can't handle our upset feelings. Walk away if you need to.
 - Establish verbal codes or gestures to convey that one or both parties need a time out: a chance to cool down before continuing a difficult discussion at a later time.
- **Discipline & responsibility:** A simple, low key, consistent approach is more important than ever, as teens become taller and stronger—not that physical restraint was ever very useful with our kids. Pick your battles. Set and enforce only your bottom line rules and expectations—matters of safety and respect. Write them down. Make

sure both parents/all involved adults agree on the rules. Give choices when possible, but not too many. Engage your teen in problem-solving; what does he think would work?

- Special interests may change, but whatever the current one is, it remains an important font of motivation, pleasure, relaxation, and reassurance for the teen.
- Make sure thorough neuropsych re-evaluations are performed every years. This information and documentation may be critical in securing appropriate services, alternative school placements, a good transition plan; choosing an appropriate college or other post secondary program; proving eligibility for services and benefits as an adult.
- A regular bed time at a reasonable hour is more important than ever, if you can put/keep it in place. Regular routines of all kinds—familiar foods, rituals, vacations—are reassuring when the teen's body, biochemistry, and social scene are changing so fast.

Possible Shifts & Changes

- AS can intensify parent/adolescent dynamics—which are challenging enough! For the neurotypical background, read *Get Out of My Life—But First Would You Drive Cheryl and Me to the Mall?* by Anthony Wolf. The "job description" of a teenager is to pull away from parents toward more independence; for our kids, the process can be extra messy—not least because they may be even less ready for independence than other teens. Although some teens with AS are more docile and child-like, be prepared to tolerate/ignore considerable distancing, surliness, or acting out, knowing that it won't last forever. At the same time, set some firm limits, and keep a close eye on the child/teen's welfare.
- With or without AS, most teens become less willing to take parent's word or advice; so we need to hook them up with other trustworthy adults. If you want to your teen to learn or try or do something, arrange for the suggestion or information to come from a trusted adult *other than a parent*. E.g.: Handpick your teen's guidance counselor. Look for other good mentors: Uncle? Scout or youth group leader? Psychologist, social worker, peer mentor, "Big Brother," social skills group leader? Weight room coach or martial arts teacher?
- Boys may need to spend increased amounts of time with their fathers, and/or other male role models, as they undertake to become men. If Dad has taken a back seat, let him know his son really needs his attention now. If you are a single mother, look especially hard for male mentors at your son's school or in the wider community.
- Yes, teens do continue to grow and develop. You may

get some nice surprises along the way, as you see the teen take an unexpected giant step toward maturity. I think of it as their neurons maturing on the vine! Maybe it's just that they figure some things out, and get used to the feel of their new body chemistry.

Hygiene

Instill the essential habit of a daily shower: peers, teachers, and future potential employers will be very put off by poor hygiene. If possible, put your teen's clothes on a well-organized shelf in the bathroom, near the clothes hamper.

Teens' Mental Health

- *Even for a previously well-adjusted child*, multiple stressors during the teen years may bring on anxiety and even depression. Stressors seem to include increased academic/abstract thinking and social demands at school, peer pressure, increased social awareness, and fears of the future. Highly anxious teens who do *not* get help may be at risk for hospitalizations, school failure, acting out (including alcohol and substance abuse), or even suicide attempts.
- Don't panic, however—there are interventions you can provide. Appropriate school placement and staff training, exercise (martial arts, yoga), and/or appropriate therapy with a carefully chosen professional, may help control the level of anxiety. Meds may need to be introduced or adjusted.
- Seek out activity-based, practical social skills groups designed especially for teens. Participating in such a group, being accepted by group leaders and peers, is probably the most powerful way to allay a teen's potential despair at not fitting in socially and not having any friends. The positive social experiences and new skills they learn will be assets for the rest of their lives.
- Teens with AS are less prepared than neurotypical teens for the new challenges of sexuality and romance. Some are oblivious; others want a girl or boy friend, but are clueless about how to form and maintain a relationship. Boys especially may be at risk for accusations of harassment, and girls especially at risk for becoming victims. Teach appropriate rules, or see that another adult does. Look for supervised activities in which boys and girls can socialize safely together, supervised by a staff person who know AS and can coach appropriate social skills.

Parents' Mental Health

- Kids with AS can be difficult to parent and to love even when they are young. Often, our kids neither accept nor express love or other positive feelings in ways a neurotypical parent expects or finds most comfortable. Kids' behavior can be trying or embarrassing for us. Adding adolescence to the mix can make this dilemma even more painful.
- As AANE's Jean Stern says, "Spray yourself with Guilt-

Away!" (See page 11.) Forgive yourself for being an imperfect parent, for not loving your child "enough." Forgive yourself for sometimes losing your temper, yelling, or handling a tense situation awkwardly. Forgive yourself for getting your teen diagnosed "late"—there are still plenty of years in which to help your child. Forgive yourself for not arranging play dates, or sports, or tutoring, the way other parents may be doing. We each offer our child our own unique talents, interests, and qualities, as people and as parents. We each do the best we can to gather the information, insights, resources, and services that will help our kids live and grow through adolescence. And—willingly or of necessity—we each end up making significant sacrifices for our kids. In the hardest years my mantra was: "The best I can do has *got* to be good enough—because it's the best I can do!" It is a hard job; we are all heroic parents (as a kind friend of mine once said to me).

- Build and use any support networks you can: extended family, close friends, church/synagogue groups, understanding school staff. At AANE parent support groups, you will find other wonderful parents who will appreciate how hard you are working for your teen, and share their strategies, resources, and spirit. Use the AANE Family Networking list to contact other parents—or just call AANE. If you don't have a good network, consider individual or family therapy for a little support during a stormy, demanding life passage. When you have a demanding teen, it's good to be reminded once a week that your needs and feelings are valid and important, too!
- If both parents can largely agree about a teen's diagnosis, treatment, and rules, it will save a lot of family wear and tear. To get your partner on the same page, attend AS conferences or classes together. When you hear the same information, you can discuss it and decide what will work best for your teen and in your family. As you learn more about AS, you may also come to better appreciate each other's contributions to your child's welfare. Attend team meetings at the school together, or alternate which parent attends. Seeing your child's therapist together (possibly without the child), or seeing a couples or family therapist, may help you weather a tough time together.
- A regular bed time for the teen gives you time you can count on each evening for yourself and/or your partner. If you can build in regular respite—such as a night your teen spends with a grandparent once a month—go for it, and plan ahead for some relaxation, fun, or culture. (Divorced parents may be able to count on a little time alone or with friends as long as they set up and adhere faithfully to a regular visitation schedule.)

Disclosure & Self-Advocacy

- If you have not talked to your teen about Asperger Syndrome, you or someone else should do so—to the extent that the teen is ready to hear it. It's tricky for

teens—they so much want to be “normal” and strong and successful. A diagnosis can seem threatening or even totally unacceptable. In truth, however, the adults with AS who do best are those who know themselves well—both their own strengths, which point them toward finding their niche in the world, and their own blind spots: where they need to learn new skills or seek out specific kinds of help.

- Teens need to learn when to ask for help, from whom, and how. It’s very helpful to have someone such as a trusted guidance counselor whose door is always open, and who can coach the teen in problem solving.
- Encourage your teen to carry a wallet disclosure card (see AANE booklet or spring 2006 last newsletter, or contact me) to show if stopped by a police officer or other first responder. A lot of teens with AS like to walk at night to unwind, and police may view their behavior as suspicious. You may want to introduce your teen to your local police community relations officer, and explain a little about AS. Refer them to AANE if they have questions.

School

- Schedule regular monthly educational team meetings to monitor your teen’s progress, to ensure that the IEP is being faithfully carried out, and to modify it if necessary. Because teens can be so volatile or fragile, and because so many important things must be accomplished in four short years of high school, these meetings are critical. (See AANE article “Some Accommodations for Students with AS.”) If a teen is doing very well, the team can agree to skip a month—but be sure to reconvene to plan the transition to the following year.
- Some teens adjust o.k. to middle/high school with appropriate supports and accommodations, Others, however, just cannot handle a large, impersonal high school. You may need to hire an advocate or lawyer to negotiate with your school system to pay for an alternative school placement, tuition, and transportation.
- See the AANE school list in the teen information packet. There are no easy answers to finding the mix of conditions where our kids can survive or even thrive; pick the best possible realistic choice, and help your teen adjust. Call AANE if you would like to discuss options. Some families hire educational placement services.
- If you can afford it, you may prefer to pay private school tuition rather than paying a lawyer to negotiate with a financially strapped or resistant school system. Some families move to a community with a better high school.
- Residential schools may be worth considering for some. The right fit can build tremendous confidence for the teen, give the parents a break, and prepare everyone for the independence of the post high school years.

Transition Planning

- Chapter 688 in Massachusetts mandates a transition

from services delivered under the aegis of the Department of Education (DOE), through graduation or age 22, to services delivered by another state agency, such as the Massachusetts Rehabilitation Commission.

Many high schools are unfamiliar with transition planning, however—especially for college bound students. The more you know as a parent, the more you may be able to ensure that a solid transition plan is written and carried out.

- The transition plan should address the skills a teen needs to acquire while in high school, in order to be prepared for the kind of independent life s/he wants to lead after graduation.
- What kind of living situation, employment, and transportation fit your teen’s picture of his/her future at age 18 or 25?
- Once the goals are set, where can the teen learn the necessary skills? Consider academic courses, electives, extracurricular activities, and additional services within and outside the high school (e.g. community college, adaptive driving school).
- Social skills are more essential to employment success than high IQ or a record of academic achievement, as indicated in the very title of Daniel Goleman’s 1995 best-seller *Emotional Intelligence: Why it can matter more than IQ*. Make sure the IEP and Transition Plan provide for social skill learning/social pragmatic language. A good overarching goal is: “Bobby will learn the social skills appropriate to a 9th grader..10th grader... to the workplace.” (Goal created by Deb Conerty; see acknowledgements at foot of article.)
- You want input and ownership from the teen as far as is possible, but parents can and should have input. You may need to have team meetings when the teen is absent, so you can speak frankly about your concerns, without fear that the teen may feel you lack respect for or faith in her/him.
- Involve your state Rehabilitation Commission in the planning process, since they may be the sole or key provider of post-h.s. services for most adults with AS.
- At the Federation for Children with Special Needs, Terri McLaughlin offers workshops on Transition Planning. See www.fcsn.org, or call her at 617 236-7210 x336. Terri will offer a basic and an advanced workshop for AANE on 10/11 and 11/9/06 respectively (box on p. 15.)
- Consider delaying graduation in order to ensure that transition services are actually provided under DOE. It may be hard to convince an academically gifted, college bound student to accept this route. However, it may be very helpful for students who will need a lot of help with independent living skills and employment issues. Services need not be delivered within high school walls. Community college courses and adaptive driving lessons and employment internships are just a few examples of alternatives to consider.

- If you have not yet made a will and set up a special needs trust, do it now. Ask the lawyer about powers of attorney or other documents you may need once your teen is no longer a minor. Few parents assume guardianship of a young adult 18 or older, but it may be necessary and appropriate in some situations.

Steps toward Independence

- Look for opportunities—e.g. in the summer—for a sheltered, successful overnight stay away from home with no parent. Examples: long weekend visits to relatives, a week or two of sleep away camp, taking a course on a college campus. AANE has a summer and recreation resource list.
- Teach laundry and other self-care/home care skills by small steps over time. Try to get the teen to take an elective such as cooking or personal finance at the high school.
- Look for volunteer activities or part time jobs at the high school or in the community. Be persistent in asking the school to provide help in the areas of career assessment, job readiness skills, and internships or volunteer opportunities. They probably have such services for intellectually challenged teens—but may not realize our kids need that help, too. They may also not know how to adapt existing programs to meet our kids rather different needs.
- An activity the teen can walk to is great—for my son it was Tae Kwon Do lessons; he could decide how many lessons to attend each week, and get himself there and back. Learning to use public transportation is also great. Consider buying a T pass, or rolls of quarters.

College (Also see page 6-7.)

- Not all teens are ready for a residential college experience. To decide, use the evidence of how the teen did at sleep away camp or similar samplings of independence, and look carefully at executive function skills. As an alternative, community colleges offer a lot of flexibility: easy admission, low cost, remedial courses if necessary, the option of a light course load, and the security of living at home. Some disability offices are more successful than others at providing effective, individualized support. However, if the teen is living at home, you may be able more easily to sense trouble, step in with help, or secure supports your young adult needs to succeed.
- If your teen seems like a good candidate for college, take him or her to visit colleges during the spring vacation weeks of the junior year of high school, or during the summers before junior and senior year. This is easy to do in Massachusetts! Visits reveal a lot about what environment the teen will prefer. Purchase a large college guide to browse (e.g. Fiske). Also look at **Colleges that Change Lives** by Loren Pope: Clark University, Hampshire College, and Marlboro are New England colleges in this book.
- The college section of the AANE teen and adult packets

includes phone numbers of parents you can call to ask about specific colleges their children attended.

- Because your college student is no longer a minor, colleges generally will not communicate openly with parents, nor disclose the student's disability without the student's permission. Some colleges will allow the student to sign a blanket waiver to release information to parents, but many will only allow limited waivers or none. The burden on the student to disclose, to ask for help, and to let parents know about problems—things that are hard for our kids.

Resources

- The AANE parents of teens information packet lists alternative schools, parent comments on driving, some post graduate programs; there is also a college section; and a parents of teens networking list.
- We have parent support groups in Watertown and Reading are especially for parents of teens.
- Subscribe to Stephanie's e-list, soon to be a blog or list-serve.
- Use the MDDC Consumer Empowerment Funds every year, regardless of income level.
- Check if you are eligible for an AANE family grant.
- The Autism Spectrum Division of Mass DMR may provide services or funds to some families. A few families already get help from DMR, and a few from DMH (usually there is a "co-morbid" diagnosis).
- Call AANE for referrals to advocates, educational consultants, psychologists, etc., who are experienced in working with kids with AS and their families.

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Terri McLaughlin, Transition Planning specialist at the Federation for Children with Special Needs, opens my eyes and grounds me every time we have a conversation.

