



# BRAVE

## *New World*

# 13 Things to Keep in Mind as Your Child with ASD Reaches **ADOLESCENCE**

By Chantal Sicile-Kira

Living with a child on the autism spectrum day after day, parents often miss the little changes that are so typical of all kids' development. One day I looked at my son, Jeremy, and realized he was already up to my chin. And what was that – facial hair? His behavior started to change as well. As a young child he'd always been compliant; we spent years trying to teach him to say “no” and mean it. So I was thrilled when he just didn't want to do what we wanted him to do anymore.

Autism and adolescence: each on their own can be interesting and challenging, to say the least. Together, they form a volatile mix that can arouse daily anxiety in even the most prepared adult. If you live with or work with a pre-teen or teen with an autism spectrum diagnosis, the following 13 points can help you and your child navigate those years a little more smoothly. One caveat: it doesn't matter the functioning level of your child with autism or Asperger's; everything here applies. You'll work them out differently depending upon his or her cognitive, emotional and/or communication abilities, but don't overlook them, thinking they don't relate to your child. They do!

### 1. Noncompliance: it may not be autism, it may be adolescence.

Whether or not they have autism, there's a definite 'shift' in behavior and personality when children turn into teenagers. Wanting your attention changes to wanting their independence. For kids on the spectrum, this behavior change may look like non-compliance; they don't follow through on your requests as before. But it's actually a normal part of their development, entirely aside from their autism. As a parent it's important to support your teen as he struggles to become his own person, and even though it may be hard to appreciate, this is a positive development. After years of being taught to do as he is told, your teen needs to start learning that it is acceptable at times to say 'No,' or he might find himself in dangerous situations with peers or others looking for an easy victim to prey upon.

### 2. Teenagers need to learn to make their own choices.

Giving choices to your growing teen will teach him about decision making and accepting the consequences of his choice (good and bad), as well as help him realize he will eventually have more control over his own life. This applies no matter what the functioning level of the child. Offer him choices, regularly, and abide by the choice he makes. Remember, as he gets older he will want and need to be more involved in his life and his transition planning. By letting him make choices now (within your parameters at first) you are teaching him valuable life skills.

### 3. Chores teach responsibility.

At any age, it's good to teach children that being part of a group (whether it is a family, a work group, or a community) brings with it a certain level of responsibility. If your

pre-teen has somehow been exempt from chores and group responsibility, let this slide no longer. Teens need to learn that living in a house with others entails responsibilities as well as pleasures. Chores teach the teen to be responsible for himself, to live independently, as well as foster self-worth and self-esteem. ALL individuals with autism can be taught to contribute at some level. Do make sure your child has opportunities to do so.

### 4. Watch out for seizures.

One of every four teenagers with ASD will develop seizures during puberty. Although the exact reason is not known, this seizure activity may be due to hormonal changes in the body. For many the seizures are small and sub-clinical, and are typically not detected by simple observation. Some signs that a teen may be experiencing sub-clinical seizures include making little or no academic gains after doing well during childhood and preteen years, losing behavioral and/or cognitive gains, or exhibiting behavior problems such as self injury, aggression and severe tantruming.

### 5. Talk to your child about his/her changing body.

Imagine how scary it must be to realize your body is going through some strange metamorphosis, you don't know why and there is nothing you can do about it. Whether your child has Asperger's Syndrome and has sat through hygiene classes at school, or he is more impacted by autism and you're not sure how much he understands, it is important to discuss the changing male and female body in a simple way he can understand. Otherwise, your teen may be overly anxious and agitated when she starts menstruating or when he has wet dreams. Visuals that include photos or drawings and simple words may be helpful, especially at the beginning. Be concrete and don't overwhelm – this is certainly not a one-time talk!

### 6. Masturbation: a fact of life.

Let's face it; masturbation is a normal activity that almost all teenagers engage in. Once discovered, it is an activity hard to stop, especially for individuals who enjoy self-stimulatory activities and can be obsessive compulsive, as are many people on the autism spectrum. The best approach is teaching your teen that this is a private activity to be done only in private at home, in a designated place such as his bedroom or bathroom.



## 7. Relationships and sexuality: topics that need to be discussed.

Sexuality is a topic that most parents are not comfortable discussing with their children, even their neurotypical teens. However, it is necessary to talk to your teen on the spectrum about sex and the many types of relationships that exist between people. It is naïve of parents to think that because their child has autism s/he won't need this information. Teens talk, and invariably your child will be hearing about it from their NT peers at school. Whatever the functioning level of your child, he needs to be taught about appropriate/inappropriate greetings, touch and language when interacting with members of the opposite or same sex. Don't leave this important part of his social-emotional development to locker room education.

## 8. Self-regulation is important for life as an adult.

An important skill for every teen to learn is the ability to control his or her reactions to emotional feelings and sensory overload. Hopefully, by the time they are teens your child or student has learned to recognize their feelings and impending emotional or sensory overload, and ways to handle the situation. In school this could mean practicing self-calming techniques or signaling to the aide or teacher they need a break and having a 'safe place' or quiet room to go to. At home, teens should have their own quiet spot to retreat to when overwhelmed. And parents: respect their need to do so!

## 9. Self-esteem is the foundation for success.

While children are young, start building this foundation by emphasizing strengths rather than weaknesses. If your child with ASD, no matter what his age, has low self-esteem pay attention to the messages he is receiving from people around him at home, at school and in the community. In all likelihood, the message he is hearing is that he can't do anything right. Teens need to be told when they are acting, responding and communicating appropriately, as well as that their (considerable) efforts to do so are appreciated. Where there are challenges, it is up to us, as the adults in their lives, to help them find strategies to be effective. Teens can be at high risk for depression. Parents



should ensure their teen knows they are valued and loved under all circumstances, not just when they 'get it right.'

## 10. Self-advocacy is required for independence.

Eventually your teen will be living away from home and will not be under your protection. He needs to know how to speak up for himself. Start this training while he is in school. IDEA 2004 mandates that students be invited to participate in transition planning and this supportive environment can be good 'training ground.' Make sure your teen is aware of his strengths and weaknesses and how he is different from others. In this way the teen can gain a real-life understanding of areas he may need to improve upon or that require assistance from others, and areas in which he is proficient, or that are his strong points to build upon.

## 11. Bullying is a serious problem and should be treated as such.

Bullying can range from verbal taunts to physical encounters. At any level it is not an individual problem, but a school problem. Unless your child's school strongly enforces a no-bullying policy from the principal on down, your teen may have a difficult time. Teens on the spectrum are poor at picking up social cues, understanding ulterior motives, sarcasm, and predicting behaviors in others. As such, they unknowingly put themselves in unsafe situations. At other times their unconventional grooming or dress, often stilted language and rule-bound obsessions can render them targeted victims. Ensure your teen learns the meaning of nonverbal behaviors and the hidden curriculum (i.e. the unstated rules in social situations). Enlist the help of a neurotypical teen or sibling when shopping for clothes or getting a new hairstyle so your teen has at least a semblance of 'fitting in' with his peer group.

## 12. The Individualized Transition Plan (ITP) is your teenager's business plan for the future.

Second only to the early intervention years, the transition years in high school are the most important years in your child's educational life. Skills your teen needs to learn to survive and thrive as an adult, in adult settings, should be the focus of this time in school. The ITP, mandated through federal special education law, is the roadmap for your teen's future. Once your child graduates or ages out of high school, mandated services are few and programs have waiting lists that extend into years. Spend time (and include your child as

much as possible) thinking about what he wants to be doing when high school ends, and 5-10 years from now. Then plan how he will get there and what skills will be needed. This “futures planning” should drive the ITP, with individual goals written into his IEP.

### 13. Parents, you need to take time out for yourself; it’s good for your child too.

With all the responsibilities you have as a parent of an adolescent on the spectrum, you need to take some time out for yourself. Whether it is a short break you take every day to go for a walk, exercise or engage in a favorite activity, or a weekly evening out with your significant other, you need to recharge your batteries. This is also positive modeling for your pre-teen and teen. It teaches that life can be stressful and overwhelming at times for all of us, and that we need to develop ways to manage our stress, and enjoy life, not just live it.

Just the other day I was looking around the house for Jeremy, who is now 17. I knocked on his bedroom door. He opened the door a crack, one of his *Guitar World* magazines in hand. I could hear *Panic at the Disco* playing in the background. “Go away, Mom,” he said, and I did, with a little smile on my face. Jeremy is significantly impacted by his autism. Yet moments such as this remind me that he is first and foremost a teenager, with his own personality, his own wants and wishes. He’s on the road to becoming his own person, figuring things out in preparation for adulthood. I wouldn’t have it any other way. 🍀



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