

# Autism Spectrum Disorders and Sexuality

## Introduction

Learning about sexuality is an ongoing, life-long process that begins at the moment of birth. As we love and care for our children, they learn about their bodies, loving touches, and trust. They become aware of themselves as a girl or a boy, and what it means in their family or culture to be female or male. By observing others around them, they learn about affection, respect, and how to behave appropriately.

Many teenagers and young adults on the autism spectrum want to be in romantic relationships. They want to date, they want to experience intimacy, and they want to get married. In order for them to make good choices, it is our responsibility as parents to teach them about these very personal topics.

If it appears that your child is not ready to learn about human sexuality, don't assume they are unable to understand its concepts. The problem may lie elsewhere – with sensory and/or communication problems. If your child has difficulty learning new information or gaining new skills (regardless of the subject matter), then you probably need to address sensory and communication issues first.

## Addressing Sensory Issues

Making sense of the world – understanding what their senses are telling them – is what most adults on the autism spectrum convey as the most important skill they needed to learn as children. In fact, it is the most important skill all children need to learn. Unless a child understands what it is they are seeing, hearing, touching, feeling, and smelling, how can they learn any other skill necessary to survive in today's world? Communication and relationship skills are essential skills that first require an awareness of the world, as well as awareness of one's place in the world.

As teaching is taking place, parents can sometimes become so intent on immersing their children in social situations that they underestimate – or forget about – the impact that sensory issues can have on their child's ability to learn social skills and develop social awareness. When sensory issues and social concerns collide, learning won't take place. It can't because the sensory issues are interfering with the child's ability to attend and learn. The anxiety over sensory issues can be acute and can completely fill the child's field of awareness. That's why anyone trying to teach social skills – even basic ones – to a child with an autism spectrum disorder (ASD) needs to first assess the environment from a sensory perspective and eliminate sensory issues that will impede the child's ability to concentrate on the social lesson. Parents scratch their heads and wonder why their child can't learn basic social skills or isn't interested in even trying, but what should they expect when the child is put in an environment that hurts. For example, fluorescent lights may not bother us, but for a child on the spectrum the flickering and humming noise may be unbearable.

## **Addressing Communication Issues**

After making sense of the world around us, communication is the most important and basic of abilities. Children on the spectrum need to be able to communicate in order to get their needs met – as do all children.

Many children on the autism spectrum have behavior problems of one sort or another for a variety of reasons. Behavior is a form of communication – the hard part is figuring out what the behavior is telling us. A child may not be able to communicate what is going on because they lack basic communication skills or they may have good communication skills but cannot use them at that moment because they are overwhelmed. This leads to behaviors from intense rocking and self-stimulatory behavior to rages and meltdowns.

Often, we focus too much on stopping and redirecting behavior without figuring out the intended purpose of the behavior. We all need to learn appropriate behavior, but more importantly, we need to have a form of communication we can ably and comfortably use to express ourselves.

There are many on the higher functioning end of the autism spectrum who are very articulate but still have trouble with aspects of typical conversation. For example, many are literal thinkers who do not understand metaphors, double meanings, or idioms. Or they may have problems understanding social cues or body language. These types of difficulties affect social relationships and how people on the spectrum respond in social situations.

But remember this: Even if your child can't communicate, that doesn't mean they don't comprehend what you're telling them. You still need to talk with them about human sexuality.

## **Specific Topics**

### **Puberty**

People on the autism spectrum usually like predictability and routine and dislike change. Some pre-teens and teenagers have a hard time with the idea that their bodies are changing and that they are getting bigger and growing out of their clothes. For this reason it is important to tell your child ahead of time about the changes that will occur when they reach puberty.

There is a risk of depression during these years as it becomes apparent to the teenager with an ASD just how different they are from their peers. As they become more interested in socializing, they may be teased and scorned by others due to their lack of required skills. Your child may be experiencing feelings of anxiety and depression that will go unrecognized if you do not encourage them to share their thoughts with you. Your child needs to know that these feelings are normal and how to recognize and identify the different feelings they are having. Picture icons or simple drawings of happy and sad faces can help the nonverbal child communicate how they feel.

Along with ASD-specific behavioral problems, children on the spectrum also have the usual noncompliance issues that go along with being a pre-teen or teenager. Early adolescence is when

most young people seek more independence from their parents, seek even more approval from their peers, and try to fit in with the crowd.

For more specific information on teaching your child about puberty, please refer to our article, “Teaching about Puberty.”

### **Hygiene**

Most children on the spectrum do not independently learn what they need to know about hygiene and self-care. The goal is to teach children to be as independent as possible in these areas. For many, this will be an ongoing life-long goal. Teaching your child hygiene skills also teaches them about modesty and responsibility.

Explaining to your child why they need to establish good self-care routines – the need for good hygiene to stay healthy and the social aspects of needing to smell good and look clean – may be especially important for children who don’t automatically understand why it is important to do things that are difficult for them to do. Using Social Stories (see below) can be helpful, and allowing them to choose their own hygiene products can give them more ownership of their self-care.

### **Private Behaviors**

For safety reasons, all children on the spectrum need to understand the differences between private and public body parts, private and public behaviors, private and public places, and private and public conversations.

Social Stories (see below) are effective at all ability levels for teaching what behaviors are to be done in private and which ones are acceptable in public.

For more specific information on teaching your child about privacy, please refer to our article, “Teaching about Private Behaviors.”

### **Sexual Abuse**

A higher functioning child may have good communication skills, but they are still at risk for sexual abuse. Unless they are taught, they do not learn on their own or from their friends (they usually have few) what constitutes a sexual act, how to withhold consent, and so on. This happens also because they are poor at predicting behaviors, they are gullible by nature, and they don’t understand – unless they’ve been taught – social cues and body language.

A child with poor communication skills may be the perfect victim for sexual abuse because they can’t say “no” to unwanted touch and they can’t report abuse after it has happened.

Social Stories (see below) are effective at all ability levels for teaching who is allowed to touch a child and who is not.

For more specific information on teaching your child about sexual abuse prevention, please refer to our activity, “Teaching Sexual Abuse Prevention: Circles and Relationships.”

## **Romantic Relationships**

It is a fallacy to think that teenagers and adults on the spectrum do not want to have romantic relationships. Those who can communicate verbally make it very clear that they enjoy having romantic relationships, as do even those who are nonverbal.

Knowing you want to relate to other people is not the same as knowing how to relate. This is a problem faced by all individuals on the spectrum, regardless of their functioning level. As with everything else, the difficulties may vary from person to person, but relationship skills need to be taught to all. Besides the challenges most people on the spectrum have with communication, they may also have problems maintaining eye contact, recognizing their own emotions and the emotions in others, and with how they respond to intimate touch. Individuals with autism don't always know how to begin, sustain, or end a conversation. Then there are the sensory stimuli present in social environments that can be overwhelming for many. All this impacts relationship building in one way or another.

For more specific information on teaching your child about relationships, please refer to our activities, "Teaching Sexual Abuse Prevention: Circles and Relationships" and "Teaching Dating and Relationship Skills to Teenagers with High Functioning Autism."

## **Sex**

Many times, parents are reluctant about teaching pre-teens and teenagers on the spectrum about sex. They assume that their children are not ready or not interested in sex or dating, not realizing that it is this lack of knowledge that makes them potential victims of sexual abuse.

The question often arises, "Will giving young people lots of information about sex simply encourage them to go out and experiment?" The answer is no – quite the reverse, in fact. Studies carried out in different countries have shown time and again that it is most often those young people who have scant information who become involved in early sexual experiences. Those who are well-informed tend to delay their first sexual encounters, and when they do become sexually active they have the confidence to negotiate effectively with a partner, and to use protection.

## **Strategies**

Every child, whether or not they have an ASD, needs to learn practical information and skills related to puberty and body changes, different types of relationships, modesty and appropriate public behavior, and other aspects of human sexuality. For pre-teens and teenagers on the spectrum, it is important that assumptions not be made about what they know or will pick up instinctively, or about their level of comprehension of what they are hearing and seeing.

Here are some general guidelines regarding what, where, how, and when to teach your child:

- Because of the high risk of sexual abuse for people with autism, it is important that lower functioning children be taught how to take care of their bathing and hygiene needs themselves.

- It is important to teach your pre-teen about puberty before their body starts developing. Otherwise, a girl may think she is bleeding to death when she has her first period and a boy may think he is “wetting the bed” when he has his first wet dream.
- Usually, teens with ASDs are emotionally less mature than their peers without autism. They may not be ready for some information about intimacy and sexuality, but they will need to have some sexuality education to reduce the risk of behaving inappropriately or being sexually abused. Also, children who are mainstreamed will be hearing their peers discuss the subject and need to be aware of what it all means.
- All teenagers need to know about grooming and dressing, but if your child is mainstreamed, you will need to teach them much more about grooming, dressing, and styles, and why these areas are so important to their peers without autism. Fitting in is a necessary skill that is important for self-esteem as well as for future success in the world of people without autism. At the very least, it’s important that teens on the spectrum look neat and clean; but having an item or two of “cool” clothing will help them fit in even more. Fitting in may also reduce the chances of being bullied.
- Sexuality talks with pre-teens and teens who have problems with eye contact may work better if you are not sitting face-to-face. Try talking while you walk side-by-side, work alongside each other (for example, when preparing a meal), or drive together in the car.
- How you decide to teach the different sexuality topics will depend on how much understanding your child has. Explain to your child as if they understand, then back it up with visual and auditory input in the form of Social Stories (see below). If necessary, do a task analysis or put up a word or picture schedule (see below). All children on the spectrum can learn about human sexuality, even if it takes them longer to learn than children without autism. It’s finding out how to teach them that is the key.

Here are some specific strategies that may work with your child:

### **Social Stories**

For many children, social skills training is a particularly important area of focus. Research has shown that many people with autism have “mind blindness” – they do not understand that other people think differently than they do. This may be why they are often unable to anticipate what others may say or do, which creates problems in social behavior and communication. There are different methods of teaching social skills and communication, but one method that can work especially well at home is Social Stories.

Social Stories must be specific to the child and the particular situation. To create a Social Story, you must start by identifying the behavior that you are trying to change. For example, a child may engage in profound emotional displays when confronted with a minor conflict, such as the inability to tie their shoe. The story must reflect the shoe incident specifically in order to have the optimum effect on the child. Once the behavior is evaluated, the story creator begins with a descriptive sentence that explains the situation or environment where the problem is occurring: "Every day before school, I must put on my shoes and tie them." A perspective sentence then gives the perspective of the child or others on the situation: "When I cannot tie my shoes, I feel very angry." Finally, a directive sentence gives the child specific instructions on what to do or not do. "When I feel angry, I should not scream and cry," or "When I am having trouble tying my shoes, I should quietly get up and ask mom for help."

The presentation will depend on the age and ability of your child. With young children it may be appropriate to have just pictures or a picture and one sentence per page. An older child may want their stories to appear more adult-like in their presentation. The number of descriptive, perspective, and directive sentences may also vary according to the ability level of your child. A Social Story is usually a first-person, present-tense story.

As a Social Story is intended to be written from the perspective of the child, it is important that you try to get that perspective. Higher functioning children can help write the story, discussing those areas where they are having difficulty and helping you write from that perspective. With lower functioning children, this may not be possible – which means that you will have to carefully observe your child to figure out the reason behind the behavior.

Here is a sample Social Story:

My name is Jason. I am a student at Rosa Parks Middle School.

I like several girls in my class. I like to go up and touch them. Although I like to touch them, the girls don't like it at all. They often yell at me or tell the teacher.

I get to decide who touches my body. Now I must learn that the girls also get to decide if they want to be touched. It's okay for me to ask the girls if I can touch them, but if they say "no," then I must not touch them.

According to the developer of Social Stories, Carol Gray, half of all the stories you write should be about things your child does well.

### **Comic Strip Conversations**

Comic Strip Conversations may be used independently or with Social Stories to help solve communication problems that a child may encounter. These drawings serve to illustrate verbal communication, providing additional support to individuals who struggle to comprehend the quick exchange of information that occurs in a conversation.

A Comic Strip Conversation is a conversation between two or more people using simple drawings. Stick figures, speech and thought bubbles, symbols, and color are used to enable the child to see things in a conversation that they may not otherwise understand. Speech bubbles can be drawn in different ways to get across different emotions (for example, sharp edges for angry thoughts). Text is written in different colors to convey different emotions or meanings (for example, green for happy, red for sad, yellow for scared, black for facts, and orange for questions). These colors can be chosen by you and your child. Strips once drawn can be stored in a book for future reference and revisions.

Comic Strip Conversations can be used to explain the sarcasm and teasing that so many children with an ASD find confusing. Since children on the spectrum have difficulty interpreting other people's thoughts, comic strips can also be used to show that different people have different thoughts.

## Social Behavior Mapping

Social Behavior Mapping focuses on behavior modification through internal self-regulation. It works best with children on the higher functioning end of the autism spectrum.

This technique requires a child to consider the difference between “expected” and “unexpected” behaviors, even though they’re really examining the difference between “appropriate” and “inappropriate” behaviors. By changing the language in this way, the focus is shifted to the impact a behavior can have on one’s peers. The child is asked to consider whether their actions were expected by others, and whether this would influence how their peers react to them.

Here is an example of Social Behavior Mapping:

Timothy is a teenager who likes to spontaneously touch and hug the girls in his class. A Social Map for this situation would show that touching or hugging others without their permission is “unexpected.” It would help Timothy to see how others feel about these behaviors and how they might react to them.

Appropriate behavioral choices are listed in the “expected” behaviors component of the Social Map, along with the pleasant outcomes that can result from these behaviors. Unexpected behaviors and their resulting unpleasant outcomes are listed in the “unexpected” behaviors component of the Social Map. Asking Timothy to compare the two components will help him to see how different behaviors can produce different outcomes.

Here’s what Timothy’s Social Map might look like:

<b>Expected behavior</b>	<b>How it makes others feel</b>	<b>Outcome</b>	<b>How I feel about myself</b>
Keeping my hands at my sides or on my desk	Relaxed	Girls don’t mind sitting next to me	Happy
Not touching girls in my class	Comfortable	Girls feel okay being around me	Happy
Only hugging girls if they say I can	Safe	Girls respond positively to me	Accepted

  

<b>Unexpected behavior</b>	<b>How it makes others feel</b>	<b>Outcome</b>	<b>How I feel about myself</b>
Moving my hands away from my sides or off my desk	Uncomfortable	Girls and boys tell me I’m weird	Unhappy
Touching girls without asking them first	Annoyed	Girls tell me to leave them alone	Embarrassed
Hugging girls without asking them first	Disgusted	Girls and boys get mad at me	Ashamed

If you decide to try this technique, be sure to keep the map handy. Appropriate behaviors can be tracked by placing checkmarks beside them.

### **Specific Techniques for Teaching Hygiene and Grooming Tasks**

Sometimes the lack of learning or implementing hygiene and grooming tasks has to do with remembering the different steps, remembering which tasks to do when, or not having the necessary physical skills. Here are some techniques you can use to teach basic self-care skills to your child:

- **Make a schedule.** Place the self-care schedule near where the task should be performed. For example, in the bathroom or bedroom place a schedule for taking a shower, putting on clean clothes, brushing teeth, or brushing hair. Perhaps your child prefers a notebook that they like to consult instead of reminders on the wall. Some children prefer words, some prefer pictures. Whatever works is what you should use.
- **Use picture icons.** For visual learners who may not be reading, picture icons are great tools for teaching them about these topics, and also for visual reminders on the schedule. For those who are nonverbal, they can communicate by pointing to these icons.
- **Do a task analysis.** Perform the task a few times yourself; then analyze and note each and every step necessary to perform the task. Have your child follow the same steps to see if that's also the best way for them to complete the task. Once you know the sequence of steps that works best for your child, provide them with a written or pictorial list of the steps. Then watch your child and note for each step if they do it independently or with prompts, and what kind of prompts they need. This is the baseline. You will then know which steps to focus on when teaching the task.
- **Use backward chaining.** If you need to teach all the steps of a self-care routine, consider starting with the last step. When that is mastered, add the next-to-last step, and so on. For example, if you are teaching your child how to wash their hands, start by having them dry their hands off on a towel. When that is mastered, add the next-to-last step of turning the faucet off. Keep working backwards from there – from rinsing to soaping up to turning on the faucet in the first place. By starting with the last step and working backwards, your child always completes the routine. This may be rewarding in itself, but it also teaches the importance of completing tasks.
- **Adapt for poor motor skills.** Certain hygiene and grooming tasks require motor skills that your child may not possess. For example, poor fine motor skills may make it difficult for your son to shave or for your daughter to place a sanitary pad in her underwear. Alternative strategies, perhaps requiring adaptive equipment, will need to be developed in these situations.
- **Teach “motor memory.”** Some people on the spectrum have motor planning difficulties. Individuals have described this problem in much the same way that stroke patients do – they try to “order” their limbs to move but they don't. However, by placing your hand on your child's hand and physically motoring your child through the self-care task one step at a time, you can create a “motor memory” for that skill. Don't expect instant success – you may have to repeat this process many times before “motor memory” kicks in.



- **Use music or songs.** Rhythm, repetition, melody, and rhyme can all aid memory. Many individuals with autism can learn sequences to self-care by hearing the steps sung to familiar tunes (such as “Twinkle, Twinkle, Little Star”). You can sing the tune as the task is performed, and then record it so your child can turn it on when performing the task on their own. Eventually they may sing or hum the tune as a memory aid.
- **Use video modeling.** Watching videos of people performing a task can be a good way for some children to learn. The videos can be fun and easy to make with your own camera or phone – you don’t have to be an expert. Watching the video where someone they know is modeling or where they themselves are modeling the correct way of doing something can be a great way for your child to learn.

### **Other Strategies**

- Some of the techniques outlined above (making a schedule, doing a task analysis, or using video modeling) can also be used to teach relationship skills – such as how to flirt, how to ask someone out on a date, or how to get ready for a date.
- If your child acts inappropriately in a social situation (such as asking strangers personal questions or not knowing how to sustain a conversation instead of a monologue), make a note of it. Then write down what the rule is for that social behavior and explain it to your child. Write a Social Story with your child using the rule and then practice the behavior by having your child role-play the situation with other willing participants. Reminding them of the rule when necessary will help them to remember. Keeping the rules and Social Stories in a binder for easy reference and review can be helpful as well.
- Many teens on the spectrum have reported that acting classes and drama clubs have been a great way for them to develop social confidence. In acting classes, individuals often start out with a script – just what a child on the spectrum may need for any new social situation. Then, as the actors learn their lines, they become less reliant on the script. They also learn what facial expressions and gestures are appropriate to the situation and how to give expressiveness to their voice. Such lessons can provide a safe environment for basic skill and confidence building.
- Enlist the support of a sympathetic young person who is up to date with teenage language, behavior, and fashion to guide your child through these social minefields. They can help your child work out what to say, do, or wear in given situations. Just as importantly, they can also help them recognize what not to say, do, or wear. This individual can also tell your child when they are being too trusting or gullible – typical traits for a person on the spectrum.
- Do plenty of “what if?” scenarios with your child. For example, “What if your period starts at school?”, “What if a boy teases you about your breasts?”, “What if you get an erection in front of the class?”, or “What if your voice cracks and people laugh at you?”. Together, you and your child can work out possible solutions to these scenarios.
- Be aware of any infatuation your child may have with another person. Help them to understand that crushes are normal and okay, just so long as they are not pursued to the point of stalking or harassing another person. Teach your child that healthy, mature relationships are reciprocal and respectful.
- The Internet presents parents with a whole new set of safety concerns that will need to be addressed. Make sure your child is fully aware of the potential dangers of the Internet, and knows how to use the Internet safely. Be prepared to supervise your child’s use of the Internet.

For more information, please read our two articles on Internet safety. One was written for parents of children with developmental disabilities and the other was written for parents of children with typical development. You should find both articles useful.

## **Final Thoughts**

Young children on the spectrum do not seek out help (when they are hurt on the school playground, when their shoes come untied, etc. etc.), but this is a skill they should be taught from early on. Learning to ask for help, and later, advice from trusted people will prepare them for different types of social relationships when they are teenagers and adults.

Studies of teenagers' sexual attitudes have revealed that, while many young people choose to turn to their friends for support and the informal sharing of sexual information (which, of course, can mean misinformation), most would like to be able to talk with their parents about sexual matters. This can be even more vital for young people with autism. They are often excluded from teenage discussions, and thus may become the object of ridicule owing to their social clumsiness and ignorance of current terminology. There is no doubt, therefore, that parents must provide sexuality education for their teens. And it's not a one-shot deal – communication with teenagers needs to be ongoing, open, and honest. There are many tasks required of the parent of a child with an autism spectrum disorder – teaching about human sexuality may not be the easiest one you'll tackle but it may be one of the most important ones.

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