

Section One

BASIC INFORMATION ABOUT TS, OCD, AND ASSOCIATED DISORDERS

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1.1. What Is Tourette Syndrome (TS)?

- Tourette Syndrome (TS; sometimes also known as Tourette's Disorder) is a complex neurobiological movement disorder resulting from a chemical imbalance in the brain.
- It is characterized by involuntary movements and vocalizations referred to as motor and vocal tics.
- TS occurs three to four times more frequently in boys than girls.
- At present there is no cure for TS.
- TS is hereditary.
- TS is not a degenerative disorder and does not get progressively worse.
- Several genes most likely cause TS, and to date only one has been identified. The genetic basis of tic disorders and TS is currently being intensely studied.
- There is currently no medical test that will clinically diagnose TS.

Although it is well documented that TS is a neurological disorder, onlookers sometimes mistakenly believe that TS symptoms are intentional behaviors.

- Tourette symptoms are sometimes misinterpreted as emotional, psychiatric, or behavioral problems. At school, children may be reprimanded and punished for their symptoms, and some are even asked not to return to school.

As with Parkinson's disease, dopamine, a brain chemical involved with movement, is believed to be prominently involved in Tourette Syndrome. (But having TS does not mean that the patient will develop Parkinson's.)

- With Parkinson's, the brain is no longer producing enough dopamine, so people with Parkinson's exhibit slowed-down movements such as tremors, slurred speech, and muscle rigidity.

- Because of the involvement of dopamine and the involuntary movements and vocalizations that people with TS exhibit, TS can be easily seen as truly neurological. (Again I emphasize that TS does not lead to Parkinson's.)
- Because there is currently no medical test to diagnose TS, it is identified by the presence of these five observable diagnostic criteria:
 - Multiple motor tics
 - At least one vocal tic
 - Waxing and waning of symptoms
 - Childhood onset of symptoms
 - Symptoms lasting for at least one year

Although educators cannot formally diagnose TS, it is extremely important for them to know where the diagnosis comes from, what they are looking for, and what they may see with a child with whom they are working who has TS.

- Educators can be key in helping to identify a child with TS.
- They can often be a resource to the family by providing them with TS literature and by helping them to locate a knowledgeable physician in their area to obtain a proper diagnosis.

1.2. Manifestations of Motor Tics

A motor tic is defined as a rapid, repetitive movement of any voluntary muscular group in your body. There are two categories of motor tics: simple and complex.

- Simple motor tics are the easiest to recognize because they look like tics. They affect just one muscular group.
- Over the years people have referred to these movements as twitches or nervous habits, thus equating them with a psychological problem. The official term for them is *tics*.
- Simple motor tics rarely interrupt a classroom, so they often go unnoticed by teachers. *Simple motor tics* include:
 - Rapid eye blinking
 - Head jerking
 - Facial grimaces
 - Arm flailing
 - Finger tapping
 - Neck twisting
 - Nose twitching
 - Hand and finger movements
 - Lip smacking
 - Leg jerks
 - Hair tossing
- Although these simple movements may not disturb other students, they can be very interfering to the child who has TS.
- Imagine constantly shaking your head back and forth and trying to read or twisting your wrists over and over again and trying to write.
- These tics can occur in bouts that sometimes seem purposeful, and children are sometimes unjustly accused of performing their tics to get attention or to get a laugh from other students.

- *Complex motor tics* are intricate and complicated movements, and the list of them is seemingly endless. Almost any simple or complex movement can be a motor tic.
- These complex movements involve more than one muscular group and don't always look like what most people would define as a tic.
- These tics are the most difficult to recognize and the most misunderstood. Examples of *complex motor tics* are:
 - Hopping
 - Knee bending
 - Whole body bending
 - Twirling
 - Clapping
 - Touching objects and/or other people
 - Obscene gestures
 - Stomach crunching
 - A series of what look like simple motor tics
 - Self-abusive tics such as hitting oneself in the head or hitting one's leg against a desk
 - Handstands and cartwheels

See the Appendix at the end of the book for many more examples of complex motor tics.

1.3. Manifestations of Vocal Tics

- Vocal tics can often be the most problematic type of tic. They are called vocal tics because you hear them. A vocal tic can be defined as follows:
 - The repeated uttering of a sound, word, or phrase
 - A noise that someone makes over and over again
 - A change in speech pattern or voice inflection, stuttering, or speaking with an accent
- Vocal tics, like motor tics, are divided into *simple* and *complex* types. Simple vocal tics involve noisemaking, while complex vocal tics are usually something linguistically meaningful that a person says—a word, a phrase, a complete sentence, or an atypical speech pattern.
- Examples of *simple vocal tics* are:
 - Constant sniffing
 - Throat clearing
 - A squeaking sound
 - Snorting
 - Howling
 - Barking
 - Grunting
 - Humming
 - Hissing
 - Screeching
 - Sighing
 - Coughing
- Examples of *complex vocal tics* are:
 - Vocal repetition of a phrase or word. (One of my favorites was a boy who would repeat, “chickens are fuzzy, chickens are fuzzy” and “I have a chicken in my pants.”)

- Changes in tone or volume of speech in the middle of a sentence
- Stuttering
- The urge to speak in a foreign accent
- Speaking in a baby voice

The three very complex vocal tics can seem quite strange to those hearing them for the first time:

- *Echolalia*: the repeating of someone else’s words or words one has picked up from television or the radio (such as “Can you hear me now?” or “Afflac!”).
- *Pallilalia*: the repetition of one’s own words. (One child needed to say hello to his teacher each morning in eight different tones of voice. If he was interrupted, he had to start all over again.)
- *Coprolalia*: the involuntary uttering of anything inappropriate, from cursing to ethnic slurs, negative comments about a person’s appearance, or even sexual comments (such as “dumb ass,” “you’re fat,” or “I had sex last night”).
 - Coprolalia can certainly be a part of Tourette, but it is *not* necessary for a diagnosis.
 - Coprolalia occurs very infrequently—in only about 15 percent of people with TS—but is often the most problematic of all tics.
- Many people are under the impression that such inappropriate words are uttered randomly, but this is not necessarily the case.
 - People with TS can be very suggestible; they may be reacting to something or someone they have seen or heard (as when a child sees someone wearing a revealing outfit and has to shout out “Whore”).
 - The inappropriate words can be completely random, but they can also be triggered just as easily by someone or something that one sees. (See the Appendix for many more examples of this phenomenon.)

- Vocal tics, like all tics, are a result of an imbalance of brain chemicals, and they sometimes affect the person's ability to inhibit behavior. This tendency is similar to some people's experience after a stroke or a traumatic brain injury: they suddenly become disinhibited while the brain is healing. People understand the trauma situation because they can see that the brain has been damaged, but with TS, that's just how the brain functions day to day.
- TS has often been referred to as a disability of disinhibition.

1.4. Waxing and Waning of Symptoms

The third criterion for a diagnosis of TS is the *waxing and waning of symptoms*. This criterion has two implications.

- The first implication is that tics naturally change all the time.
 - You could be teaching a child who has a snorting tic and in a few weeks that tic could disappear and he could instead be shouting a word across your classroom.
 - Tics change much more frequently in children than adults, which makes this particular criterion one of the most difficult for educators to comprehend.
 - You just get used to one set of symptoms, and suddenly a new tic appears and replaces an old one. Sometimes the old ones don't disappear, but new ones are simply added on.
 - Typically tics tend to worsen right before puberty and improve in adolescence. There probably couldn't be a worse time in a person's life for this change to happen.
 - TS is very difficult socially, and most peers simply do not understand it.
- Waxing and waning also mean that tics change in severity depending on environmental factors. The most common of these are:
 - Stress
 - Anxiety
 - Excitement
 - Fatigue
 - Illness
- Testing situations can be very stressful and are also the time when the classroom is most quiet, which makes vocal tics especially problematic for children with TS.
- Events such as family birthdays, vacations, and field trips can be very exciting for a child, which could temporarily cause symptoms to worsen.

- Tics almost always tend to worsen at the end of the day because of the level of fatigue.
- Overheating of the body can cause an increase in tics for some children.

Childhood Onset

- TS is a disorder of childhood onset. It first manifests itself anywhere between the ages of two and eighteen.
- The most common age of onset of symptoms is six or seven.
- The first tics to appear are commonly facial tics of some sort.

(My first tic at age six was eye blinking. Since no one had any idea why I was doing this, it was suggested that my mother take me to the eye doctor. I grew up in a very small town with very few medical options. The only optometrist in town prescribed bifocals for me at age six. To this day I call them my Tourette glasses. A few years later my brother got his Tourette glasses from the same doctor.)

1.5. Suppression of Symptoms

The *suppression of symptoms* may sound counterintuitive: although tics are involuntary, a person with TS does have the ability to suppress symptoms for very short amounts of time. This can be compared to trying to hold in a sneeze. One can do it for a short time, but the sneeze will eventually happen and will be much louder if you try to suppress it. Another analogy that might help you understand these phenomena is trying not to blink.

- Try not to blink your eyes for fifteen seconds. Some people can't do this at all, and for those who can it takes tremendous effort and concentration.
- As soon as the fifteen seconds are up, those who have succeeded will invariably begin to blink rapidly.
- If someone had continued to lecture to you while you were trying not to blink, could you listen attentively to what was being taught? The response is always no: you would be focused on trying not to blink.
- Holding in tics is never a good thing to ask a student to do: the tics become worse and the student will not be able to concentrate on anything but holding in his tics.
- Suppressing tics produces a great deal of anxiety.
- People try to suppress despite these undesirable consequences because ticking can be embarrassing and disruptive.
 - People with TS are frequently teased, made fun of, imitated, and even feared because of the strangeness of their symptoms.
 - People with TS will do anything to avoid these reactions.
 - Many students will simply become the "class clown," pretending to tic on purpose to avoid the teasing. (A middle school student once related that in school there was a club for bad but there was no club for weird, so he often pretended to do his tics on purpose to "be bad.")

Understanding TS is the first step to dealing with it appropriately in a classroom setting. When I speak to educators about TS, my first piece of advice is to be creative. Several chapters in this book will discuss the impact of TS and OCD on classroom performance and offer a plethora of strategies, techniques, and accommodations that will allow these kids to remain in a school setting, be understood, and be academically and socially successful.

1.6. Other Related Tic Disorders

It is important to note two milder tic disorders that are related to TS but are not full-blown Tourette Syndrome:

- Transient tic disorder
- Chronic motor or vocal tic disorder

Transient Tics

- It is estimated that as many as one in ten children will develop a transient simple motor or vocal tic at some point during their school years.
- Such tics usually occur in just one muscle group and *last no more than a few months*.
- Doctors will not give a diagnosis of TS until the symptoms have existed for at least a year because of the high prevalence of transient tics in childhood.
- Transient tics may become more prominent when a child is stressed, tired, or excited.
- You will very likely see more than one child in your class experiencing a transient tic disorder.
 - The tic develops quickly.
 - It lasts for only a few weeks or a few months.
 - The tic will disappear just as quickly, never to be seen again.
 - This is a transient tic and is quite common.
- The prevalence of transient tic disorder is the reason for the fifth diagnostic criterion for TS—symptoms lasting longer than one year. Doctors want to be sure these symptoms are not just transient tics of childhood.

Chronic Motor or Vocal Tic Disorder

- A chronic motor or vocal tic disorder manifests itself as one or two tics that start in childhood, never change, and never go

away. These tics may change in frequency and intensity over time.

- A chronic tic disorder is probably the manifestation of the TS gene. It is not at all uncommon for a family member of someone with TS to have a chronic tic disorder.
- Think about a person you know or have encountered who has a constant sniffing, head jerk, eye blink, or some other single tic.
 - They always have it and it never changes.
 - We tend to get used to such phenomena in people we know well, and we usually stop noticing the tic.
 - These phenomena could be a chronic tic disorder.

1.7. Medical Treatment of TS

The medical treatment of TS is a very complex matter. When I was first diagnosed twenty-five years ago, only one medication was used to treat the tics of TS, and that was haloperidol (Haldol).

- Haloperidol is a very powerful neuroleptic medication. (A neuroleptic is a drug used in the treatment of neurological conditions that has a tranquilizing effect by reducing nerve activity.)
- When used for TS, haloperidol is prescribed in much smaller doses than it would be for a patient with a psychotic disorder.
- Many doctors will now initially prescribe either clonidine (Catapres) or guanfacine (Tenex), both antihypertensive medications, which have helped some patients and have far fewer side effects. These drugs are traditionally not as effective for suppressing tics as the neuroleptics.
- Pharmaceutical research has since produced many other medications that are now used to treat TS. Many of these are in the same family as haloperidol.
 - There is considerable argument about whether the “newer” neuroleptic medications have fewer neurological side effects.
 - These medications will reduce tics, but none is a cure. There are no medications that will immediately, completely, and permanently eliminate tics.
- A few other medications in the neuroleptic group of drugs that have a similar effect on tics are:
 - Pimozide (Orap©)
 - Risperidone (Risperdal©)
 - Olanzapine (Zyprexa©)
 - Ziprasidone (Geodon©)
 - Aripiprazole (Abilify©)
- Response to any of these drugs can vary widely from patient to patient.

- Medication treatment of tic disorders can be complicated and should always be supervised by a physician experienced in the management of these disorders.
- Extreme patience is required of everyone concerned as the medication is introduced and the dose adjusted.
- New medications are always being studied. Nonetheless, many of these can still produce unpleasant side effects such as:
 - Depression
 - Significant weight gain
 - Glucose intolerance
 - Increased irritability
 - Lethargy
 - Fatigue
 - Cognitive dulling
 - Increased aggression
- Comprehensive Behavioral Intervention for Tics (CBIT) is a relatively new treatment for tics. A DVD on CBIT is available from TSA (www.tsa-usa.org).
- Each person is an individual and can react quite differently from others to a medication.
 - It is always the parents' decision whether to medicate their children.
 - Some choose not to medicate because of unwanted side effects.
- Some families turn to more natural approaches to treating the disorder involving diet, nutritional supplements (which are not regulated by any agency, may contain additional ingredients not listed on the label, and ingredients may not be correct amounts), environment, exercise, relaxation techniques, and so on.
- TS rarely exists alone. (This critical point will be discussed further in upcoming chapters.)

- TS is frequently accompanied by other neurological disorders.
- These associated disorders may need to be treated with completely different classes of medications.
- Physicians' referral lists for all states in the United States are available through the Tourette Syndrome Association (www.tsa-usa.org) and other state TS and OCD agencies.

1.8. Associated Disorders

Up to now we have looked at the five criteria necessary for a diagnosis of TS, but this discussion is just the tip of the iceberg for TS. TS is a neurological disorder, and as such it is almost always accompanied by other neurological and neuropsychiatric disorders.

The most common of these disorders are:

- Attention deficit hyperactivity disorder (ADHD)
- Obsessive-compulsive disorder (OCD)
- Learning disabilities (LD)
- Other common disorders and issues often coexisting with TS are:
 - Executive dysfunction (see List 1.11 later in this section for full definition)
 - Depression
 - Anxiety disorders
 - Sleep disorders
 - Fine motor skill difficulties (dysgraphia; see List 1.10 for full definition)
 - Sensory defensiveness (see List 1.14 for full definition)
 - Social skills deficits
 - Behavioral issues
 - Repeated anger-generated episodes (RAGE)
- Any of these disorders can exist alone without the others, but it is also extremely common to see these disorders in combination.
- Although the autism spectrum is considered a separate range of neurological disorders from TS, significant overlaps are increasingly appearing between these spectrums. The autism spectrum includes full-blown autism, Asperger syndrome, and pervasive developmental disorder.

1.9. What Is Attention Deficit Hyperactivity Disorder (ADHD)?

Jossey-Bass has published numerous books on attention deficit hyperactivity disorder (ADHD), so I will not duplicate the wonderful work of other authors on that topic here. I do, however, feel it is extremely important to discuss the relationship between TS and ADHD and how this complicates the lives of the numerous children who have both disorders.

- More than 50 percent of persons with TS also have ADHD, which can often be the precursor to TS.
- ADHD appears within the first few years of life, and the tics usually start around the age of five or six.
- ADHD is characterized by several symptoms, which include:

1. Inattentiveness

- Easily distracted by even the smallest extraneous noise
- Difficulty sustaining attention
- Difficulty staying on task

2. Impulsiveness

- Blurting out comments without being called on
- Failing to think before acting
- Doing dangerous things without thinking of consequences
- Difficulty regulating emotional responses to situations

3. Hyperactivity

- Nervous system is understimulated
- Inability to sit still for long periods of time
- Needing constant movement: finger tapping, chewing gum, and so on
- Concentrating better when they are making some movement

4. *Disorganization*

- Difficulty with tasks requiring organization, memory, and time management; this symptom is also known as executive dysfunction. (See List 1.11 for in-depth discussion of executive dysfunction.)

5. *Socially Immaturity*

- Social-emotional age is often about two-thirds of their chronological age
- Difficulty in social interactions with children their own age
- Preferring to play with younger children
- Often responding in a manner that is not age-appropriate

In the classroom, ADHD children can display several behaviors:

- Are very fidgety
- Have a difficult time remaining seated for any length of time
- Seem to be in constant motion
- Have a very short attention span
- Get in your face and shout out answers before being called on
- Have a difficult time initiating or finishing any task
- Are some of the most disorganized children you will ever encounter
- Always come to your class unprepared and with the wrong materials
- Lose everything—pencils, pens, paper, and homework

Children with ADHD can be some of the most frustrating children you will ever teach. Although it is initially tempting for us as educators to view this disorder as simply bad behavior, that couldn't be further from reality. Medications traditionally used to treat ADHD are stimulants, and these medications may exacerbate the tics and/or the OCD. *A certain number of children with TS are able to take stimulants without significant increases in tic activity, but many cannot.*

1.10. Dysgraphia

Dysgraphia is a specific learning disability that affects how easily children acquire written language and how well they use written language to express their thoughts. It affects an extremely large number of children with TS and/or ADHD.

- Many people with dysgraphia have gone undiagnosed their whole lives.
- Dysgraphia can be the result of fine motor skills weakness, and/or a disconnect between what the mind sees and what is actually produced on paper.
- Dysgraphia is one of the primary reasons why affected children become frustrated, refuse to do their work, and ultimately fail. When you can't write, you can't do your work: it's as simple as that.
- Characteristics of dysgraphia can include:
 - Slow and laborious writing
 - Hand and finger cramping
 - Letter reversal (“d” becomes a “b”)
 - Letter reversals within a word (“read” becomes “raed”)
 - Sloppy handwriting, uneven spacing, irregular margins, and inconsistent lettering
 - Inability to copy correctly from book to paper or chalkboard to paper (poor visual-motor skills)
 - Difficulty with written expression: getting thoughts onto paper
 - Difficulty with punctuation and capitalization
 - Difficulty with note taking
 - Poor spelling
- In addition to these characteristics, we also add interfering tics, obsessions, and sensory issues that interfere with writing

for children with TS and OCD. Handwriting can be extremely difficult, if not impossible, for these children.

- These children will be seen writing a few words, then stopping and shaking out their hand before they can continue—it actually hurts to write.
- The more they write, the more it hurts and the more fatigued their hand becomes, which results in completely illegible work and increased frustration.
- There are times when a child can write a few sentences without too much trouble, but that ability waxes and wanes just like the tics.
- Any hand, finger, eye, or upper-body tic can interfere with the writing process.
- Obsessions such as writing and erasing words until they look perfect can also hinder writing.
- Some children with sensory issues may have a difficult time touching certain types of paper.
- Children who exhibit signs of dysgraphia should be evaluated by an occupational therapist, who can identify this disability and provide therapy as well as useful accommodations.
- When occupational therapists test these children, they *must*:
 - Give them a writing sample that is long enough to reveal a wide array of possible writing difficulties.
 - Test them under less-than-optimum conditions that mimic what they would normally be doing in a classroom setting.
 - Collect a large sampling of their everyday written work to conduct a more accurate evaluation.
 - Look for interfering tics, obsessions, writing rituals, and so on.
- Following are common classroom difficulties for children with dysgraphia:
 - Numbers may be reversed when students are copying math problems from the textbook to note paper.

- Numbers may be lined up incorrectly (for example, the tens column may be lined up with the hundreds column), resulting in a wrong answer.
- Homework assignments may be copied incorrectly from the board.
- Individual letters and letters within a word may be reversed.
- Cursive writing may be an impossible skill to acquire.
- A child can know very well how to spell a word verbally, but when she writes it she reverses letters.
- Taking notes may be impossible.

Children with dysgraphia may be very creative writers, yet they continually write the shortest amount possible. This is not because they are lazy, but because it hurts too much to write anything longer and it will invariably be illegible. This disability can be easily accommodated, but it must first be recognized as a disability and not misinterpreted as lazy or oppositional behavior.

1.11. Executive Dysfunction

Executive functioning refers to the mental processes involved in goal-directed activity. Executive functions most directly related to academic performance include:

- Setting goals
- Making a plan to accomplish a task
- Keeping the plan in one's working memory while executing it
- Sequencing the steps in the plan
- Initiating those steps and shifting from one to another
- Monitoring one's progress
- Regulating one's attention and emotional responses to challenges that arise
- Being flexible in changing the plan if necessary
- Evaluating the plan for possible use in a subsequent similar activity

In a classroom setting, these challenges translate to a child who will have great difficulty:

- Keeping track of his belongings
- Organizing her materials
- Getting started on a task and staying on task
- Breaking down long assignments or projects into smaller tasks
- Sequencing information
- Forming goals
- Writing down homework assignments
- Managing his time
- Performing to her potential

Children with executive function problems will likely:

- Lose their homework and other materials
- Come to class unprepared

- Have a disorganized desk and locker
- Fail to finish anything
- Have difficulty managing workload
- Become quickly overwhelmed

1.12. Depression

- Depression is unfortunately often difficult to detect in children.
- Depressed children may not exhibit the same traits and behaviors as depressed adults.
- Depressed children often become increasingly oppositional, aggressive and defiant and begin to act out.
- Depression is not uncommon in children with these disorders and must be assessed and treated by a qualified physician.

1.13. Sleep Disorders

Children with TS and OCD can experience a number of sleep disorders. Rarely will teachers know that the problems they are seeing in the classroom result from sleep problems: what they see is a tired, cranky, out-of-sorts child. Children with sleep disorders will have a difficult time functioning and performing to their potential in the classroom. Sleep disorders related to TS and OCD may include:

- Insomnia
- Restless sleep
- Night terrors
- Difficulty waking up
- Very deep sleep
- Walking or talking in one's sleep

1.14. Sensory Processing

Sensory processing disorder is the constant bombardment of sensory input that is neither perceived nor interpreted correctly. It can affect any of the senses and cause great anxiety or pain for the child, as well as problems with:

- Daily functioning
- Family relationships
- Regulating emotions and behavior
- Self-esteem
- Learning and performance at school

In the course of a day children with sensory processing issues may vacillate between being hypersensitive and hyposensitive. They may be extremely sensitive to light touch, jerking away from a soft pat on the shoulder one moment, while at another time be seemingly indifferent to pain. When you see a child do the following things, you may be seeing red flags signaling *hyposensitivity*:

- Appear sluggish
- Have self-abusive behaviors, tics, or obsessions
- Pick at skin, scabs, or nails
- Repeatedly touch surfaces or objects that are soothing
- Crave strong sensory input

If you see a child doing these things, you may be seeing examples of sensory *hypersensitivity*:

- Is sensitive to sudden touch or the feel of certain fabrics
- Can't touch certain surfaces such as paper or a countertop
- Needs to have tags cut out of clothes or socks without seams
- Is very sensitive to bright or fluorescent lights

- Can't tolerate the texture of certain foods in her mouth
- Is very sensitive to certain smells
- Is overreactive to certain sounds
- Appears to hear everything at equally loud volume
- Melts down or becomes more aggressive in noisy chaotic environments where there is high sensory overload

When I visit a school to work with a child who has developed “behavioral” problems and I question teachers about where the behaviors most frequently occur, they often respond with:

- The hallways between classes
- The cafeteria
- The playground
- The school bus
- Physical education class
- School assemblies

These are all areas of high sensory overload, which may be intolerable to children with this disorder. The environment plays a huge role in the day-to-day functioning of these children. We need to consider making environmental accommodations to help meet their needs and eradicate certain behaviors that are caused by reactions to the environment.

1.15. Learning Disabilities

Learning disabilities affect the brain's ability to receive and process information and can make it problematic for a person to learn as quickly or in the same way as someone who isn't affected by a learning disability.

- A significant number of children with Tourette Syndrome also have learning disabilities.
- Virtually any learning disability can be present.
- A full battery of neuropsychological evaluations should be performed to help identify which learning disabilities are affecting the child.
- Very frequently these disabilities are found in the nonverbal areas.
- The most common of these, some of which have already been discussed, are:
 - Auditory processing difficulties
 - Dysgraphia
 - Executive dysfunction
 - Social skills deficits
- The learning disabilities are usually not directly related to the severity of the child's tics.
- Tics in themselves can be disruptive to the child's performance, as can the mental effort it takes to attempt to suppress tics. This ongoing effort can interfere with reading, handwriting, and attention, to name a few challenges.
- The other associated disorders of ADHD and OCD can also have a significant impact on attention, concentration and task completion.
- It is essential that these children receive appropriate testing, which should usually include occupational therapy and speech language evaluations, in light of the considerable number of children with TS who have deficits in these areas.

1.16. Auditory Processing Difficulties

Many children with TS and OCD have some difficulty processing spoken language. This difficulty could be a symptom of a true auditory processing disorder or it could be the result of what I call a “dysregulated auditory system.” It can also mimic ADHD.

- Sensory issues, discussed earlier in this section, often affect auditory abilities, making it difficult for children to sift out noises and speech in the environment.
- Affected children seem to hear everything at the same volume, which makes them very distractible.
- Background noises are very distracting for these students, even when they are at a very low volume.

It is always a good idea to have the child tested by a speech language pathologist or possibly even an audiologist to help sort out what is really going on. Regardless of what the issue is, the results often look the same and cause the same difficulties for a child:

- Processing and following directions, both simple and complex
- Processing abstract information (math word problems)
- Following conversations
- Performing well in noisy environments
- Processing spoken language quickly
- Remembering information such as directions or lists
- Hearing the difference between sounds or words that are similar
- Higher-level listening tasks
- Focusing

1.17. Social Skills Deficits

Many children with TS and associated disorders exhibit social skills deficits similar to children on the autism spectrum. Children with social skills issues will have difficulty with the following:

- Interacting with peers
- Understanding social “rules”
- Establishing eye contact
- Understanding social nuances and picking up on social cues
- Perceiving the feelings of others
- Understanding pragmatic language (saying inappropriate or unrelated things during conversations, telling stories in a disorganized way, having little variety in language use)

They will tend to:

- Interact normally with adults, but not with their peers
- Experience social anxiety
- Prefer activities they can do alone
- Demonstrate lack of judgment
- Experience social rejection
- Play with children much younger than they are
- Be able to *explain* what they need to do in social situations, but unable to *demonstrate* it in real-life situations

1.18. Behavioral Issues

Children on the TS and OCD spectrum of neurological disorders are often prone to difficult behaviors. These behaviors can include:

- Bouts of crying
- Inappropriate responses or overreactions to situations
- Tantrums (RAGE)
- Throwing things
- Complete meltdowns or rage attacks
- Impulsive behaviors

Although these behaviors may look like those of a spoiled, defiant, and undisciplined child, they are decidedly not. These behaviors are almost always triggered by some aspect of the child's neurological disorders.

It is up to the parents and professionals to figure out what is causing these behaviors and implement environmental accommodations and specific strategies to help eliminate these incidences. Sections Three and Four of this book have behavioral assessments that have been created specifically to work with these children. It is critical that everyone working with these children understand why the behavior occurs. As an analogy, consider the following scenario:

- Most of us start each weekday with the ringing of an alarm.
- Some days we push the snooze button two or three times before waking up enough to get out of bed.
- Once we have finally arisen, had coffee, showered, and had breakfast, we are usually in an optimum mood to face the responsibilities of the day and be nice to our family members and co-workers.
- In only a handful of times in the course of our lives will we find ourselves in a state of mind where we say and do extreme

things that we normally never say or do. We often don't even remember that we have said or done such things. Examples of these situations are:

- A traumatic incident
- A car accident
- Sudden hospitalization of a loved one
- A house fire
- Sudden death of a loved one
- Loss of a job
- In any of these cases we may say or do things that are completely out of character. We might swear at a police officer, scream at a loved one, or throw something.
- People almost always understand this type of reaction in light of the exceptional circumstances and usually forgive us for our words and actions.
- We almost always feel terrible and apologize. Fortunately, this only happens a few times in a lifetime.
- Children with these disorders can go *unpredictably* in and out of this “zone” several times a day. They may say inappropriate things, push other children, scream at their mother or teacher, or go into a full-blown meltdown for what appears to most people to be absolutely no reason.
- If we analyze these behavioral episodes using the assessments provided, we will quickly see a pattern developing that will lead us to the actual trigger of the behavior.
- The most common precipitating factors of such behavioral episodes are:
 - Sensory overload in noisy, chaotic environments
 - Getting stuck (for children with OCD)
 - Fatigue (from medications or lack of sleep)
 - Teasing
 - Inability to write

- Anxiety or obsessive fears
- Feeling of being overwhelmed by a long assignment or several assignments

Consider, for example, a child with sensory issues in the tactile area who maneuvers through his day as if he had the worst sunburn of his life and his mother made him wear a wool sweater over the sunburn. If someone simply bumps into him in the hallway, his immediate reaction might be to hit that other student because bumping into someone with a wool sweater over a sunburn hurts. But to the onlooker, this appears to be an extreme overreaction to any everyday occurrence.

- It is up to the adults working with the affected child to look at the behavior and the precipitating factors and help change the child's environment and/or give her compensatory strategies that will prevent the behavior from recurring.
- Children who demonstrate such over-the-top behaviors always feel badly afterward for what they have done. They simply can't stop themselves.

1.19. What Is Obsessive-Compulsive Disorder (OCD)?

In my opinion, obsessive-compulsive disorder (OCD) may be the most closely related disorder to the tics of TS. I often refer to obsessions and compulsions as “tics of the mind.” As the body ticks, the mind also ticks, as it gets “stuck” on thoughts and ideas—the difference is that obsessions are not usually as apparent to onlookers as tics.

- An obsession is an intrusive and recurring thought, image, or impulse that your mind gets stuck on which is unpleasant and disrupts functioning.
- Compulsions are behaviors that are used to reduce the anxiety accompanying the obsessions.
- It is often difficult to separate obsessions from compulsions.
- OCD also shares the chronic waxing and waning traits of TS.
 - The tics and the obsessions change frequently.
 - Obsessions and compulsions are exacerbated by stress, excitement, and fatigue, as are the tics of TS.

1.20. Manifestations of OCD

OCD has an enormous number of manifestations. Each person you encounter will be different and may experience a variety of obsessions and compulsions that can change over the course of his lifetime. Some of the most common OCD traits are:

- The need for symmetry, perfection, and neatness
- Repeated counting
- Checking things over and over
- Constant doubt or worrying
- Obsessive fears
- Fear of germs and contamination
- Ritualistic behaviors
- Asking questions repeatedly
- Difficulty with transitions or any kind of change or inflexibility
- An obsessive sense of justice
- Obsessive thoughts

OCD almost always appears irrational to the onlooker and often even to the person who has it, but despite the absurdity of these obsessions and compulsions, the affected person cannot stop. Children with OCD are often referred to as obstinate or oppositional because they get stuck and can't move on. One young child taught me a great analogy for this tendency: she likened her OCD to a hamster on a wheel. The wheel keeps going round and round and you can't get off.

Below are specific examples of common OCD traits and how they may manifest in a child with this disorder. Parents and educators need to learn to look for these "red flags" for OCD.

Symmetry, Perfectionism, and Neatness

- Pencils, pens, and books must be lined up perfectly.
- Window blinds must be precisely symmetrical.

- The bedspread cannot have any wrinkles and must hang evenly on all sides of the bed.
- Words must be written and erased over and over again until they look perfect.
- Pencils must be sharpened repeatedly as the lead wears down even slightly.
- Clothes in the closet must be hung by color.
- Homework must be copied over and over until it appears perfect; even the shortest assignment takes hours to accomplish.
- On tests that require bubbling answers on a separate sheet, the bubble must be filled in flawlessly.

Counting Obsessions

- A person can become obsessed with counting things over and over again. This practice goes on inside her head, so no one ever sees it happening.
- People with OCD always doubt that they did something right the first time, so they must do it repeatedly, just to be sure.
- People with this obsession may find it necessary to count:
 - Stairs as they climb them
 - Ceiling tiles
 - Chairs in a classroom
 - Words as they read or write
- This counting takes endless amounts of time, impedes concentration, and interferes with the task to be accomplished.

Checking Things Over and Over

- Everyone tends to check things, but the person without OCD can check once or twice and be done. The person with true OCD cannot stop checking.

- People with OCD may have to check the stove, the coffeepot, the iron, and the thermostat eight or nine times before they can leave their house.
- A student could become stuck checking the combination lock on his locker.
- Students may have to check their work over and over again; they are often the last ones to turn in their tests.
- Some people with OCD spend an inordinate amount of time with bedtime rituals such as:
 - Checking all the door locks several times
 - Checking to make sure all the lights are off
 - Making sure the alarm clock is set properly
 - Saying goodnight to people several times

Constant Doubt and Worrying: Generalized Anxiety

- Kids who struggle with doubt and worry often look like kids who are just trying to get out of attending school or doing their work.
- The worry sometimes seems to come out of nowhere, with no precipitating incident.
- It can take the form of irrational fears that start suddenly.
 - A child may be unable to attend school or go into a certain class for a long period of time.
 - A student may have to call home several times a day to ensure that everyone is OK.
 - Some may have to always sit near the classroom door or carry a cell phone in their pocket for extra assurance.

Obsessive Fears

- Obsessive fears may be precipitated by an event or simply come out of nowhere.
 - A child may suddenly become terrified of fire and be unable to stay in the kitchen when her mother is cooking or is terrified by a fire drill at school.

- A child may suddenly become fearful of sleeping in his own bed or riding the school bus.

Germ and Contamination

- One of the most common obsessions that we hear about is a germ obsession. Affected people have a fear of germs and contamination, most often irrational.
- To alleviate this obsession, these people must wash and/or avoid touching things that they believe to be contaminated. They may:
 - Wash their hands over and over again
 - Take very long and frequent showers
 - Clean their houses and belongings continually
 - Be unable to open doors without covering their hands
 - Be unable to use public restrooms at all
 - You can imagine the disruption this causes in someone's life. Some people have germ obsessions so severe that they cannot leave their homes. (One young boy had to wash his money to disinfect it before he was able to use it.)

Ritualistic Behaviors

- Many people with OCD develop rituals that they have to complete over and over again. They may have to:
 - Touch certain things in a certain order
 - Back out of a room that they have walked into
 - Have their parents or teachers repeat something over and over again until it sounds just right to them
 - Keep pushing on a glass full of something until it spills

Asking Repeated Questions

- At some point in her career, every teacher has encountered a student who asks constant questions. This is a huge red flag for OCD.
 - A child may ask the same question over and over again.

- There is a fear that they haven't received the correct information the first time and must keep asking.
- They may ask you to repeatedly check to make sure they have the correct homework assignment recorded or have the correct due date for a project.

Difficulty with Transitions or Any Kind of Change

- Most children with OCD have difficulty with change.
- The change can be just a simple transition from one activity to another within a class or a major life adjustment such as changing schools or moving to a new city.
- These children are often referred to as stubborn or obstinate.
- They appear very inflexible, and any even minor changes in the day's schedule—what's for dinner or a cancelled play date—can cause them to melt down for lengthy periods of time.
- What looks like an insignificant incident to others may be more than the chronically inflexible child with OCD can cope with.
- This inflexibility can quickly turn into a “behavior” issue.
- Children with OCD may have a strong need to complete things:
 - If they are asked to put something away and start something new when the original task is not completed to their satisfaction, they become very irritable and oppositional.
 - They need transition warnings.
- A child may find it impossible to shift from one activity within a class period to another without a five-minute advance warning and repeated reminders every minute after that.
 - If the teacher simply says, “Put away your math homework and take out your spelling book,” the math paper will invariably go flying across the room.
 - A “To Finish Later” basket can be created in the classroom where work that was not completed to a child's satisfaction can be placed. It may also be necessary to decide at that

moment exactly what time the child is going to come back and finish the work so that she can move on to the next activity.

An Obsessive Sense of Justice

- Many people with OCD have what I call “an obsessive sense of justice.” Red flags for this tendency in a classroom may include:
 - Tattle tales: children who must make sure that you know about every infraction of other children in the class
 - A child who debates every issue, from a grade on a test to a new rule
 - A child who is overly critical of other children if they don’t measure up to his expectations

Obsessive Thoughts

- Obsessive thoughts are words, songs, poems, or other thoughts that repeat over and over in one’s head, sometimes for months at a time.
- These thoughts can be violent and create fear for the individual.

The items in this list are certainly not the only manifestations of OCD that you will ever see. Other less common OCD traits include:

- Hoarding
- Collecting things
- Pulling out one’s hair (tricotillomania)
- Compulsive stealing (kleptomania)

1.21. Medical Treatments for OCD

For many years there was no medication available for the treatment of OCD. Several medications are now used, many of which are the same medications used for depression. Referred to as SSRIs (selective serotonin reuptake inhibitors), these medications include:

- Fluoxetine (Prozac©)
- Sertraline (Zoloft©)
- Paroxetine (Paxil©)
- Fluvoxamine (Luvox©)
- Citalopram (Celexa©)
- Escitalopram (Lexapro©)

Atypical antidepressants such as bupropion (Wellbutrin©) and venlafaxine (Effexor©) are sometimes used to augment OCD medication. It is critical that people seek treatment from specialists in their area, so that medication can be properly prescribed and monitored.

1.22. Behavioral Interventions for OCD

A researched and tested behavioral therapy called cognitive behavioral therapy (CBT) has proven helpful for many people with OCD.

- At the core of this behavior therapy is a technique similar to exposure and response prevention based on the process of habituation.
- Many doctors and therapists who treat OCD use a combination of medication and CBT for optimum results.

Again, it is critically important to locate doctors who specialize in treating this spectrum of disorders. Local Tourette Syndrome and OCD chapters and agencies can assist you with this search.