

Advanced Medical Issues: Tourette Syndrome and Associated Disorders

Tuesday, November 17, 2009

Handout Materials



**New York State
Office of
Children & Family
Services**

New York State
Office of Children and Family Services
and
PDP Distance Learning Project

ADVANCED MEDICAL ISSUES: TOURETTE SYNDROME AND ASSOCIATED DISORDERS

**November 17, 2009
Teleconference**

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CATALOG OF ACCOMMODATIONS

**for Students with Tourette Syndrome,
Attention Deficit Hyperactivity Disorder
and
Obsessive Compulsive Disorder**

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INTRODUCTION

Many of the telephone calls and e-mails to the Tourette Syndrome Association (TSA) are from families concerned that their child's tic-related symptoms will negatively impact his/her learning in the classroom. Often these parents make a great effort to educate the teacher about the nature of the child's tics, knowing full well that the tics might easily be misinterpreted as simply bad behavior unless the teacher has accurate information. This document has been written in response to requests from teachers and other educational personnel seeking appropriate accommodations and strategies for working with children with TS in a school setting.

Fortunately, educators are more aware of TS and understand it better today than in the past. Many teachers have asked the TSA to help them find more effective ways of providing an environment in which students with TS can learn and thrive along side students without the condition. Providing such an environment in the classroom takes planning, creativity and persistence. It also takes effective and appropriate strategies to accommodate the needs of both the student with TS and the rest of the class. This paper was written with that purpose in mind: to offer suggestions to teachers who are looking for ways to improve the educational experience for all their students.

WHAT ARE ACCOMMODATIONS?

Working with students diagnosed with Tourette Syndrome in a classroom setting can be quite challenging. One of the best ways of meeting that challenge is by "accommodating" the *symptoms* of TS rather than fighting them or trying to make them "go away" through harsh or punitive methods. By way of illustration, a real world example follows:

Tap, Tap, Tap

A child with TS developed an annoying hand tic which caused him to feel the need to tap a pencil in one spot on his desk. The constant tap, tap, tapping was, of course, very disturbing. The teacher, thinking creatively, brought in a large, flat sponge and she and the student with TS, taped it to the desk. The symptom was "accommodated," the child's tic wasn't ridiculed or punished, but instead the noise was softened, thus the disruption to teacher and class was greatly reduced.

At first, the behavior in the example might be seen as simply willful bad behavior, even disrespectful of fellow classmates and the teacher. However, if families and educators work together to understand TS, the insight they will gain can lead to better problem solving as shown in the example. On the other hand, understanding the nature of TS and its associated disorders can be a major stumbling block to successfully overcoming the challenges it creates for the classroom teacher. If educators feel they have a handle on what TS is, how it may manifest itself in class, the other neurological disorders most often associated with it, and how all the disorders impact on classroom performance, they can then proceed to the next step: finding effective, creative ways of handling the situation they and their students face.

That said, a very important point to always keep in mind is, ***what's fair is not always equal and what's equal is not always fair.*** Teachers may feel that they are giving unfair advantage to kids with TS when they make these accommodations. Actually, the accommodations just “level the playing field” so children with TS (or any special needs child) have an equal chance to be successful despite their disability.

HOW TO USE THIS CATALOG

I urge you to read the educational pamphlets listed in the Education and Publications section of the TSA web site (www://tsa-usa.org) before reading or using this catalog. The brochures will give you the information you need in order to understand how TS and associated disorders impact educational performance for the student with TS. When you have been armed with this knowledge, you can more easily make use of the recommendations in this publication.

The catalog is divided into sections by symptoms of the disorder (ie; “Motor and Vocal Tics,” “OCD,” etc.). Many, of course, overlap. At the beginning of each section, I have tried to provide an authentic or real world example of a student with TS with whom I have worked. I hope that these examples will help you to develop your own solutions. Under each category is a list of possible accommodations (marked by ❖) that may be helpful in accommodating those symptoms. There may also be additional comments and/or “do’s” and “dont’s” (marked by —, ✓, or ✖). Obviously, you will never need to use all the suggestions in this publication, but I urge you to read it all with an open mind. Often, the simplest of strategies is exactly what a particular child needs to be successful and a problem in the classroom to be resolved.

LAST THOUGHTS

Students with TS may exhibit symptoms unlike any other disorder you’ve ever dealt with. Your accommodations might also have to be “outside the box,” unlike any other solution/strategy you’ve used before. To that end, remember to speak frankly with and listen openly to the parents, the child and the treating physician before determining what areas are problematic for the child in question. A teacher may not be able to observe every symptom a child is exhibiting. Children with TS often try to suppress or camouflage tics that they feel might be disturbing to the class or might call attention to themselves. They rarely share their hidden OCD symptoms with a teacher. When you’ve explored the situation by talking openly, listening acutely, and reading thoroughly, you will have a better handle on what is interfering with the child’s ability to be academically successful and will be able to put together an appropriate accommodation plan and/or Individualized Education Plan (IEP) for him/her.

Finally, I strongly urge you to look at the whole child, not just the symptoms of this baffling disorder. Children with TS and associated disorders are still children—with feelings and aspirations—just like other children. They want to succeed, but they need you—the educator—to help them attain their dreams.

MOTOR and VOCAL TICS

A REAL WORLD EXAMPLE:

The Clipboard Chronicle

John was a 12-year-old student diagnosed with Tourette Syndrome, Obsessive Compulsive Disorder (OCD), Attention Deficit Hyperactivity Disorder (ADHD) and several related learning disabilities. In 7th grade, he developed a socially very inappropriate tic/obsession. When he was in the presence of females, he would grab their breasts. Teachers first tried to modify the behavior with punishment. This was highly unsuccessful and actually made the tic worse by adding to John's stress (uncontrollable symptoms of the disorder are often exacerbated by stress).

Intervention on the part of the local Tourette Syndrome Association led to trying an environmental modification, which proved to be very effective. Each teacher was asked to carry a clipboard which they could hold in front of themselves every time John approached them to have a conversation. The bigger the clipboard, the better. It actually became a sort of competition among the teachers to see who had the biggest, thickest clipboard. This humorous take on the situation served to change attitudes about John and his very difficult symptom.

We were, of course, concerned about John doing this to fellow female students, so every effort was made to have John in the hallways and common areas when no other students were present. He would leave each class three minutes early, sit up front on the school bus, etc. All these steps reduced John's anxiety about being punished for something that he truly could not control, so as the stress eased, so did the tic. We also did a peer in-service so that the other students understood TS and were no longer "fearful" of John. The environmental modification solved the problem.

POSSIBLE ACCOMMODATIONS:

- ❖ Tests taken in a separate location with time limits waived or extended.
- ❖ Educate the other students who come into contact with the child with TS.
 - TSA has a peer in-service entitled "Educating Classmates about TS."
 - An advocate from the local TSA chapter may also be helpful.
- ❖ Provide a refuge where the student may go to calm down, release tics or obsessions.
 - ✓ Nurse's Office, School Psychologist's Office, etc.
 - ✗ The Principal's office should be avoided as this may be perceived to be a punishment.
- ❖ Give frequent breaks out of the classroom to release tics in a less embarrassing environment:
 - ✓ The bathroom,
 - ✓ The drinking fountain
 - ✓ A real or made-up errand to run.
- ❖ Give the child his/her own laminated pass for a quick exit from class when a quick break is needed.
- ❖ Seat the student with TS in an area where his/her tics will be less noticeable and embarrassing.
 - ✗ Never seat him/her in the center front of the classroom.

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- ❖ If tics are socially inappropriate (spitting, swearing, touching people inappropriately), it may be necessary to brainstorm possible solutions; e.g., a spitting tic could be resolved by giving the child a tissue to spit into.
 - ❖ Try scheduling core academics toward the beginning of the day because tics tend to worsen when a child is tired.
 - ❖ Communicate with parents frequently and report worsening tics or the development of new ones.
 - ❖ Create a supportive, accepting classroom environment.
 - Students will feel safe and this will alleviate much of the anxiety and frustration which tend to aggravate tics.
 - You, the teacher, are always the model. Set a tone that is accepting and tolerant of the child's symptoms and this will naturally dictate how the other students treat him/her.

A REAL WORLD EXAMPLE:

"I Have a Chicken in My Pants"

A 7th grader with TS (we'll call him Chris) suddenly developed a vocal tic that involved shouting three or four times during a class period, "I have a chicken in my pants." The first time it occurred, teachers were perplexed as to what to do. Having TS myself, I admit to having a bit of a warped sense of humor about the strange symptoms that suddenly pop up. I've also been a teacher for 33 years. The first inclination of most staff members was to tell Chris that this was not appropriate and to ask him to leave the room before he said it. After a few minutes of thought, I knew this plan wouldn't work. First, unfortunately, people with TS don't usually sense the tic coming in enough time to be able to leave the room before it happens. Second, I could envision this child spending most of the class time trying to anticipate the tic, then leaving the room in anticipation. Imagine how this would interfere with his ability to concentrate on the lesson, to say nothing of the time spent out of the classroom.

My suggestion consisted of two steps. First, I asked the teachers to keep track of the number of interruptions that occurred during one class period on one day. They were to count all interruptions—sneezing, coughing and nose blowing; pencil sharpening, chairs scraping, and things dropping; intercoms blaring, and planes outside flying. I asked them to compare the number of these interruptions with Chris shouting three or four times, "I have a chicken in my pants." His "chicken in the pants" paled in comparison to all of the daily interruptions to which we have become accustomed.

The second step involved explaining to the other students (with the permission of Chris and his parents), what TS was and why Chris said what he did. With everyone's agreement, a peer in-service was held. You see, all of us (students *and* teachers) were used to and understood all the other interruptions. Now Chris became just one more. He can now tell us endlessly about the chicken in his pants and no one even raises an eyebrow. Attitude and knowledge are everything. And the chicken lived happily ever after.

ADD / ADHD SYMPTOMS

A REAL WORLD EXAMPLE:

I Try Not to Say It, But It Just Comes Out

A school psychiatrist working with a second grader diagnosed with TS, ADHD and OCD was having a difficult time distinguishing between tics and impulsive behaviors. He was not convinced that every time the student said something inappropriate or acted in an impulsive manner that it was a tic. Tics are defined as sudden and repetitive movements or sounds and not everything that this child was exhibiting could “technically” be classified as a tic. A representative from the Tourette Syndrome Association explained to her that it is sometimes better to consider the difficulties a student is experiencing as “symptoms” rather than tics. This can be helpful because all too often we associate verbal and physical tics as being the only symptoms of TS. In reality, many students whether they have severe or mild motor and vocal “tics”, have a significant difficulty with the invisible but extremely disruptive symptoms of dysinhibition. When this student was told that his turn on the computer was over, he said something extremely inappropriate to the teacher. This was not a tic per se, but was indeed a symptom of his TS/ADHD. In these instances, the best way to handle the situation is to ignore the behavior, but at the same time include in the behavior plan counseling support that will assist the child in learning other techniques to help him recognize that his “brakes” do not work well. Over time, he may learn to substitute a more appropriate behavior, but since the actions are impulsive, it will require a great deal of practice and patience on everyone’s part.

POSSIBLE ACCOMMODATIONS:

- ❖ Provide preferential seating in the classroom.
 - ✓ In front and to one side of the room is ideal—the teacher can assist the child in staying on task.
 - ✗ The center front is often embarrassing for the child with obvious tics.
- ❖ Provide a quiet place in the classroom for student to work independently.
- ❖ Allow for freedom of movement—a quick trip to the bathroom, drinking fountain, a classroom task.
- ❖ Structured, but flexible classrooms are the best setting for the child with ADHD. Change tasks frequently.
- ❖ Use visual cues in addition to auditory ones.
 - Establish a hand gesture as a reminder to refocus and get back on task.
- ❖ Break down assignments.
 - Give one paper at a time rather than several.
 - Break down all long-range assignments and projects into shorter, more manageable parts e.g., Part 1 may be due in two days rather than the entire project in three weeks.
- ❖ Reduce the length of homework assignments—*quality*, not quantity is the important thing.
- ❖ Provide a daily assignment sheet to be filled out by the student and verified by the teacher.
 - Parents could then check to make sure that all the work is accomplished and assist with homework prioritizing and management.

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- ❖ Allow student to leave the last class a little early in order to pack up and organize materials.
 - The student will have a little more time to be at his locker without the distractions of a crowded hallway.
 - An adult's assistance may also be necessary.
 - ❖ Provide an extra set of textbooks for use at home.
 - ❖ Color code textbook covers, notebooks, folders, etc. (i.e.; the *blue* folder goes with the *blue* science book).
 - ❖ Keep a supply of paper, pens, and pencils to lend students who forget or lose such things.
 - ✖ Don't penalize a student who forgets or loses basic classroom supplies.
 - ✓ Make arrangements with parents to "re-supply" the missing materials.
 - ✓ To make sure of getting supplies back at the end of class, take something of the student's as hostage—one shoe, for example.
 - ❖ Teach children basic study skills and organizational strategies:
 - How to sequence and break down tasks into more manageable segments,
 - How to prioritize for better time management.
 - ❖ Use concrete, experiential, hands-on teaching, rather than only lecture or abstract methods.
 - ❖ Don't assume that if the student is not sitting perfectly still and looking you in the eye that he/she is not paying attention—the opposite is usually true of children with ADHD.
 - Allow the student some sort of motor activity during times of intense concentration. For example: squeezing a soft ball, pencil tapping on something soft (a sponge), foot tapping (without shoes), body-rocking, or doodling.
 - ❖ When giving directions, always have the student repeat them back to be sure they were understood.
 - ❖ Structure assignments.
 - Make lists that can be crossed off when the student has finished.
 - For longer assignments, provide frequent breaks.
 - ❖ Give student a "word bank" to select from on fill-in-the-blank tests.
 - ❖ Establish a method of daily communication between home and school through an assignment book.
 - ❖ Assign a "homework buddy" for the child to call on for help with such matters as, "what was the assignment?," "when is the paper due?," etc.
 - ❖ Always allow time during the day for physical activity.
 - ✖ Never punish an ADHD student by taking away physical education, recess or any appropriate opportunity to use physical activity as an outlet.
 - ❖ Post a schedule of the day's activities in front of the class so nothing comes as a surprise or is unexpected.

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- ❖ Students with ADHD do much better using a three-ring binder or trapper keeper in which all folders can be kept together.
 - The trapper keeper can be zipped to ensure that materials are not lost.
 - Organize the folders in the binder by each day's class schedule.
 - Keep a zippered, three-hole-punched pouch in the binder and fill it with lots of extra supplies. Check the pouch frequently and replenish when necessary.
 - Be sure to put hole reinforcements in the binder to maintain and repair torn papers.
 - ❖ Keeping a separate folder just for homework that has been completed helps many students. They are less apt to lose the completed assignments if they are all kept together.
 - ❖ Weekly folder and locker clean out may be necessary and can be part of resource room time.

You Don't Look Like You're Paying Attention

When her teacher was lecturing, Sue would walk around the room, softly slapping the sides of her legs. Her teachers had learned that she couldn't attend to what was going on in the classroom if she sat quietly in her seat. Walking allowed her to pay attention.

Once, as I was observing the class, I saw Sue was working at a computer while the teacher was reading a story which would be the subject of a test for the entire class immediately after the reading. I asked Sue's aide if the child was taking notes and was told that she was writing a mystery. Surprised, I asked why she wasn't listening to the story and was told to wait a few minutes and watch. When the test was given, the aide scribed for her and Sue scored 100%. The teacher later assured me that if she had insisted that Sue sit and listen to the reading, she would have probably failed the test.

An extreme example perhaps, but it is not unusual for students with ADD/ADHD to be able to pay attention better if they are "fidgeting" with something or moving in some manner. Research is beginning to suggest that the movement stimulates the brain and helps to focus the person's attention.

FINE MOTOR/VISUAL MOTOR IMPAIRMENT

A REAL WORLD EXAMPLE:

When Writing Hurts

Andrew was a second grader with TS, ADHD, fine motor deficits, and OCD. He was very bright, but struggling to keep up and was also becoming increasingly defiant and refusing to do his work.

The local TSA sent an observer who noticed that Andrew was always in motion—sometimes standing next to his desk, sometimes sitting under it, or walking around it. Early on, his teacher had recognized Andrew's need for movement and had placed his desk by the door, not in full view of the other students. When he moved about in his little space, no one else was disturbed and the movement helped him to pay attention (as is the case for most children with ADHD).

Andrew's problems began the minute the children were asked to, "take out their papers and write a story." Andrew played with things in his desk, went to his locker in the back of the room, to the bathroom—everything he could think of to avoid writing his story. The observer asked him what he was going to write about and he immediately came up with his topic. When she asked him to write his opening sentence, the 7-year-old blurted out, "It hurts to write!"

The emotional power and overwhelming truth of the statement wasn't lost on the observer. She suggested to Andrew that he dictate his story to her. She would be his "secretary" and write everything down for him. Immediately, his thoughts flowed freely. With a vocabulary way beyond that of a second grader, he completed six very good sentences in record time. He had the story in his head from the beginning, but like many students with TS, he simply could not get it onto paper. Fine motor skill deficits make writing painful and, indeed, for Andrew writing attempts had become very upsetting experiences. His handwriting was almost illegible, staying on the line was impossible, his margins were uneven, and every few words he had to stop, rest and shake out his hand because it hurt so much. It occurred to Andrew, that the simplest solution was to refuse to write and avoid being upset and in pain.

Today, he has an IEP with many writing supports, has a scribe, uses the computer whenever possible, and the amount of homework has been reduced. His grades have improved dramatically and he is a much happier child.

POSSIBLE ACCOMMODATIONS:

- ❖ Occupational Therapy (OT) Intervention, Physical Therapy (PT) with a Sensory Integration Evaluation.
 - OT and PT support might be helpful with handwriting difficulties, but frequently they are not.
 - The best use of these therapies should be determined on an individual basis.
 - Sensory issues may be present and these could be helped by OT.
- ❖ Provide alternatives for tests, assignments, reports, etc.
 - Tests can be given orally.
 - Waive or ease time limits on tests.
 - Standardized test answers can be written directly in the test booklet and transferred onto the answer sheet by teacher or assistant.
 - Reports can be delivered orally or on tape.

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- ❖ The use of a computer/word processing software is a reasonable, often necessary accommodation.
 - ✦ Don't penalize students for poor handwriting.
 - ✦ Don't penalize for spelling errors but encourage the use of spell checking software.
 - ❖ Shorten or consolidate assignments.
 - For example, assign ten math problems instead of twenty.
 - The quality of the assignment is important, not the quantity.
 - ❖ Verify that all homework assignment directions are copied accurately.
 - ❖ Provide graph paper to help line up math problems or allow the child to turn lined paper sideways.
 - ❖ Provide class notes rather than having the student copy from the chalkboard or overhead.
 - The student can take class notes, but provide him/her with a second set—these can be either your notes or notes you photocopy from a reliable student.
 - ❖ Photocopy materials rather than requiring the student to copy. This becomes especially important when assigning math homework.
 - If photocopying is not possible, allow a parent or teacher's aide to copy the problems.
 - The math *calculations* are important, not the ability to *copy* problems.
 - ❖ Encourage the use of an index card to visually track the page during reading assignments.
 - ❖ The use of a calculator for math can circumvent visual-motor difficulties.
 - ❖ Allow extra time for written work.
 - ❖ Scan homework and tests into a computer.

OCD SYMPTOMS

A REAL WORLD EXAMPLE:

Towing the Line

Anna was a 7th grader with TS, OCD and some learning disabilities. She suddenly developed an obsession with her written work that required her to write every letter of every word perfectly on the lines of her paper. Night after night she was up until the wee hours of the morning copying and recopying her homework until every word was exactly on the line. Her teachers struggled to find strategies and interventions. They thought of many things—providing a scribe, reducing homework, and so on. None seemed appropriate. Finally, we asked Anna what she thought would work. She came up with the best idea of all—why not simply allow her to use unlined paper? It worked! Going even further, we encouraged her to use word processing whenever possible, and this also helped to solve the problem.

POSSIBLE ACCOMMODATIONS:

- ❖ Obsessions and Compulsions can take so many different forms that it is difficult to arrive at creative, effective accommodations without knowing the particular, individual nature of the child's OCD. The best advice that I can offer is to first assess the nature of the obsession and then brainstorm possible solutions with the other teachers and the parents. Always be sure to include parents who know their child better than any of us. The following are a few examples of particular obsessions and compulsions and creative steps that were taken toward a solution:
 - A student with an obsession to count words on every line she reads was provided with Books On Tape.
 - A student with a germ obsession was encouraged to carry antiseptic hand wipes in his pocket and clean his hands whenever he felt "contaminated."
 - A student who couldn't write without a perfectly sharpened pencil and was always at the pencil sharpener getting the perfect point was given a mechanical pencil.
 - A student with a symmetry obsession was constantly erasing his work and doing it over because it "didn't look right." Allowing him to use a computer for his work alleviated his problem.
- ❖ Provide the support that reduces stress.
 - Anxiety is often the difficulty for students with OCD.
 - The school must be a place where it is safe to make mistakes.
 - Punishing or ridiculing only serves to increase anxiety and the difficulties associated with it.
- ❖ Distraction can be a good way to break an obsession that a child is stuck on.
 - Change the environment.
 - Allow the student some physical activity in order to help redirect the obsession.
- ❖ Allow transition time between activities.

SHORT FUSE/OPPOSITIONAL BEHAVIOR

A REAL WORLD EXAMPLE:

Hash Browns, French Fries, Tater Tots, Any Kind of Potatoes Will Do

Pete was a sixth grader with TS, OCD, ADHD and Asperger's Syndrome. As you can imagine, it was a challenge for his teachers to come up with creative solutions to meet his needs but we were managing his tics, obsessions and overactive behavior quite well.

Our biggest challenge was how to manage the impulsive, inappropriate social behaviors he sometimes directed toward his peers and teachers. He was easily agitated and when in this emotional state, he would not only become verbally abusive but would act out physically as well—throwing any object that was close at hand out of frustration.

We needed to find a positive way to help Pete get these behaviors under control. A behavior plan was set up targeting two behaviors: the verbal explosions and the throwing tantrums. First, we strategized with Pete about using more appropriate ways of expressing frustration. He was given a laminated pass to be able to leave the room whenever he felt he might commit either or both of the two bad behaviors. We practiced the strategy, but they worked only up to a point—the hurdle being finding a suitable reward. Nothing worked, everything we tried only interested him minimally until one day he had a conversation with his special education teacher. For fully a half hour, he related his “profound” love of potatoes, expounding on all and every kind he knew delighted in.

Of course, this was the answer. As strange as it might seem, potatoes would be his reward. With his mother's approval, the last 15 minutes of the day were potato time for Pete if his behavior chart had been good that day. We reviewed the chart with Pete frequently throughout the day so that he could regularly assess his progress toward his potatoes. If a day came when he had lost his potatoes by noon and we knew that the rest of the day had the potential of being a disaster, we started over and gave him the opportunity of earning at least half of them back. His behavior improved dramatically and he became lovingly known as “Potato Pete,” a title he thoroughly enjoyed. [Potato] Pete is now in ninth grade and doing very well. His reward isn't potatoes any more, but the name has stuck.

POSSIBLE ACCOMMODATIONS:

- ❖ Allow the child to leave the classroom 2 to 3 minutes early to avoid crowded hallways.
- ❖ Have a teacher's aide nearby in the cafeteria to prevent confrontations.
— An alternative eating site with a friend is sometimes ideal.
- ❖ Seat the child up front on the school bus and educate the bus driver.
- ❖ Make sure that the child is in the classroom of a structured, but flexible teacher.
- ❖ Help the child learn to remove himself/herself from the room before a situation escalates out of control and then reward the child for doing so.

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- ❖ Give the child a laminated pass that will allow him to leave class for a few minutes when he feels that a situation is escalating out of control. Seating up front by the door will facilitate this “exit.”
 - ❖ Counseling can help students to verbalize feelings prior to losing control.
 - ❖ Provide a refuge or safe place where the student can go to regain control.
 - ❖ Avoid power struggles—they escalate a bad situation.
 - Use humor to defuse and de-escalate the tension and as a distraction to the situation.
 - ❖ Remain composed and speak in a calm, non-emotional voice when attempting to redirect the child.
 - Never try to discipline or punish the child who is the midst of a “melt-down.”
 - Get them quietly out of the room to a safe place and deal with the problem after the child has calmed down.
 - ❖ Difficult behaviors may be the only way a student has to demonstrate that there is an unresolved problem. Ask yourself if any of the following is true:
 - Is the task beyond the student’s capabilities?
 - Does he understand the directions?
 - Does he require support with writing?
 - Is the environment overwhelming?
 - ❖ Seeing the child as *having* the problem rather than the child *being* the problem allows you to be creative and supportive. Look at what you can do *with* or *for* the student instead of *to* the student when he displays difficult behaviors.
 - ❖ Teaching a student strategies is more effective than punishing. Punishment only instructs what *not* to do instead of revealing what *should* be done.
 - ❖ Be specific about expectations. For example, instead of saying, “Stop being rude,” you could say, “Instead of telling an adult that this work is stupid, you could say instead that you don’t understand the work.”
 - ❖ Attempting to change more than two behaviors at a time is typically overwhelming for everyone involved.
 - ❖ A counselor can provide the student with a “toolbox of strategies” that he can use when in a difficult situation. These will need to be reinforced in a positive manner by other staff members.
 - ❖ Providing incentives that are true motivators can sometimes assist the student while learning and practicing new strategies. Negative consequences should be avoided because they generally do not work as well as positive reinforcers.
 - ❖ Don’t take behaviors personally. The behaviors are due to the disability and are not a true representation of your relationship with the student.

Why Theresa Feels Trapped

Theresa, a middle school student, began to exhibit agitation for no apparent reason, which would frequently escalate into a confrontation with another student or sometimes even with the teacher. After many months, Theresa had developed a trusted relationship with a counselor and confided that she often felt trapped. She imagined that the door was locked and that she would not be able to get out of the room when it was time to go home. Whenever possible, the door was left open. If this was not possible, she would sit close to the door with permission to get a drink of water whenever she felt the trapped feeling begin. After using this technique for a few days, she rarely left the room. Since she had permission to leave, she no longer felt trapped. This prevented her from becoming anxious which reduced her difficult behaviors as well as her need to leave the room.

ONE LAST THOUGHT: Children with TS and associated disorders may easily experience frustration, overstimulation and increased anxiety. Their most difficult areas are crowded hallways, the cafeteria, the school bus and the playground. They do not function well in an unstructured, disorganized classroom. They live daily with a disorder that never allows them to be still. They have difficulty transitioning from one activity to another. A large majority of these children also have sensory defensiveness. Any or all of their senses can become quickly overloaded, causing them to be easily “set off.”

A Workbook for Conducting a Functional Behavioral Assessment and Writing a Positive Behavior Intervention Plan for a Student with Tourette Syndrome

Susan Conners, Education Specialist
Kathy Giordano, Advocacy Specialist

A Functional Behavioral Assessment is designed to explore the need for strategies and support systems to address any behaviors that may impede the learning of the child with the disability. This assessment is conducted exclusively to provide information which will assist in developing positive and proactive interventions and supports to be provided by the school district. The ultimate purpose of these interventions is to limit the likelihood of the behaviors re-occurring by providing accommodations or teaching skills and/or replacement behaviors. These are written into a positive and proactive behavior intervention plan (PBIP).

Includes ADHD, Obsessive Compulsive Disorder, Executive
Dysfunction & Sensory Integration Issues



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Materials included in this packet

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Important Facts to Consider

- Writing a functional behavioral assessment for a child with TS can be very challenging. TS is one of the most misunderstood and complex neurological disorders that educators are likely to encounter.
- We, as educators, are not always aware of the symptomology of TS and of the several other associated neurological disorders that often accompany TS. It is therefore not unusual to misinterpret symptoms of the disorder as behavioral problems rather than the neurobiological symptoms that they are.
- It is understandable that educators sometimes may make erroneous assumptions about the function or reason for the behaviors of children with complicated neurological disorders. FBA's must involve some element of guessing and developing hypotheses. Some guesses are made with a higher percentage of accuracy but rarely should we assume that something is so clear that our guess **MUST** be correct.
- The materials that you will find in this packet should assist you in sorting out behaviors from symptoms and in formulating more reasonable and appropriate assumptions about reasons for particular problematic behaviors that a student with this disorder may exhibit. This information can then be used to establish a positive and proactive behavior intervention plan.

Even More Important Facts to Consider

- Behavior plans should **never** address tics. However, if the tic is self-injurious or socially **very** inappropriate, environmental changes and supports may be necessary. See anecdotal examples in the packet.
- Please be sure that someone on the team working on the Functional Behavioral Assessment and subsequent Positive Behavior Intervention Plan is **knowledgeable about TS** and its associated disorders. Several brochures and video presentations that will assist you in this area will be recommended. **Don't forget to use the child's parents as a resource.** They are often very well versed in TS and able to direct you to invaluable sources of information about the disorder. Involving the student in this process is also important as he may be able to provide insights into understanding the behavior.
- A major component of TS is the symptom known as dysinhibition or difficulty in consistently inhibiting thoughts and/or actions. Inappropriate statements or behaviors very frequently result from the student's inability to consistently apply "mental brakes".

How to Proceed

- In a middle or high school setting, be sure that **at least 3-5** teachers / support personnel / paraprofessionals who work closely with the student complete the worksheet portion of the assessment. In an elementary setting, the classroom teacher and at least 2-5 other special teachers / support personnel / paraprofessionals should complete the worksheet.
- Key members of the child's educational team should then compile the results of the worksheets onto the actual Functional Behavioral Assessment Summary Form.
- Be sure to use the facts and conclusions on the FBA to create the PBIP (Positive Behavior Intervention Plan). Make sure that you read through the anecdotal materials before attempting to complete the worksheets. They can be extremely helpful in gaining a more in depth and personal understanding of TS.
- It is helpful to conduct an observation of the student in the environments where the behavior in question is most likely to occur. A person acting as an observer may notice something (a specific task, various elements of the task, instructional style, other students, symptoms) that are important considerations to take into account when determining how the environment affects the behavior and what modifications need to occur to the environment.

What would have been your analysis of this behavior?

The Saga of Steve

Steve was constantly blowing in other students' faces. The teacher had tried all the typical positive and negative consequences but he continued to blow in their faces when they were close to him. Finally the teacher simply asked him why he was blowing in the other students' faces. He replied that he was trying to learn how to whistle. The teacher asked him if he could think of a way to learn to whistle without blowing in children's faces. He said that he could probably turn his head away from the other students while he practiced.

This worked for a few days and then he began once again blowing in people's faces. The teacher asked him what had happened. He had initially told her that he was learning to whistle because the boy knew it was more "normal" than the actual truth. He was blowing in children's faces only when they were close enough that he perceived that he was breathing in their "breath germs". This is a common example of an obsessive compulsive behavior. In reality, Steve was blowing their germs away from him and back at them. With this new understanding of the behavior, it was easy to change the boy's environment so that he was not likely to "breath other people's germs".

Overview of Functional Behavior Assessments

When the Individuals with Disabilities Education Act (IDEA) was reauthorized in 1997, language was added that includes Functional Behavioral Assessments and Positive Behavior Intervention Plans. Under the IDEA, the IEP team must now explore the need for strategies and support systems to address any behavior that may impede the learning of the child with the disability or the learning of his or her peers. IDEA 2004 includes language which now emphasizes functional performance as well as academic achievement. In most instances, this should not be a complicated and involved process. However, guidelines are inadequate and little funding is provided to train educators as to what an FBA is or how one should be conducted. As a result, many schools are struggling with the process of developing FBA's and subsequent PBIP's that are effective for students with neurological disorders such as TS. FBA's and PBIP's are a very important aspect of an educational plan for a child with TS. FBA's and PBIP's are designed specifically to address identified BEHAVIORAL weaknesses (as opposed to academic weaknesses) of the student, and are, therefore, of central importance in the IEP's of students with TS, when behavior is so often an issue open to various interpretations.

**When starting the process of conducting an FBA, we encourage
you to keep the following in mind:**

- 1) A Functional Behavioral Assessment is an on-going process. It is not a one time evaluation. Each child is an individual and every environment is unique and both are ever changing and evolving.
- 2) FBA's should involve utilizing a variety of techniques in an attempt to determine the cause of specific behaviors. (evaluations, data collecting, team discussions, parent and student input, observations, research on specific symptoms of the disability/disorder, etc.).
- 3) This assessment is conducted exclusively to provide information which will assist in developing positive/proactive interventions and supports to be provided by the school district in the finalized intervention plan.
- 4) The ultimate purpose of these interventions is to limit the likelihood of the behaviors re-occurring by providing accommodations or teaching skills and/or replacement behaviors. These are written into a positive and proactive behavior intervention plan (PBIP) that will be given to all school personnel working with the child.
- 5) FBA's should be compiled by a team of individuals involved with the student including the parents, who will share observations and gather information about specific difficulties the student is experiencing.
- 6) The goal of the child's team is to develop hypotheses as to the reason for the behavior by analyzing environmental conditions that exist when the problem behavior occurs.
- 7) FBA's should examine where, when, and how often a specific behavior occurs and, of equal importance, where and when the behavior does NOT occur.
- 8) Always in the forefront should be the need to ask what the team can do FOR the child using positive behavior interventions to prevent the behavior instead of looking at what to do TO the child after the behavior occurs.
- 9) The accuracy of the FBA is critical to the appropriateness of the PBIP. It should never be assumed that the behavior is simply purposeful misbehaving.

Having said all of this, it is important to point out that neurological disorders can be very complex. With accurate knowledge about TS and related disorders, however, FBA's for students with these disorders do not have to be a frightening and overwhelming process. It is critical that the team include someone who is very knowledgeable about TS and its associated disorders or is willing to educate themselves regarding TS symptoms as well as interventions that have been proven to be successful for other students with similar symptoms. A valid FBA and PBIP can be invaluable for students with Tourette Syndrome.

It is our hope that this document will provide you with the assistance that you need by leading you in the right direction while developing FBA's and PBIP's for students with TS and any of its associated disorders (ADHD, Obsessive Compulsive Disorder and specific learning disabilities, to name a few).

Recommended TSA Brochures and Videos
(These can be found on the TSA web site at <http://www.tsa-usa.org>)

1. Learning Problems and the Student with TS
2. Specific Classroom Strategies and Techniques for Students with Tourette Syndrome, (2nd edition)
3. Article by Sue Conners in October 2002 issue of *Communiqué*, the magazine of the National Association of School Psychologists, "Tourette Syndrome: An Inside Perspective"
4. Section 504, the Americans with Disabilities Act (ADA) vs. The Individuals with Disabilities Education Act (IDEA)
5. Writing the IEP for Students with TS - An Educator's Handbook
6. OT and TS
7. Discipline and the Child with TS: A Guide For Parents and Teachers
8. Video - *A Regular Kid, That's Me*
9. **New Video** - *A Teacher Looks at Tourette Syndrome*
10. Educator's Curriculum - CD Presentation

Functional Behavioral Assessment Worksheet for a Student with Tourette Syndrome

A) General Information

Student's Name _____ Grade _____ Date _____

Name of Person Completing Worksheet _____ Position _____

B) Behaviors Observed

1) The specific behavior(s) impeding learning is:

Off task behavior Out of seat frequently Talking out in class

Refusal to work Aggressive behaviors

Disrespect Dysinhibition

Socially inappropriate behavior with peers

Other _____

Be more specific about behavior. (Describe what the behavior looks like) _____

2) How often does the behavior occur? _____

3) Where does the behavior occur?

In a particular class (Indicate class) _____

Hallway Cafeteria School bus Other

4) Where does the behavior NOT occur?

In a particular class (Indicate class) _____

Hallway Cafeteria School bus Other

5) When does the behavior most frequently occur?

- During completion of written work At transition times Testing situations
 - In unstructured environments When tics are exacerbated In noisy environments
 - Interacting with peers Working in groups
 - During a specific task; (Reading, math, writing on board, using a pen or pencil, etc.)
 - When directions are being given (oral written simple complex)
 - Other
-

6) From # 2,3,4 & 5 which of the following conclusions might you draw as to the possible reasons for the behaviors?

- Attentional difficulties Interfering tics Difficulty transitioning
- Stress in testing situations Anxiety Poor social skills
- Difficulty with written work Difficulty processing directions
- Difficulty remaining seated Difficulty working with peers
- Interfering obsessions Sensory overload in noisy environments
- Sensory overload in unstructured environments
- Other _____

**** It is always important to consider medication side effects and/or changes in medications when evaluating behaviors. Frequent communication with the school nurse and the parents is crucial.**

Summary of Functional Behavioral Assessment Worksheets for a Student with Tourette Syndrome

This is intended to be a summary of the information from all of the completed FBA worksheets as the final step in focusing on which specific behaviors should be addressed when writing the PBIP.

A) General Information

Student's Name _____ Grade _____ Date _____

Name of Person Completing Worksheet _____ Position _____

B) Behaviors Observed

1) The specific behaviors impeding learning are: (Target no more than 2 behaviors.)

2) How often does the behavior occur? _____

3) Where does the behavior occur? _____

4) Where does the behavior NOT occur? _____

5) When does the behavior most frequently occur? _____

6) From # 2,3,4 & 5 which of the following conclusions might you draw as to the possible reasons for the behaviors?

- Attentional difficulties
- Stress in testing situations
- Difficulty with written work
- Difficulty remaining seated
- Interfering obsessions
- Sensory overload in unstructured environments
- Other _____
- Interfering tics
- Anxiety
- Difficulty processing directions
- Difficulty working with peers
- Sensory overload in noisy environments
- Difficulty transitioning
- Poor social skills

C) Strategies / Supports to be Implemented

1) What changes/supports are needed to decrease the likelihood of the behavior reoccurring?

- Writing supports
- Testing modifications
- Assistance with transition
- Assistance in reducing anxiety
- Reduction in amount of time in unstructured situations
- Occupational Therapy/ Sensory Integration Evaluation & SI Supports
- Provide student with specific strategies to assist with impulsivity, dysinhibition or other symptoms
- Homework reduction
- Assistance with directions
- Social skills education
- Assistive Technology Evaluation
- Organizational supports
- Peer education

2) What positive interventions can be implemented by the staff to assist the student in maintaining appropriate behavior?

(See accompanying accommodation sheet)

Proactive Interventions/Accommodations to Be Implemented

This sheet needs to become a part of the child's Positive Behavior Intervention Plan (PBIP) and must be given to all teachers/staff members working with the child. Flexibility and creative strategies are critically important. Keep in mind that providing an accommodation BEFORE the behavior occurs is more successful than punishment after the behavior occurs as is emphasized in the IDEA.

Please check where appropriate

Writing Supports

- The use of a word processor is a reasonable and necessary accommodation.
- Occupational Therapy Intervention.
- Tests/reports given orally. Allow extra time for written assignments.
- Shorten assignments.
- Verify all homework assignments to make sure they were copied accurately.
- Provide graph paper to help line up math problems or allow child to turn paper sideways.
- Do not penalize students for poor handwriting. Provide alternatives for doing tests, assignments, etc. (orally, taped).
- Accept printing rather than cursive writing.
- Provide class notes or a scribe rather than having the student take notes or copy from a book, the chalkboard or overhead.
- Assistive Technology evaluation to determine feasibility of technological supports such as spell checker, voice activated computer program, math assistive programs, computer art programs, etc.
- Worksheets scanned into the computer.
- Tape recording spelling tests when a teacher is unavailable.
- Tape recording various answers on tests.
- Frequent breaks during assignments.

• Testing Modifications

- Tests taken in a separate location.
- Time limits waived or extended on tests.
- Tests taken orally, with a scribe or on a computer.
- Use of headphones or music during test.
- Standardized tests answers written directly in the test booklet and transferred onto answer sheet by teacher or assistant.

- Tests scanned into the computer.

Organizational Supports

- Break down assignments. Give one paper at a time rather than several. Break down all long range assignments and projects into shorter more manageable parts.
- Reduce the length of homework assignments if it does not compromise academic success. Quality, not quantity is the important thing.
- Provide a daily assignment sheet/agenda to be filled out by the student and verified by the teacher.
- Teach alternative methods for recording assignments (small tape recorder; electronic organizer, e-mail, voice mail, etc.).
- Assist student with homework prioritizing and management.
- Allow student to leave his last class a little early to pack up and organize his materials.
- Assign someone to assist the student at the end of the day to be sure all necessary items are ready to take home.
- Provide an extra set of textbooks for home.
- Assist student in color coding textbooks & folders.
- Do not penalize students who forget or lose basic classroom supplies. Keep a supply of paper, pens, pencils to lend. Parents could also supply these materials.
- Assign a homework buddy for the child to call for assignments, etc.
- Establish a method of daily or weekly communication between home and school through an assignment book, e-mail, etc.
- Meet briefly with student at beginning of day to go over the day's activities.
- Provide student with a daily schedule that he can check off as the task is completed and see what the next scheduled activity is.
- Provide support in adjusting to a new schedule.
- Laminate a list of what goes in the backpack to go home.

Assistance with Transition

- Allow student to leave each class a little early to avoid crowded hallways.
- Give warnings of transitions from one activity to another in the classroom; e.g., in 5 minutes we will be changing activities.
- Provide a debriefing session the last 5-10 minutes of school.

Assistance with Processing Directions

- Use visual cues in addition to auditory ones.
- Have student repeat directions back to you to ensure comprehension.

- Assist student with the processing of oral or written direction.
- Allow extra time to process questions before expecting an answer. (e.g., ask a question and say that you will get back to student in a minute for the answer and/or tell student at the beginning of class that you will be asking him a specific question).

Assistance in Accommodating Tics

- Educate the other students who come into contact with the child with TS. TSA has a peer in service entitled “*Educating Classmates about TS.*” (order on line <http://www.tsa-usa.org>). An advocate from the local TSA chapter may also be helpful. (Parental and student permissions should be obtained before proceeding with this.)
- Ignore tics whenever possible. Understanding leads to acceptance which negates the tics being disruptive.
- Rather than time out, provide a refuge where the student may go to calm down, release tics or obsessions. e.g., the nurse, school psychologist, social worker, counselor or other appropriate support staff. **THE PRINCIPAL’S OFFICE SHOULD BE AVOIDED, AS THIS MAY BE PERCEIVED TO BE A PUNISHMENT.**
- Give the child frequent breaks out of the classroom to release tics in a less embarrassing environment.
- Give the child his/her own laminated pass to allow him to leave the room when needed for a quick break. Allowing the student to sit near the door provides him with an easy exit which frequently reduces the number of times the student will need to leave the room as this reduces anxiety.
- If tics are socially inappropriate (spitting, swearing, touching people inappropriately), it may be necessary to brainstorm possible solutions. e.g., a spitting tic could be resolved by giving the child a tissue to spit into.
- Always model acceptance of the child’s symptoms. The teacher sets the tone in the classroom and will dictate how the other students treat the child with TS.
- Never seat student in center front of classroom where tics will be more noticeable and embarrassing.

Attentional Difficulties

- Preferential seating in the classroom; up front on the side is ideal where the teacher can assist the child in staying on task.
- Provide a quiet place to work in the classroom. A headset with instrumental music might help block out distractions.
- Allow for freedom of movement at his desk, within the room and out of the room if necessary. (A quick trip to the bathroom, drinking fountain, a classroom task).
- Change tasks frequently. Structured, but flexible classrooms are the best setting for the child with ADHD. Change tasks frequently.
- Establish a hand gesture as a reminder to refocus and get back on task.
- Involve the student in some sort of motor activity during times of intense concentration. For example squeezing a soft ball, pencil tapping on something soft (sponge), foot tapping (no shoe), body rocking, doodling. Don’t assume that just because the student is not sitting perfectly still and looking you in the eye that he/she is not paying attention. Usually just the opposite is true with children with ADHD.
- Allow time during the day for physical activity. Never punish an ADHD student by taking away physical education, recess or any other outlet for physical activity.

- Chewing on gum or hard candy has been shown to increase students' ability to attend.
- Use a bright colored note card to hold under sentences to help child follow along when reading.
- Highlight items that a child needs to focus on in chapter or page of reading.

Sensory Processing Issues

- Allow student to leave each class a little early to avoid crowded hallways.
- Find alternatives to the cafeteria where the student can eat with a small group of friends in a quieter environment.
- Seat the child up front on the school bus and train the bus driver regarding the involuntary nature of tics.
- It is extremely important that a sensory integration evaluation be conducted and recommendations sought for a sensory diet or therapy from the occupational therapist who performs the evaluation. Sometimes something as simple as chewing gum or doodling allows a distractible student to attend better.
- Provide assistance in unstructured environments.
- Teach student to recognize first signs of anxiety and provide techniques for reducing stress prior to losing control. For example, ask permission to leave class, establish a specific place to go or a person to visit on these occasions.
- Other _____

Social Skills Deficits

- Social stories / Social story notebook (Carol Gray is an excellent resource).
- Pragmatic language support.
- Social skills groups / Social skills coach / Social skills note card reminders.
- Lunch with school social worker or school psychologist.
- Role-playing.
- Selecting one or two social deficits to focus on and implementing positive supports to reinforce the use of positive strategies that have been discussed during counseling.
- Creative methods of teaching appropriate social interactions (e.g.: if you can touch the person, you are too close).
- Teaching methods of reading social cues.
- OT Evaluation to determine if there are sensory issues.
- Anger management.
- Providing specific alternatives to confrontation (e.g., getting a drink of water, walking to a specific counselor, social worker, etc.).
- In more severe situations, modified school days may need to be implemented for a period of time
- Regular meetings with student to discuss positive preventive methods for dealing with future situations, rather than focusing on what has occurred in the past, since this may result in the student becoming re-agitated.

Aggressive Behaviors

Aggressive behaviors are typically a result of one or more of the following; unmet needs, frustration due to demands that cannot be met by the student, inflexibility on the part of both the student and/or the teacher, touching the student who is hypersensitive to touch, restraining the student, student's sense of total failure, bullying or teasing, anxiety, hypersensitivity to criticism.

- Allow student frequent breaks.
- Counsel the student to develop skills necessary to become aware of increased tension followed by involving the student in developing a plan as to specific alternative responses.
- Examine more closely possible related disorders that have been overlooked (sensory processing difficulties, obsessive compulsive behaviors, attention deficit disorder, executive functioning deficits, nonverbal learning disabilities, dysgraphia, homework issues, transition, peer issues).
- Be creative in developing a plan that will provide a sense of success and accomplishment.
- A modified day and/or home tutoring in extreme cases.
- A change of teachers may be necessary.
- Allow for choices that will empower the student.
- Anticipate difficult situations and avoid them.

Positive Behavior Intervention Plan for a Student with Tourette Syndrome

A) General Information

Student Name _____ Grade _____ Date _____

Name of person completing PBIP _____ Position _____

B) Behaviors Targeted

1) _____

2) _____

C) Hypothesized Function of the Behaviors (From # 6 of the FBA)

D) Behavioral Supports to be Implemented by Staff

1) _____ 4) _____

2) _____ 5) _____

3) _____ 6) _____

E) Environmental Changes to be Implemented by Staff

1) _____ 3) _____

2) _____ 4) _____

F) Positive Rewards to be Provided to Student for Progress on the PBIP

G) Communication Plan

1) Who will coordinate the PBIP?

2) What is the date of the next PBIP review meeting?

3) Has every teacher/ staff member working with the student received and signed the PBIP?

yes no

4) Has the student and parents been informed of strategies?

yes no

**** Be sure to include the accommodation sheet when this is shared with the child's teachers. ****

Anecdotal Stories

The following are real life vignettes of students with TS and associated disorders. They not only provide specific examples of creative classroom strategies and accommodations, but they also very clearly illustrate the effectiveness of positive and proactive interventions and accommodations when working with students with these disorders.

The Clipboard Chronicle

John was a 12-year-old student diagnosed with Tourette Syndrome, Obsessive Compulsive Disorder, ADHD and several related learning disabilities. In 7th grade, he developed a tic/obsession which was very involved and socially very inappropriate. When in the presence of females, he would grab their breasts. Teachers first tried to modify this behavior with punishment. This was highly unsuccessful and actually added stress and therefore exacerbated the tic which was simply an uncontrollable symptom of his disorder.

Intervention on the part of the local Tourette Syndrome Association led to trying an environmental modification which proved to be very effective. Each teacher was asked to buy a clipboard that they could hold in front of themselves every time John approached them to have a conversation. (The bigger the clipboard, the better.) It actually became a sort of competition among the teachers to see who could find the thickest, largest clipboard. This added humor and immediately served to change attitudes about John and his very difficult symptom.

We were, of course, concerned about John doing this to a fellow female student, so every effort was made to have John in the hallways and common areas when no other students were present. He would leave each class three minutes early; sit up front on the school bus, etc. John's anxiety about being punished for something that he truly could not control was reduced, so the tic became less and less prevalent. We also did a peer in-service so that the other students understood TS and were no longer "fearful" of John. The environmental modification solved the problem.

I Have a Chicken in My Pants

A 7th grader with TS (we'll call him Chris) suddenly developed a vocal tic which involved shouting out several times a class period, "I have a chicken in my pants". The first time it occurred, teachers were mystified as to what to do. Having TS myself, I admit to having a bit of a warped sense of humor about these strange symptoms that suddenly pop up. I've also been a teacher for 33 years. The first inclination of most staff members was to tell Chris that this was not appropriate and to ask him to leave the room before he said it. I mulled this plan over in my mind for a few minutes and knew immediately that it wouldn't work. First of all, people with TS unfortunately do not usually have enough time to sense the tic coming and to leave the room before it happens. Secondly, I could envision this child spending most of the class time trying to anticipate the tic and then leaving the room in anticipation. Imagine how that would interfere with his ability to concentrate on the lesson think nothing of the time he spent out of the classroom.

I approached the other teachers and suggested that we do two things. I asked them to keep track in one class period during the day of the number of interruptions that occurred during that class. They were to count **all** interruptions, sneezing, coughing, nose blowing, pencil sharpening, children dropping things, the school intercom, a plane flying overhead, etc. Then I asked them to compare that number with Chris' 3 or 4 times saying "I have a chicken in my pants". The "chicken in the pants" paled in comparison to all of the other daily interruptions that we are accustomed to.

The problem was that students were used to and understood all of the other interruptions. I secondly suggested that we explain (with Chris and his parents' permission) what TS was and why Chris said what he did.

Everyone was in agreement and the peer in-service took place. Chris can now tell us endlessly about the chicken in his pants and nobody even raises an eyebrow. It worked!! Attitude and knowledge were everything!! And the chicken lived happily ever after.

I Like Ben Better

Ben was an 8th grader with TS, ADHD, OCD and learning disabilities. When his class schedule arrived in the mail before school started in September, he observed that he had five academic classes in a row before lunch with no break. And because he was an 8th grader, he had the last lunch period at 1:10 PM. By the time he arrived at his last class, it was nearly impossible for him to sit still and pay attention and his tics were at an all time high. The teacher of that class quickly realized this and decided to have a private meeting with Ben to brainstorm about possible solutions. It was her suggestion that Ben would report to her class, put his supplies on his desk and leave to take a five minute walk to the drinking fountain, bathroom, etc. to release tics and get a bit of exercise. This hopefully would assist him in attending better and tic less when he returned to class. The first five minutes of class were usually spent taking attendance, passing back papers, etc., so he would not miss any of the lesson.

However, in about a week's time, the inevitable happened. Ben arrived as usual five minutes after class had begun. One student raised her hand and asked why Ben was always allowed to come to class late. The teacher had not prepared for this, so simply answered, "Because I like Ben better". The other students were speechless. They knew in their hearts that this was not true, but did not know how to respond. They also knew about Ben's TS. Nothing more was said until later in the class when the teacher directed the class back to her off the cuff comment. She used it as "teachable moment" and communicated to them a very important lesson. What's fair is not always equal and what's equal is not always fair. Each student gets what he or she need and it may never be the same as another student. She compared it to a child with diabetes who needed to have a snack in the middle of the morning. Did that mean that that everyone had a snack? Certainly not. No one ever asked again why Ben came in late or why anyone else in the class seemed to be favored at any given time. It was a lesson well learned.

Hash Browns, French Fries, Tater Tots, Any Kind of Potatoes Will Do

Pete was a sixth grader diagnosed with TS, OCD, ADHD and Asperger's Syndrome. As you can imagine, it was a challenge for his teachers to come up with creative solutions to meet his needs. The tics, obsessions and overactive behavior were well accepted by all of his teachers. He had a one-on-one aide who assisted him with organizational deficits, transitioning difficulties, etc. The biggest challenge became how to manage some impulsive and inappropriate social behaviors directed toward peers and teachers. He was very easily agitated and would become verbally abusive to others. He would often even throw his pencil, notebook or whatever he had in his hand out of frustration. We needed to find a positive way to help Pete get these behaviors under control. The behavior plan was set up targeting 2 behaviors: 1)being verbally abusive to peers and teachers, and 2)throwing things. We first strategized with him about more appropriate ways of expressing frustration. He was given a laminated pass to be able to leave the room whenever he felt he would break these two rules. We practiced these strategies. The hurdle became finding a suitable reward. Nothing we tried seemed to interest him until one day he was relating to his special education teacher about his "profound" love for potatoes. He perseverated on potatoes of all kinds for a half hour. Suddenly, we all realized that as strange as it appeared, potatoes would be his reward. (With his mother's approval, of course) The last 15 minutes of each day was potato time for Pete depending on what his behavior chart looked like for the day. The most important thing that we did with Pete was to have frequent reviews of his chart throughout the day so that he could frequently assess his progress toward his potatoes. There were a few days when he had lost the potatoes by noon and we knew that the rest of the day had the potential of being a disaster. We started over and gave him the opportunity of earning at least half of his potatoes back. As strange as it may seem, this was the

answer. His behavior improved drastically. He became lovingly known as Potato Pete, a title he thoroughly enjoyed. Fortunately, there are many types of potatoes to choose from so boredom never became an issue. "Potato Pete" is now in 9th grade and doing very well. His reward is no longer potatoes, but the name has always stuck.

I Was Sitting There First!!

An elementary student whom I will call "Tom" had been diagnosed with mild tics, Asperger's and severe Obsessive Compulsive Disorder. One day when the teacher announced that it was "snack time", Tom ran to the beanbag chair in the back of the room. The "rules" for the chair were whoever was sitting in it first had domain. The teacher asked him to return to his desk to pick up something off the floor that he had dropped. At that point another boy sat in the beanbag chair. Tom came back and demanded that the boy move because he had claimed the chair first. The boy refused, saying that it was his chair now. The teachers attempted to intervene and to come to a "fair and logical" compromise. This only increased Tom's frustration and anger which resulted in a meltdown with Tom eventually being sent to the office.

Tom's viewpoint was that he had claimed the chair by getting to it first and therefore it was rightfully his to use for snack time. To add insult to injury, Tom's attempts at asking, then pleading and finally demanding that the teacher make the student get up so he could reclaim the chair, were unheeded. Everyone, at this point, was in a difficult place. The adults in the room were thinking that this was a good opportunity for the students to learn about compromise and the many times in life when they will not get what they want. Tom had crossed over into a neurological rage episode because it was his perception that he had followed the rules and had been cheated out of what was rightfully his. He had what many children with OCD demonstrate, an obsessive sense of justice. The rage increased and he was sent to the office. Everyone had his or her own perception and "reality" of the situation. His IEP was changed to reflect counseling that focuses on social stories. In this way, his reality is validated but also is receiving assistance from a counselor to learn strategies that will result in a better outcome when he encounters similar situations in the future.

Stop It, I Can't

I received a phone call from a mother who told me that for the past two weeks her son had been coming home from school and immediately running to his room crying and ticcing so hard that he was hurting himself. She was also having a very difficult time getting him to go to school when he had always been eager to get onto the school bus. I had a meeting scheduled with his teachers the following morning, and told her I would ask them if anything had changed. The teachers began the meeting by telling me that Johnny's behavior had improved dramatically over the past two weeks and they were anxious to share their successful strategy with me. They told me that they had talked with the other children when Johnny was out of the class. They had told them that it would help Johnny if every time Johnny had a vocal or motor tic, they would politely tell him that he was bothering them.

I explained to them that they had succeeded in putting enough pressure on him that he was expending all his energy trying to suppress his tics all day in school. I asked them if they were ever in a situation where they had had an excessive amount of liquid to drink and there was no bathroom available. They remembered the amount of distraction, pain and energy it took to suppress their need to use a bathroom for hours until they returned home.

Telling a student that their behavior is not appropriate is helpful only if the behavior is not a manifestation of his disability. In the case of TS, that would be a vocal or motor tic, over which the child has little or no control. If the behavior is a tic, the reminder will not only be ineffective but will actually increase the need to repeat the tic. Imagine for a moment that blinking was not "socially acceptable". You are well aware that it makes people angry when you blink because people have told you this over and over, but you continue to blink your eyes because no matter how hard you try not to, you must blink your eyes. Now imagine that you are in a classroom and the teacher whispers to you a reminder not to blink your eyes. Her "helpful" reminder will only serve to increase the likelihood of you blinking.

Reminding people with TS to inhibit their need to complete a tic is not helpful and generally will increase the need to have the tic because they have been reminded of it.

In a similar story, an older student diagnosed with TS was in social studies class one day. The teacher asked each student to take turns telling the boy why his tics bothered them. I truly believe that both these teachers were not intending to do harm to the child. They were attempting to "motivate" the student to stop doing his tics. These are not uncommon stories. Adults frequently attempt to use humiliation in an attempt to motivate the student into stopping doing their tics. The truth is that ignoring tics is more likely to reduce the frequency and intensity while anything that increases stress will most likely increase the need to tic. If the humiliation is significant enough, the student may exert an extraordinary amount of energy in suppressing tics, but this holding in typically results in an explosion at some point in the day especially when he arrives home. At the same time, instead of teaching tolerance they had role modeled to the other students intolerance of people who are different in any way.

You Don't Look Like You're Paying Attention???

Whenever the teacher was lecturing, Sue, a student with TS and ADHD, would walk around the classroom softly slapping the sides of her legs. Her teachers had learned that if Sue sat quietly at her desk, she was unable to attend and by walking she could indeed pay better attention. One day I walked in to observe Sue. She was working at a computer while the teacher was reading a story on which the entire class would be tested immediately afterward. I asked her aide if Sue was taking notes and was told that she was writing a mystery story. When I asked if she was supposed to be listening to the story, it was suggested that I stay a few minutes and watch. When the teacher was finished reading the story to the class, the test began. Sue's aide scribed for her as she took the test on which she scored 100%. The teacher later assured me that if she had insisted that Sue sit with her hands folded and her feet on the floor, she would have most likely failed the test. This is an extreme example, but it is not unusual for students with ADD to be able to better pay attention if they are "fidgeting" with something, sitting on one leg or moving in some manner. Research is beginning to suggest that this movement stimulates the brain indeed, allowing the person to be able to attend better.

Billy and the Cracker Crumbs

Bill was a very active young boy in 5th grade. One day after snack, he purposely stepped on some crackers that had fallen to the classroom floor. Instead of punishing him, the teacher announced to him that the class would be sitting on the rug for an activity and the crumbs might be uncomfortable to sit on. She asked him to get the tape dispenser from her desk. When he returned with it she asked him to wrap some tape around his hand because that would help him as he picked up all the crumbs. Sending him out of the room, or having him write 100 times that he will never step on crumbs again most likely would not have been effective. Picking up the crumbs was a natural consequence that he probably is not going to want to repeat and it makes sense. Natural consequences have the advantages of making sense, of keeping everyone calm, and of being more effective because children see a direct correlation between the action and the consequence.

Why Theresa Feels Trapped

Theresa, a middle school student, began to exhibit agitation in school for what seemed to be no apparent reason. This agitation would frequently escalate into a confrontation with another student or sometimes even with the teacher. After many months, Theresa had developed a trusted relationship with the school counselor and confided that she often had a feeling of being trapped. She imagined that the classroom door was locked and that she would not be able to get out of the room when it was time to go home. Whenever possible, the door was left open. If this were not possible, she would sit close to the door with permission to get a drink of water whenever she felt the trapped feeling taking over. After using this technique for a few days, she rarely left the room. Since she had permission to leave, she no longer felt trapped. This prevented her from becoming anxious, which reduced her difficult behaviors as well as her need to leave the room.

Why Rachel Won't Read

Rachel, a 4th grader with TS, Anxiety Disorder and OCD would refuse to read aloud during "group reading time". It was suggested that Rachel might be more willing to read if she worked one-to-one with the teacher. The teacher tried this technique, but Rachel continued to refuse to read out loud. However, she did very much enjoy reading to classroom volunteers, and at home she was an avid reader. The one difference that the team finally determined was that the teacher always asked questions of her while she was reading to check for comprehension. She had significant issues with perfectionism that resulted in anxiety. It was theorized that her refusal to read might be related to this need for perfection. Rachel was told that she would no longer be asked questions during reading, but that she must ask the teacher a question every few paragraphs. The girl very much enjoyed the control that this afforded her and the refusal to read ended.

It Hurts To Write

Andrew was a second grader who had been diagnosed with TS, ADHD, fine motor deficits and OCD. He was very bright, but struggling in school to keep up with the work that everyone else was doing. He was also becoming increasingly defiant in his refusal to do his work. An observation was conducted by someone from the local TSA. The observer noticed that Andrew was always in motion. He was sometimes standing next to his desk or sitting under his desk. He would even walk around his desk. The teacher had realized early on Andrew's need for movement and his desk was by the door and not in full view of the other students, so when Andrew was moving about in his space no one else was disturbed by this. When he was moving, he was paying much better attention, as is the case with most children with ADHD.

The problem arose the minute the students were asked to take out their own sheet of paper and to start writing their own story. Andrew played with things in his desk, he went to his locker in the back of the room, he went to the bathroom, and did just about everything he could think of to avoid writing his story. The observer asked him what he was going to write about. He immediately came up with his topic. She then asked him to write his opening sentence to which this 7 year old replied, "It hurts to write". What a powerful statement this was! The observer then suggested that he could dictate his story to her and that she would be his "secretary". The thoughts began to flow freely. His vocabulary was way beyond what you would expect of a second grader and he completed 6 or 7 very good sentences in record time. He had the story in his head, but like many students with TS, he could simply not get it onto the paper. His fine motor skills deficits did indeed make writing painful for him. His teacher had noticed that his handwriting was almost illegible. He could not stay on the line, his margins were off and every few words he had to stop and shake out his hand because it hurt so much. So, the simple solution for him was not to avoid and often refuse to write.

The result has been that Andrew now has many writing supports in his IEP. He has a scribe, he uses the computer whenever possible and the amount of homework has been reduced. His grades have improved drastically and he is a much happier child.

I Try Not to Say It But It Just Comes Out

A school psychiatrist working with a second grader diagnosed with TS, ADHD and OCD was having a difficult time distinguishing between tics and impulsive behaviors. He was not convinced that every time the student said something inappropriate or acted in an impulsive manner that it was a tic. Tics are defined as sudden, rapid repetitive movements or sounds and not everything that this child was exhibiting could "technically" be classified as a tic. A representative from the Tourette Syndrome Association explained to her that it is sometimes better to consider the difficulties a student is experiencing as "symptoms" rather than tics. This can be helpful because all too often we associate vocal and motor tics as being the only symptoms of TS. In reality, many students, whether they have severe or mild motor and vocal tics, also have significant difficulty with the invisible but extremely disruptive

symptoms of dysinhibition/impulsivity. When this student was told that his turn on the computer had ended, he said something extremely inappropriate to the teacher. This was not a tic per se, but was indeed a symptom of his TS/ADHD. In these instances, the best way to handle the situation is to ignore the behavior, but at the same time include in the behavior plan counseling support that will assist the child in learning other techniques to help him recognize that his "brakes" do not work well. Over time, he may learn to substitute a more appropriate behavior. However, since the actions are impulsive, it will require a great deal of practice and patience on everyone's part.

ON-SCREEN GRAPHICS

“Advanced Medical Issues: Tourette Syndrome and Associated Disorders”

1. Tourette Syndrome (TS)

- Genetic neurobiological disorder characterized by tics– involuntary, rapid, sudden movements and/or vocal outbursts that occur repeatedly
- Symptoms change periodically in number, frequency, type and severity
- No definite cause, but evidence points to abnormal metabolism of dopamine
- No cure but some medication therapy available
- No medical test to determine TS

2. Tourette Syndrome (TS)

- Estimated 1 in 700/800 people may be affected by TS
- Males affected three times more than females
- Age of onset is typically between 2 – 18 yrs of age
- TS affects all ethnic groups and can be also be hereditary
- Many people are not diagnosed until later in life

3. Common Symptoms of TS

- Simple Motor Tics: eye blinking, grimacing, nose twitching, leg movements, shoulder shrugs, arm and head jerks, etc.

4. Common Symptoms of TS

- Complex Motor Tics: hopping, clapping, throwing, touching (self, others, objects), funny expressions, sticking out the tongue, kissing, pinching, tearing paper or books, echopraxia (repeating actions), copropraxia (obscene gestures)

5. Common Symptoms of TS

- Simple Vocal Tics: whistling, coughing, sniffing, screeching, animal noises, grunting, throat clearing.

6. Common Symptoms of TS

- Complex Vocal Tics: linguistically meaningful utterances such as “I’ve got it.”, “Oh boy”, or “Now you’ve seen it.”
- Speech Atypicalities: unusual rhythms, tone, accents, intensity of speech, stuttering

7. Behaviors Associated with TS

- A “short fuse” and a low frustration tolerance that can lead to all-out loss of control
- Unpredictable rage “storms” all day long and may not even remember what they are doing or saying
- These affect the ability to momentarily control behavior and comprehend the consequences

8. Remember:

- TS is involuntary motor or verbal tics –simple and complex
- Don’t assume your client is just difficult or disruptive
- TS is hereditary and might affect the whole family

9. Remember:

- Tics start early in life (typically between ages 6 -8) and typically worsen during puberty
- Stress, anxiety, fatigue and illness can exacerbate TS symptoms
- No cure but some medication therapy

10. Suggestions for the Classroom:

- Frequent breaks for the TS student
- Purposeful seating of TS students
- Look at specific tics and how any disruptions can be minimized
- Suggest training for the whole class from an advocacy group

11. Suggestions for the Home:

- Allow for “activity time” after school
- Allow use of headsets while doing homework
- Involve an occupational therapist for help with sensory-driven issues
- Clearly explain expectations for behavior
- Develop a positive behavior plan

The Tourette Syndrome Association of Greater New York State

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