Understanding Behavioral Symptoms in Tourette Syndrome

TS is More than Tics

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Tourette Syndrome and its related disorders can manifest as behaviors that often appear to be purposefully disruptive, attention seeking or manipulative. It is therefore not unusual to misinterpret symptoms of the disorder as behavioral problems rather than the neurobiological symptoms that they are.

The following quote is from the U.S. Department of Education (DOE) regarding common misperceptions of Tourette syndrome, explaining why they included Tourette Syndrome under the IDEA definition of"“other health impaired':
….., we do believe that Tourette syndrome is commonly misunderstood to be a behavioral or emotional condition, rather than a neurological condition. Therefore, including Tourette syndrome in the definition of other health impairment may help correct the misperception of Tourette syndrome as a behavioral or conduct disorder and prevent the misdiagnosis of their needs.

Children with TS may be punished for symptoms and behaviors that educators decide are disruptive and *purposeful*. Even an empathetic teacher who recognizes the student as a child who has abilities, may be frustrated because of the difficulties in understanding the cause of the behavior. Dr. Ross Greene, noted psychiatrist and author of *The Explosive Child*, and *Lost at School,* writes that, “It is your *explanation* of the behavior that leads directly to how you respond to it.” If, for example, your explanation for a child rolling his eyes while you are speaking to him is that he is being rude and disrespectful, your response might be to reprimand and discipline him. Alternatively, if you're thinking that the eye-rolling is a symptom of the child’s neurological disorder, then you'll be more likely to be compassionate and provide support.

Consider a student who is refusing to do work. One educator sees this youngster as being capable but is refusing to complete the task because he doesn't want to comply. This educator assumes that the student *chooses not* to do the assignment, and therefore uses a punitive approach. Another teacher sees the student as having the ability, but realizes that the student has learned that it is safer to not even try than to make an attempt and fail. It's important to recognize that the student’s refusal to do a task is not necessarily because he's oppositional or lazy. Perhaps knowing the real reason for the behavior - that the student doesn't like failing - can make the teacher’s response positive and proactive rather than reactive and negative.

Educators are more likely to punish a student whom they see as BEING the problem. If the educational team recognizes that the student HAS a problem and is *not deliberately causing the problem*, they'll be more likely to provide unique and creative strategies for that student. When educators consider what they can do FOR the child and not what they can do TO the child, strategies are more positive, proactive and effective.

TOURETTE SYNDROME BEHAVIORAL SYMPTOMS

1. DYSINHIBITION

Difficulty consistently inhibiting thoughts and/or actions. Inappropriate statements or behaviors result from the student's inability to consistently apply "mental brakes" - the child can't stop himself consistently from expressing behaviors, thoughts, or displaying actions that someone else might be able to control. Behaviors might seem to be excessive silliness, being sassy, free-associative comments, emotional outbursts, contextual swearing, blurting out, inappropriate comments, explosive anger, and oppositional defiance.

For those with dysinhibition, a sign saying "Don't Touch, Wet Paint" is an invitation to touch the paint. Obeying the sign means inhibiting the very behavior suggested by the sign. Inhibiting behaviors is challenging for all children, but presents a far greater challenge for students with TS due to their impulsivity and inconsistent ability to apply their mental brakes. This is not purposeful disobedience, but the inconsistent dysfunction of a brain affected by the chemical imbalances that cause TS.

> *A second grader's teachers had a difficult time believing that every time the child said something inappropriate or acted in an impulsive manner that it was a "tic". Tourette Syndrome is more than tics, and many of a student's 'behaviors' can be "symptoms" rather than tics. Verbal and physical tics are not the only symptoms of TS. Many students, whether they have severe or mild physical and vocal "tics", also have significant difficulty with invisible (but extremely disruptive) dysinhibition. When a student is told that his turn on the computer is over and he makes an inappropriate remark, it may be due to his having TS. In these instances, it is best to use 'planned ignorance', but then include counseling support to help him recognize that his 'brakes' don't always work well. Then, teach him strategies that allow a more appropriate response. Since his actions are due to a neurological disorder and are not purposeful, this may require a great deal of practice and patience.*

2. OPPOSITIONAL BEHAVIORS

Many students with TS have a secondary diagnosis of Oppositional Defiant Disorder (ODD). Dr. Ross Greene refers to these children as being chronically inflexible and will typically display ODD behavior. The

support team must look for the underlying difficulties such as OCD, ADHD, tics, processing difficulties, written language deficits, and sensory issues which prevent the child from expressing his needs or responding appropriately. For example, a student who becomes oppositional only during a task requiring writing may be communicating through his behavior that he is not capable of writing. If a student displays defiant behavior in a particular setting, this may indicate that he is somehow overwhelmed in this setting.. Dr. Ross Greene's books *"The Explosive Child"* and *"Lost at School"* are excellent resources.

3. IMMATURE BEHAVIORS

Does the student get along well with peers? Does he have friends? Are his social skills on the same level as those of his peer group?

Frequently students with TS act in an immature fashion and display behaviors that are typical of much younger students, even though they may have more advanced academic abilities. Dealing with ongoing frustration or anxiety may have caused delays in developing skills necessary to inhibit inappropriate behaviors. The child then displays behaviors that are not age appropriate, which are often perceived by adults as being purposeful. It's also not unusual for the child to get along with either younger children or with adults better than with children their own age. Immature behaviors are frequently seen in children with TS, and should be perceived as a component of the disability, and not manipulative and purposeful misbehavior.

4. REFUSING SUPPORTS AND ACCOMMODATIONS

A student may refuse supports and accommodations because he doesn't want to be singled out as being*different.*

Guidance, support and patience by parents and educators may be able to overcome the child's resistance. A positive and proactive plan should include discussions with the student emphasizing that "fair is not always equal, and equal is not always fair." Because the child requires different supports, it's not "bad" or "weird" but simply "fair" for his situation.

5.' RAGE'

A small percentage of children with TS have outbursts of uncontrollable anger often referred toin the TS community as "rage, as a symptom of TS. Generally, but not always, this is displayed in the home setting more frequently than at school. Usually the child or adult might yell, throw things, perhaps call names, all in a manner that seems unprecipitated. This symptom is neither the fault of the child nor the parets. As it can seem dramatic, many parents blame themselves. In certain school or other systems, they may also be blamed by professionals, friends and family. The matter merits further exploration by school teams, teachers and families. The R.A.G.E. (Repeated Anger Generated Episodes) brochure (Publication M-357, or downloadable publication M-357DD) available for a nominal charge in TSA's online store is an excellent resource for professionals and for parents with children with these symptoms. It will help them understand that there's no one to blame, and which strategies to employ for children who have neurologically based

rage. Sometimes a change in routine or expecation of an event for a child who is inflexible may set off an episode. In fact, experience shows that typical interventions (including negative consequences) only serve to increase these rage episodes. It is critically important that adults in the life of a child with TS become aware of what reduces or increases the child's explosive responses. In addition, children who are affected by the devastating symptom of neurological rage need trusted adults who can provide care with flexibility and calmness.

6. 'FIGHT OR FLIGHT'

In general, students with TS have a heightened response to their environment. A teacher's volatile manner may cause the student to become overwhelmed – which may escalate into a 'flight or fight' response by the student with TS. It's important that the student be placed with teachers who can remain calm in a difficult situation.

7. DIFFICULTIES WITH TRANSITIONS

Very often individuals with TS have problems with transitions – they are internally driven to complete the current task or stay in the current environment and not move on. For the student with TS and additional anxiety caused by obsessive compulsive behaviors, transition difficulties can be exacerbated. Transition strategies can be written into the IEP for teachers to follow. If a strategy hasn't yet been established, the current teacher may need to experiment with different ways of preparing the student for approaching transitions.

8.USE OF INAPPROPRIATE LANGUAGE (Coprolalia)

Coprolalia is a symptom of Tourette Syndrome characterized by unwelcome, unwanted and uncontrollable utterances of words or phrases that are not appropriate. Commonly, people come to know coprolalia as the "swearing tic". Certainly this symptom is mocked in moves and other media.

Many people believe that a person must have coprolalia in order to have a diagnosis of Tourette Syndrome. In fact, only a small minority have this symptom. Ironically, while this is the most recognizable symptom, it's also the symptom that is most misunderstood. It's the symptom most responsible for students being removed from class, receiving detention or suspension, and being moved to a more restrictive environment. Coprolalia is any socially inappropriate sound, word, phrase or group of words. A limitless variety of sounds, simple phrases or words can also be coprolalia. Examples: 'elephant', 'toys', 'coffee', 'shut up', 'jerk', 'donkeys have knees' could be examples of coprolalia.

A common misunderstanding is that in order for 'inappropriate words or sounds' to be a symptom of TS, they must be said "out of the blue" and must be repetitive in nature. This leads to the mistaken belief that if a student swears once and/or at an "appropriate" time, then it is *not due to TS and therefore deserves punishment*. Coprolalia can be one word, a string of words, or a phrase, said many times or said once but repeated over time. However, TS symptoms, including coprolalia are different for every individual, inconsistent, change periodically, wax and wane and are increased by stress. The inconsistency of a child

with TS to inhibit the use of inappropriate behaviors and statements adds to the difficulty of understanding the symptoms of this disorder. For example:

> *A polite 4th grade girl was being punished for being disrespectful to her teacher. The teacher reported that every time she said that the class was going to have a test or homework, the girl would say 'shut up'. There is no denying that this was inappropriate. However, it is also a symptom of the TS. It is easy to recognize that when the teacher told the class there was going to be homework or a test, most likely there were other students who were thinking 'shut up' — or worse. These students were able to stop from expressing these thoughts because they didn't have affected brain processes which reduced their ability to inhibit saying what they were thinking. The little girl with TS was not able to inhibit blurting out inappropriate statements that appeared to be purposeful. Stress makes symptoms worse which increases her inability to inhibit in a stressful or undesirable situation. Stress increases the likelihood of symptoms of dysinhibition and decreases the ability to inhibit 'inappropriate' behaviors and statements. Difficulty inhibiting verbal expressions may result in the occurrence of the more easily recognized swearing vocal tic for a small percentage of students with TS.*

SOME COMMON DIFFICULTIES IN STUDENTS WITH TOURETTE SYNDROME

1. AUDITORY AND VISUAL DIFFICULTIES IN PROCESSING INFORMATION

Frequently students with TS have difficulty processing information presented to them either verbally or visually. They may require more time to answer a question or respond to a directive. Some have learned to fill in the awkward silence by saying something. What they say can be negative, such as "this is dumb"; "I don't care about your stupid question"; "Shut up", "I don't have to do this."

An effective support would be assisting the student to develop a different response when he requires more time to process. A positive strategy for a teacher might be to ask the question, then tell the student that you'll come back to him in a minute for the answer; this works well for some students. Any kind of stress reduction is helpful. Most importantly, teachers should understand that the reason for the delay in processing information is due to the child's neurological difficulties, and not deliberate misbehavior.

2. SENSORY INTEGRATION ISSUES

Sensory issues and /or 'tactile defensiveness' may be seen in children diagnosed with TS. Students who are hypersensitive

to light, sound, touch, taste. or smell frequently have difficulties processing specific sensory stimuli. Behaviors may include a child exhibiting a need for excessive sensory input (chewing, hitting or hurting himself in some manner), or becoming easily over-stimulated by minimal sensory input such as noise, bright lights, the feel of certain fabrics, certain tastes or smells.*Involving an Occupational Therapist qualified in sensory integration issues is essential. Developing a "sensory diet" can sometimes be beneficial for the child and everyone who works with him.*

3. ATTENTIONAL DIFFICULTIES

Inconsistent or chronic difficulties in focusing are common for students with TS. In addition, symptoms of ADHD, complex tics or obsessions can interfere with a student's ability to pay attention. Sometimes this happens when the student is concentrating on suppressing his symptoms in public. He may concentrate so hard on suppressing tics that he's not able to attend to classroom activity. However, there are times when the student *is* paying attention, even though it appears otherwise. For example, many students and adults with TS will doodle to help them concentrate on a lecture.
Educators may periodically ask questions to determine the level of attention. Many students with TS are capable of paying attention even while experiencing a bout of complex tics, or while apparently directing their attention to doodling or other activities.

4. READING DIFFICULTIES

Does the student love reading? Does he have a particular interest in reading specific topics? Does he hate reading? Do tics interfere with the ability to read? If a student has difficulty reading, many possible reasons should be considered, including a learning disability involving reading. One student loved to read at home but would refuse to read in school or to read anything assigned by the school. It was finally determined that the child loved to read, but had severe written language deficits. She'd decided that, if she read school-assigned books, she'd then be required to write, which she couldn't do. So, she refused to read the assigned books.
Any form of dyslexia (difficulty reading) needs to be considered. Even mild tics can make reading difficult. In addition some students with TS and OCD have an obsession that compels them to count every word in a sentence and every sentence in the paragraph. This makes reading not only very arduous, but next to impossible. Professional help may be needed to discover the specific causes for the reading problem, and then to choose appropriate supports.

5. DIFFICULTIES WITH HANDWRITING

Difficulties with writing can include sloppiness, frequent erasing, time-consuming efforts at perfectionism, reduced output, slow writing, refusal to write, and writing that's difficult to read.
The vast majority of students with TS, or TS and ADHD, have written language deficits causing difficulty in getting thoughts from brain to the paper consistently, for a wide variety of reasons. The child may write very little or refuse to write altogether; margins and spacing may be uneven. Causes may include hand, finger, wrist, arm, neck, shoulder, head and eye tics or hand cramping. Or, there may be a lack of coordination or fine motor skills. Sometimes there's an unexplained disconnection between ideas and the ability to express these ideas in writing. Handwriting can become laborious, and a struggle for the child. Some students, due to obsessive compulsive behaviors, become 'stuck' on writing perfectly, and it can take them an inordinate time to accomplish a task, leaving them frustrated, exhausted and unsatisfied with the results.

Parents and teachers frequently assume that the child is refusing to write because they don't like to do it. The reverse is very likely true. The child refuses to write because he is experiencing the symptoms described above. Writing can become extremely difficult and sometimes even painful. The resulting failure and subsequent refusal to write, are all part of the complex and confusing symptoms of TS.

Occupational therapy support for very young students is sometimes helpful. For the most part, though, practice, or specialized pens/pencils will not have a positive outcome. Extra practice or rewriting typically won't result in better penmanship. Teaching the child keyboard skills is frequently a better use of time and energy. Note too, that a student's handwriting can be fine sometimes and messy at other times. Remember that all aspects of TS are inconsistent; symptoms wax and wane and are affected by stress and other environmental factors. Short assignments may be written neatly, but longer assignments may result in disintegration of writing and readability. OT's should evaluate a student while tics are more interfering, and get a lengthy writing sample.

Recognizing the prevalence of handwriting difficulties for students with TS is extremely important. Teaching keyboarding skills as early as possible is recommended. Frequently, printing is easier for the child than is cursive, and the student's teachers may need to accept printed work.

Providing a scribe (someone who writes what the student dictates) can be helpful if keyboarding skills are weak. The student can then demonstrate his knowledge on a subject without the interference of dysgraphia. Having someone scribe as the student speaks also teaches dictation skills - very useful for students to later use voice-activated computer programs. Good keyboarding skills should always be the priority (and a valuable life skill), as there are times when speaking into a computer isn't practical.

Many students with TS are excellent auditory learners. For them, the concentration required to take notes can actually interfere with their learning. Providing notes for them to study can be beneficial.

Common classroom modifications that may be important for written language deficits are:

- *Use of computer for taking notes, writing essays and long answers*
- *Printing allowed*
- *Grading on the quality and not the quantity or appearance of work*
- *Notes provided. Sometimes, teachers will hand out copies of notes with blanks prior to the lesson, so students can write the appropriate words in the blanks. If this works, it may help the student pay attention, and benefit from writing key words. Another strategy to try is to provide the student with a copy of notes and a highlighter pen, so that he can highlight the important sections of the notes as the teacher lectures.*
- *Reduction in length of homework assignments that require writing.*
- *Providing alternative methods of assessing acquired knowledge such as oral reports, oral tests and quizzes.*
- *Extended time for tests, quizzes, and projects requiring writing*
- *Allowing for testing in separate locations with scribing support available.*
- *A scribe as needed for any and all written work (even math).*

A trial period to see if a specific support strategy improves grades, attitude, and performance is highly recommended. A child's frustration and embarrassment over sloppy, immature handwriting frequently leads to more than academic

difficulties. Support in this area can be critical to the overall success of the child.

6. EXECUTIVE DYSFUNCTION DISORDER

Executive function involves the skills necessary to succeed in school and in life; two examples are time management and problem solving. A person with executive deficits can have extraordinary talents and abilities, but not possess the organizational capacities necessary to demonstrate these abilities in a useful and productive manner.

Many people with Tourette Syndrome are chronically disorganized. They have difficulty developing strategies to overcome problems, or implementing strategies suggested to them. In other words, they experience "output failure" which creates significant obstacles to academic success.

These students frequently require substantial support from a consultant teacher to manage work flow and learn strategies to assist them to overcome their "output failure" due to executive dysfunction. Improved executive function skills enable students to prioritize tasks, complete assignments, and manage time in a manner more accurately reflecting their true abilities.

7. SOCIAL SKILLS DEFICITS

Many children with TS score above average and higher on IQ tests, but may not act in a socially appropriate manner. Social deficits can cause an inability to understand acceptable social behaviors. Many children with TS talk continuously and/or have a tendency to interpret things in a very literal fashion. This can create significant social difficulties.
Speech therapists can teach pragmatic language skills. In many instances, students who don't intrinsically acquire social skills are bright. When they are motivated to have friends, they can be taught the social skills necessary to be successful. Schools offer social skills classes using social stories, and often including materials like cue cards or social story notebooks. School counselors are often knowledgeable in teaching social skills techniques.
If a child is demonstrating delays in the area of social skills, it is important to include social skills training in an IEP or 504 Plan. The person in the school setting responsible for working with the student in this area should be designated in the plan. Simply writing a goal stating that the child will act more age appropriately is not sufficient for students to learn the techniques and skills they lack.

8. INCONSISTENT PERFORMANCE

Doing well on any given day is not always to the advantage of a student with disabilities - adults then expect him to perform consistently at that level. The only thing that's consistent about Tourette syndrome is the inconsistency of symptoms. The student with TS is very often bright and creative. When he says he can't complete a task, or performs poorly, adults may think they're being manipulated. The adults may try encouraging the child, reminding him that he did this exact task yesterday. Or, an adult may urge the child to just try harder, and he'll be able to accomplish the task again. Sometimes this helps, but sometimes it increases the child's stress (which will, in turn increase his tics and other symptoms). Do we expect baseball players to hit a home run every time they're at bat? Do we think they're just not trying hard enough, or they're manipulating us by striking out or hitting a pop fly? The very nature of TS is changing levels of brain chemistry resulting in

fluctuating symptoms and the ability to perform consistently.

9. BEHAVIORS THAT ARE DIFFERENT AT HOME AND SCHOOL

The exhaustion of "holding it together" all day can provoke some children with TS to unload all of the day's frustrations as soon as they arrive home. This can result in not only an increase in tics, but in very difficult and destructive behaviors at home. It can be described as the Dr. Jekyll/Mr. Hyde phenomena. No matter how the difficult behavior is expressed, it's important that all school personnel understand that the demands of the school day can result in this type of behavior at home, whether or not TS symptoms are suppressed while the child is in school.

It may be necessary for the family to have an outside counselor involved. This person can be instrumental in developing supports and accommodations in the school setting which could, in turn, help alleviate problems at home. If a school requires that the child with TS who manifests "rage" complete the same quantity and quality of homework as other children in the class, the question to ask is, "At what cost?" What is the cost to the family and to the child's physical and emotional well being? In some cases, the desired outcome of completed homework needs to be weighed carefully against the child's welfare and best interests.

10. ANXIETY AND FEAR OF RISK TAKING

"Anxiety is always the enemy of intelligence. The minute anxiety arises, intelligence closes to search for anything that relieves the anxiety." Joseph Chilton Pearce. Is the child reluctant to take risks? He may have anxiety issues surrounding specific tasks or situations. The child may be unable to articulate the reasons for his anxiety, or embarrassed to do so. Refusing to attempt tasks may indicate some underlying anxiety that's preventing the child from being successful.

Strategies to help reduce anxiety need to be very specific and supported by everyone. Consistency is critical because this creates a sense of security. If a plan is in writing and everyone involved is on board, then the child will feel less anxious and more confident. Some strategies are relatively simple, e.g., being allowed to sit near the door with permission to leave when necessary. Frequently this reduces anxiety to the extent that the student will no longer need to leave the classroom.

11. NEED FOR A SENSE OF CONTROL

Inconsistencies in a child's abilities to perform tasks can be confusing for the child and adults involved. Is the behavior purposeful, or is it neuro-based? A child's refusal to do work may look like he wants to be in control. For the child with TS, however, the behavior may be a desperate attempt to bring a sense of control to his world of inconsistent difficulties and loss of control. If the child is attempting to gain some control, support staff should consider how to have him gain control without relying on disruptive behaviors. Teaching the child strategies that result in his getting control of his environment may be extremely helpful in the short term as well as for the future.

Asking a student what can be done to help him be successful, instead of asking why he isn't successful often aids adults in developing appropriate supports. This can also help establish an atmosphere of teamwork between the student and the educators; the student can 'take ownership' of a positive and proactive intervention plan.

HELPING THE STUDENT WITH TS SUCCEED

Students with TS are more likely to find success with a proactive and positive behavior plan. When teachers and students share in the positive feelings of success, confidence develops for both teacher and student, encouraging still more positive and proactive strategies.

1. THE ROLE OF EDUCATORS
Educators must carefully scrutinize a situation that's creating difficulty for the student and examine clues that may suggest an explanation for the problem. Often children with TS do not understand what precipitates what's perceived as difficult and disruptive behaviors. Typically, the best course of action is to:

- ignore symptoms
- be alert to possible precipitating event(s)
- provide accommodations and modifications
- acknowledge the student, separate from the symptom;
- work around it, with it, or through the process with the student as his symptoms are expressed

Recognizing, teaching and supporting the student with alternative strategies and techniques to manage significantly inappropriate symptoms instead of relying on punishments and negative consequences are likely to prove most effective. Remember to consider your reasoning for the behavior before you respond. (For more information on Education Strategies, please refer to our 'Education Strategies' website section; in addition, you may find publications of interest in our online store, particularly Publication #E115b "Classroom Strategies and Techniques for Students with Tourette Syndrome" for a nominal charge; also available for immediate download as Publication #E115bDD).

2. ACCENTUATING STRENGTHS
Does the child have an extraordinary interest and/or talent in art, music, science, sports, creative writing, crafts or other hands-on activities? The importance of encouraging areas of talent cannot be overemphasized. Recognizing and knowing how to support a student's strengths is critical to the success of the child.

This doesn't mean that the preferred activity should be used as a carrot, given and taken away as a reward (or punishment) pursuant to a "behavior plan". One disenchanted student said, "Don't ever let them know what you like because they will either take it away or make you earn it." But, being rewarded with extra time for a favored activity can sometimes work effectively as an incentive, depending on the individual child.

3. SELECTING TEACHERS
Many students require a teacher who is adept at creating a structured environment, which also allows for flexibility and

choice. This can reduce the child's stress and therefore his symptoms, By giving the child a choice, he's much less likely to lose control in an inappropriate fashion - this is particularly true for a child who tends to be inflexible or oppositional.

Some examples:
• A student who has difficulties with transitions, may benefit from a teacher who provides a great deal of structure with consistent signals for transitioning - this may result in the student experiencing less anxiety related to unexpected changes and less opposition to transitions.
• A child who demonstrates difficulty being flexible will not benefit from a teacher who is equally as inflexible.
• The best environment for learning is one that is safe for students to take risks.

4. TRIAL AND ERROR
Working with the unique problems of children with TS often becomes a matter of trial and error. Many times a support will work for a while and then will need to be altered as situations, tasks, and people change. Maintaining a file describing strategies that have been successful or unsuccessful can be a valuable aid in this process.

The role of educators is to carefully examine a situation that is creating difficulty for the student and to look for clues that may suggest an explanation for the problem. Recognizing alternative strategies to assist the student instead of relying on punishments and negative consequences is of the utmost importance.

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