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TS is More than Tics

(Other Important Issues to be Considered)

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Tourette Syndrome is complicated by symptoms and related difficulties that often appear to be purposefully disruptive, attention seeking, and manipulative behaviors. Educators do not need to be experts, but a certain level of familiarity with the most common difficulties is essential.

It is important to have a general knowledge of symptoms and difficulties and an ability to recognize their impact on a specific child. Some of the most frequently related disorders and difficulties are discussed on the Educators Web page on the national TSA web site (<http://tsa-usa.org>).

HANDWRITING

Difficulties with writing can include sloppiness, frequent erasing, time consuming effort at perfectionism, reduced output, slowness of handwriting, refusal to write, and writing that is difficult to read.

The vast majority of students with TS have dysgraphia. Dysgraphia can be defined as the inability to get thoughts from the brain to the paper for a wide variety of reasons. This is a well-documented symptom for students with TS and ADHD and results in handwriting that is messy, sloppy and difficult to read. The child may write very little or refuse to write altogether. The reasons are complex but can include hand, finger, wrist, arm, neck, shoulder, head and eye tics or hand cramping. Frequently margins and spacing are uneven. It can also (but is not always the case) be due to lack of coordination or fine motor skills. Sometimes it is an unexplained disconnection between ideas and the ability to express these ideas in writing. Handwriting can be laborious and, as a result, an area of struggle for the child. Some students, due to obsessive compulsive behaviors, become stuck on writing perfectly and it takes them an inordinate amount of time to accomplish the task leaving them frustrated, exhausted and unsatisfied with the results.

Unfortunately, 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 does not like to write because he is experiencing the symptoms described above. Writing can become extremely difficult and

sometimes even painful. This results in failure and subsequently a refusal to write due to the complex and confusing symptoms of TS.

Occupational therapy support for very young students is sometimes helpful. However, for the most part, practice and specialized pens/pencils will not have a positive outcome. Extra practice or rewriting typically will not result in better penmanship. Teaching the child to use a keyboard is frequently a better use of time and energy. It is important to note that a student's handwriting can at one time be fine and at other times messy. Remember that all aspects of TS are inconsistent; they wax and wane and are affected by stress and other environmental factors. Some students are able to write neatly for a short time but with longer assignments the dysgraphia becomes more of an issue. OT's should evaluate when tics are typically more interfering and for a lengthy sample.

Recognizing the prevalence of this difficulty for students with TS is extremely important. As a proactive measure, teaching keyboarding skills as early as possible is wise. In most cases, printing is easier for the child to accomplish than is cursive and printing may need to be accepted by the student's teachers. Providing a scribe (someone who writes what the student dictates) can be helpful if keyboarding skills are weak. This allows the student to demonstrate the extent of his knowledge on a subject without the interference of dysgraphia. Having someone scribe as the student speaks has the added bonus of teaching dictation skills. This can be very useful for students who can use this same skill later with voice-activated computer programs. Good keyboarding skills should always be a priority as there are times when speaking into a computer is not practical. Keyboarding is an invaluable life skill that should be acquired as early as possible by all children with TS.

Many students with TS are excellent auditory learners. The concentration required to take notes can actually interfere with this style of learning. If this is the case, providing notes from which the student can study will be beneficial.

Common classroom modifications that may be important for dysgraphia 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 the work
- Notes provided. Sometimes, teachers will hand out copies of notes with blanks prior to the lesson so that the student can write the appropriate words in the blanks. If this works, it may assist the student in paying attention and benefiting 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 be highlighting the important sections of the notes as the teacher is lecturing
- 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, projects, etc.
- 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 determine if a specific support strategy will improve grades, attitude, behaviors, etc. is highly recommended. The frustration and embarrassment of sloppy, immature and writing frequently leads to more than academic difficulties. Support in this area is frequently critical to the overall success of the child.

HOMEWORK

A student may have difficulties understanding the assignment, be inconsistent in copying down assignments, struggle to begin or complete assignments, fail due to missing assignments, not turn in completed homework, etc. This is an area of difficulty for the majority of students with TS particularly as they get into the higher grades. The energy that is required for these children to make it through a day at school can be overwhelming. Then they are expected to work for hours on homework that typically includes handwriting. A reduction in homework can be critical, but unfortunately, this is not always a practical solution. For instance, while reducing the number of spelling words or math problems is a possibility, a student cannot read a portion of the history lesson and be prepared to take a quiz or test on the entire lesson. Homework

difficulties require creative solutions. Some students prefer to get up early to complete it; others to stay after school with support; and others need time during the day to get the needed support in order to complete as much as possible prior to leaving school.

Copying the assignment from the board, making sure that all the necessary materials are brought home and then handing in the assignment to the appropriate teacher the next day can all be issues that require some creative solutions. Having a case manager, a resource room teacher or consultant teacher to assist the student is frequently essential. This person can be responsible for teaching strategies to the student, assisting the teachers with modifications and helping the student with managing and prioritizing assignments.

Many students do not have the executive function skills necessary to even copy the assignment correctly from the board. Someone (an aide, resource room teacher, etc.) may need to be responsible for doing this for the student until strategies are developed which help the student gain more independence in this area. Punishment and negative consequences are not effective in helping the student with these difficulties.

DYSINHIBITION

The phenomenon known as dysinhibition is characterized by difficulty consistently inhibiting thoughts and/or actions. Inappropriate statements or behaviors very frequently result from the student's inability to consistently apply "mental brakes". Dysinhibition means that a child cannot stop himself consistently from expressing behaviors, thoughts, or displaying actions that someone else may be able to control. Such behaviors might be displayed as excessive silliness, being sassy, free associative comments, emotional outbursts, contextual swearing, blurting out, inappropriate comments explosive anger and oppositional defiance.

Picture a sign that says, "Don't Touch, Wet Paint". For many of us with difficulties inhibiting, the sign is an invitation to touch the paint. We must fight the urge to do so if we are to obey the sign and the norms of society. We must inhibit the very behavior that has been suggested to us by the sign. We can easily recognize inhibition as being difficult when we

think of puddles on the sidewalk that are just begging to be jumped into or the chocolate cake in the kitchen begging to be eaten. Inhibiting behaviors is challenging for all children but it presents a far greater challenge for students with TS due to their impulsivity and inconsistent ability to apply their mental brakes. We must understand that this is not purposeful disobedience but is merely an inconsistent dysfunction of the brain that is affected by the chemical imbalances that cause TS.

A young boy's teachers had a difficult time believing that every time this second grade student said something inappropriate or acted in an impulsive manner that it was a "tic". It is helpful if we understand that Tourette Syndrome is more than tics and recognize that many of the difficulties a student is experiencing are "symptoms" rather than tics. All too often we think of verbal and physical tics as being the only symptoms of TS. Many students whether they have severe or mild physical and vocal "tics" also have a significant difficulty with the invisible but extremely disruptive feature of dysinhibition. Therefore when this student is told that his turn on the computer is over and he makes an inappropriate remark, it is indeed due to his having TS. In these instances, it is best to use planned ignorance, but to include counseling support in order to help him to recognize that his "brakes" do not always work well and strategies to use when this occurs. Over time, he may learn to substitute a more appropriate behavior, but since the actions are impulsive, it may require a great deal of practice and patience on everyone's part.

EXECUTIVE DYSFUNCTION DISORDER

Executive function involves the skills necessary to succeed in school and in life. A person with executive deficits can have extraordinary talents and abilities, but they do not possess the organizational capacities necessary to demonstrate these abilities in a manner that is useful and productive. Time management and problem solving are examples of the kinds of skill areas that can be affected.

Many people with Tourette Syndrome are chronically disorganized. They have difficulty developing strategies to overcome problems they encounter or implementing strategies that are 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 in managing work flow and learning strategies that will assist them throughout their lives in overcoming their "output failure" due to executive dysfunction. Improved executive function skills will enable the student to prioritize tasks, complete assignments and manage time in a manner that will more accurately reflect their true abilities.

ACCENTUATING STRENGTHS

Does the child have an extraordinary interest and/or talent in art, music, science, sports, creative writing, hands-on activities, etc.? The importance of encouraging areas of talent cannot be overemphasized and will help the student with TS complete school with a good self-esteem intact. Recognizing a student's strengths and knowing how to support them is critical for the eventual success of the child.

This doesn't mean that the preferred activity should be used as a carrot that is given and taken away in response to a "behavior plan". One student said, "Don't ever let them know what you like because they will either take it away or make you earn it." However, being rewarded with extra time for a favored activity can sometimes work effectively as an incentive depending on the individual child. But most experts agree that it should not be taken away as a punishment or be allowed only if the privilege is earned.

SOCIAL SKILLS DEFICITS

Many children with TS score in the above average to superior range on IQ tests but may not act in a socially appropriate manner. Social deficits can be a very problematic area for some children with TS. This can cause rigidity in their thinking and a deficit in their ability 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 as they grow up.

Pragmatic language skills can be taught by a speech therapist to assist the student in these areas. In many instances, students who do not intrinsically acquire social skills are bright and when they are

motivated to have friends can be taught the social skills necessary to be successful. Social skill classes are becoming more popular and many school counselors are familiar with techniques that have proven to be successful in teaching these skills. Social stories, developed by Carol Gray, are being used effectively in schools and can include such things as cue cards or social story notebooks.

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 who will be responsible for working with the student in this area should be designated in the plan. Simply writing a goal that states that the child will act more age appropriately is not sufficient for students to learn the techniques and skills they lack.

“RAGE”

There are a small percentage of children with TS who have outbursts of uncontrollable anger often referred to as “rage” or “meltdowns”. Generally, but not always, this is more likely to be displayed in the home setting. This is neither the fault of the child nor the parents. Many parents blame themselves and are also blamed by professionals, friends and family. The R.A.G.E. (Repeated Anger Generated Episodes) brochure that is available through TSA is an excellent resource for professionals and parents who have children with these symptoms. It will help them understand that there is no one to blame and that different strategies must be employed for children who have neurologically based rage. In fact, experience shows that typical interventions (including negative consequences) will 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 explosive response of the child. It is also important to be flexible and remain calm when dealing with children who have the severe misfortune to be affected by the symptom of neurological rage.

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 frustration as soon as they arrive at home. This

can result in not only an increase in tics, but in very difficult and often destructive behaviors at home. It has been described as the Dr. Jekyll/Mr. Hyde phenomena. No matter how the difficult behavior is expressed, it is important that all school personnel understand that the demands of the school day can result in this type of behavior at home regardless of how the much 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 may be instrumental in developing supports and accommodations in the school setting which could in turn help to 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 must be raised, “at what cost?”. At what cost is this 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 cost to the child’s welfare and best interests.

READING STRENGTHS AND WEAKNESSES

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? Many possible reasons should be considered if a student has difficulty reading, including a learning disability involving reading. One student loved to read at home but would refuse to read in school or to read anything that was assigned by the school. It was finally determined that the girl loved to read but had severe dysgraphia. She had determined that if she read school-assigned books, she would then be required to write, which she couldn’t do. Therefore, she refused to read the assigned books.

Any form of dyslexia (difficulty reading) needs to be considered. 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 tiresome, but next to impossible. Again creative supports are needed to address the specific reason as even mild tics can make reading difficult.

AUDITORY AND VISUAL PROCESSING

Frequently students with TS have difficulty processing information that is 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 anything. Unfortunately, this is usually 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 to assist the student in developing a different response when he requires more time to process. Positive strategies such as asking a question and telling the student that you will come back to him in a minute for the answer has worked well for some students.

Any kind of stress reduction is helpful. It is most important that the teachers understand the reason for this delay in processing information and that it is due to this child’s neurological difficulties and not deliberate misbehavior.

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. If you suspect that this might be a problem, it is important that an Occupational Therapy evaluation be provided by a person qualified in sensory integration issues. Developing a “sensory diet” can sometimes be beneficial for the child and everyone who works with him.

This is a very complex problem and must be evaluated by a trained professional such as an Occupational Therapist. There are many clues that may lead one to suspect that this is an area of concern. The child may exhibit a need for excessive sensory input (chewing, hitting or hurting self in some manner). He may become easily over stimulated by minimal sensory input such as loud noise, bright lights, certain smells or tastes, the feel of certain fabrics. There are books available that explain this problem in great detail. “The Out-of-Sync Child” by Carol Stock Kranowitz, M.A. is both an informative and readable resource.

ATTENTIONAL DIFFICULTIES

Inconsistent or chronic difficulties in focusing are common for students with TS. In addition to the symptoms of ADHD, complex tics or obsessions can interfere with a student’s ability to pay attention. This becomes particularly true when the student has an overwhelming desire to “suppress” symptoms in public. He may concentrate so hard on suppressing tics that he is not able to attend to the classroom activity. However, there are times when the student is able to pay attention even though it appears otherwise. As an 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 as many students with TS are capable of paying attention even while experiencing a bout of complex tics or while trying to direct their attention through doodling or other activities.

ANXIETY AND 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 Pearson. Is the child reluctant to take risks? He may have anxiety issues surrounding specific tasks or situations. The child may either be unable to articulate the reason for the anxiety or may be embarrassed to do so. Refusing to attempt tasks may indicate that the child has some underlying anxiety that is preventing him from being successful.

Strategies that will help reduce anxiety need to be outlined very specifically and supported by everyone. Consistency is critical because this creates a sense of security. If the student feels that the plan is not being followed – the anxiety level goes up. If the plan is in writing and everyone involved is on board, then the child will feel more confident. Some strategies are relatively simple. For instance, being allowed to sit near the door with permission to leave when necessary. This will frequently reduce the anxiety to the extent that the student will no longer need to leave the classroom.

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, TS, Aspergers, processing difficulties, dysgraphia, sensory issues, etc. that are preventing the child from responding appropriately to a particular request and displaying instead behaviors that are interpreted as being generally oppositional and defiant. For example, a student who becomes oppositional only during a task that requires 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 this setting is, in some fashion, overwhelming to him. Dr. Ross Greene's book "The Explosive Child" is an excellent resource regarding children with neurological disorders and "oppositional" behaviors.

A SENSE OF CONTROL

The inconsistencies of a child's abilities to perform tasks adds to the confusion for the child as well as adults. Is it purposeful behavior or neuro-based difficulties? Refusals to do work may appear to be the child wanting to be in control. A more productive interpretation, however, is that the behavior may be a desperate attempt on the part of the child to bring a sense of control to a world of inconsistent difficulties, and loss of control. If the child is attempting to gain some control, support staff should examine what can be done to provide the student with control without relying on behaviors that are disruptive. Teaching strategies that result in the student gaining control of his environment may be extremely helpful in the short term as well as 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 team work between the student and the educators as well as allowing the student to take ownership of any positive and proactive intervention plan.

IMMATURE BEHAVIORS

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

Frequently students with TS will act in an immature fashion and display behaviors that are typical of a much younger student even though they possess more advanced academic abilities. This may be due to a delay in developing the skills necessary to inhibit inappropriate behaviors in response to frustration or anxiety. The delays result in behaviors that are not age appropriate and since the child may be academically advanced, the behaviors are often perceived by adults as being purposeful. It is also not unusual for the child to get along with either younger children or with adults better than with children their own age. This delay is frequently seen in children with TS and should be seen as being a component of the disability and not manipulative and purposeful misbehavior.

NOT WANTING TO BE SINGLED OUT

A problem that can be very frustrating for everyone is a student who refuses supports and accommodations because they do not want to be singled out as different. Guidance, support and patience on the part of all the educators working with that child may be helpful in overcoming this. It is similar to anxiety issues and will require a positive and proactive plan followed by all adults. It will require consistent support and discussions with the student regarding "fair is not always equal and equal is not always fair." Just because they require different supports it should not be viewed as being "bad" or "weird" but simply "fair" for his situation.

SELECTING TEACHERS

Many students require a teacher who is adept at creating a structured environment that will reduce stress and therefore symptoms, but also one who allows for flexibility and choice. By giving the child a choice, he is much less likely to lose control in inappropriate fashions. This is particularly true for those who tend to be inflexible or oppositional.

- 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.

FIGHT OR FLIGHT

In general, students with TS have a heightened response to their environment. It is important that the student be placed with teachers who can remain calm in a difficult situation. Many students respond in a 'fight or flight' mode when they become overwhelmed. A calm approach will be much more successful than a volatile response which generally escalates the 'flight or fight' response by the student with TS.

TIMES OF TRANSITION

Very often individuals with TS have problems with transitions from one task to another or from one environment to another. If a procedure has been established that assists with times of transition, this procedure can be written into the IEP as a strategy that future teachers should use. If a strategy has not been established, the current teacher will need to experiment with different ways of letting the student know when a transition is approaching. This can be compared to a driver who begins to down shift gears while mentally preparing to stop because a road sign is warning of a stop sign ahead. The sign allows the driver to slow down and to become prepared for braking. People with TS are frequently internally driven to complete the task in which they are involved before being able to transition to a new activity. This can be exacerbated if the student additionally has anxiety caused by obsessive compulsive behaviors.

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. It is important to remember that the only thing that is consistent about Tourette Syndrome is the inconsistency of symptoms. Very often students are bright and creative, thus making it very difficult for adults to believe that they are not manipulating everyone when they state that they can't complete a task. Adults may be tempted to encourage the youngster by reminding them that they did this very task yesterday, or that if they just try harder, they will be able to accomplish the task again. In some instances this may help, while in others it will only increase the stress which will in turn increase the tics and other symptoms. In a game of baseball, just because a player hits one home run, do we expect him to do that every time they come to the plate? Are we going to say that he just isn't trying hard enough or that he is manipulating us by striking out occasionally or hitting a pop fly?

TRIAL AND ERROR

Working with the unique problems that children with TS present often becomes a matter of simple 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 valuable 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.

For additional general special education resources visit the IDEA Practices Website:
www.ideapractices.org and www.fape.org