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FROM: Thomas B. Nevelidine

SUBJECT: "Educating Children with Tourette Syndrome: Understanding and Educating Children With a Neurobiological Disorder"

The attached document "Educating Children With Tourette Syndrome: Understanding and Educating Children With a Neurobiological Disorder" has been developed by the Tourette Syndrome Association, Inc., Long Island Chapter. It is being shared in a cooperative effort to provide parents and professionals with resources to better meet the needs of children and youth with Tourette Syndrome. Please

duplicate and share this information with your colleagues and others who may have an interest in this document.

In January and May 1995, a training program, sponsored by the Eastern Suffolk BOCES and the Tourette Syndrome Association, Inc. of Long Island, will be provided to Special Education Training and Resource Center (SETRC) staff. The program will include an overview of this material and a model for serving children and youth with Tourette Syndrome. We intend during the next several years to increase the capacity and expertise of the SETRCs, the Special Education Administrators Leadership Training Academies (SEALTAs) and other in-service networks to provide technical assistance and training to local education agencies and parents on this topic.

If you have any questions regarding this information, please contact the Office for Special Education Services at (516) 474-5548.

Attachment

Educating Children With
TOURETTE SYNDROME:

*Understanding and Educating Children With a
Neurobiological Disorder*

*Part I: Psychoeducational Implications
of Tourette Syndrome and Its Associated Disorders*

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Preface and Acknowledgments

Tourette Syndrome is a baffling medical disorder that often goes undiagnosed or misdiagnosed in children and adolescents. Until a few decades ago, most scientists and professionals believed that Tourette Syndrome was psychological in origin. Recent research, however, suggests that Tourette Syndrome is a neurological disorder that is transmitted genetically. By studying Tourette Syndrome, neuroscientists find themselves on the brink of understanding the complex relationship between genetics, the brain, behavior, and emotions.

As neuroscientists pursue studies which will hopefully lead to a greater understanding of this disorder, parents and educators continue to struggle to understand and manage the interference that Tourette Syndrome may produce in the areas of academic functioning, social relationships, and psychological development. Because most educators were never trained in rare neurobiological disorders such as Tourette Syndrome, they often find themselves unable to manage a child's symptoms in the regular classroom and unable to find support or resources to guide them.

In 1991, parents of children who have Tourette Syndrome initiated a project to increase awareness and understanding of Tourette Syndrome among educators in New York so that children with Tourette Syndrome could receive their free appropriate public education. Due to the on-going and collaborative efforts of the Tourette Syndrome Association, Inc., the children's physicians and psychologists, and some truly innovative educators, the New York State Education Department has recognized the need that exists for greater awareness and training of educators. This manual is but one aspect of a comprehensive plan initiated by NYSED in 1994 to educate the educators, and was written in response to a request from NYSED for training materials.

The Long Island Chapter of the Tourette Syndrome Association, Inc. appreciates the commitment made by NYSED to help us achieve our goal of securing appropriate educational programs for our children. We are also deeply indebted to Mr. James Fogarty, Director of Special Education, BOCES 1 of Suffolk County and Ms. Irene Witthoft, Principal, Captree Learning Center for the enthusiastic support they and the staff of the Captree and Masera Learning Centers have consistently offered. Their dedicated efforts to develop appropriate educational programs have already touched the lives of many children in New York State.

The author also wishes to acknowledge the following professionals for their technical assistance, support and encouragement: Ruth Bruun, M.D., Robert Araujo, Ph.D., Ann Katsaros, M.S., and Bonnie Hoffman, C.S.W.

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Dedication

This manual is dedicated to the dozens of children in the L. I. Chapter of TSA who have shared their experiences with the author and taught us what it means to try to function in a world that doesn't really understand a bizarre disorder. It is also dedicated to two very special children:

To Justin, who shares his good times and his bad times as he learns to cope with this spectrum disorder, and

To Loren, who has thoughtfully managed to teach me about those parts of the spectrum that Justin neglected to cover.

Finally, this manual is dedicated to all of those educators who successfully educate our children, with gratitude for their patience, creativity, compassion, and professionalism.

L.E.P.

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OVERVIEW OF TOURETTE SYNDROME

Tourette Syndrome (TS) is a neurobiological disorder that appears to be genetically transmitted. TS is one of a number of tic disorders. Tics are involuntary movements (motor tics) or sounds (phonic tics). According to the DSM-IV, the following diagnostic criteria must all be met:

time

1. Both multiple motor and one or more vocal tics have been present at some during the illness, although not necessarily concurrently.
2. The tics occur many times a day (usually in bouts) nearly every day or intermittently throughout a period of more than 1 year, and during this period there was never a tic-free period of more than 3 consecutive months.
3. The disturbance causes marked distress or significant impairment in social, occupational, or other important areas of functioning.
4. The onset is before age 18 years.
5. The disturbance is not due to the direct physiological effects of a substance (e.g., stimulants) or a general medical condition (e.g., Huntington's disease or postviral encephalitis).

There is no requirement that motor tics and phonic tics be present at the same time, and there is no requirement that the child must have involuntary cursing.

There are no neurological tests or blood tests that are used to make the differential diagnosis of TS. The diagnosis is made on the basis of the physician's observation of the patient and/or on the reported history by a reliable observer. The physician will frequently take a detailed family history with respect to tics and associated problems. The presence of a positive family history, while not necessary for diagnosis, often increases the physician's confidence in the diagnosis.

HOW COMMON IS TS?

Once thought to be extremely rare, there is now growing evidence that TS may be a fairly common childhood-onset disorder that frequently goes unrecognized or misdiagnosed (13). Kurlan and his colleagues suggest that TS may be 10 times more prevalent in children than in adults (32). In order to estimate prevalence in an elementary school-age population, Comings and his colleagues used a trained school psychologist to screen approximately 3000 students in one California school district (15). They found that 1 in every 95 boys and 1 in every 759 girls had definite TS. Because their sample had a disproportionate number of special education children, their findings probably overestimate prevalence in the general population.

The most striking findings in Comings' investigation were that 70% of students with TS were in special education classes, 12% of all children in special education classes had definite TS

(usually undiagnosed), and 28% of all children in special education classes met the criteria for a tic disorder (15). Their unexpectedly high percentage of special education children with tic disorders has been replicated in a study in Monroe County, New York (9). If more than one in every four children in special education classes has a tic disorder, tic disorders may underlie more learning disabilities and/or behavioral problems than previously recognized. The findings of both studies warrant additional research to determine the relationship between tics, learning disabilities, and behavioral problems.

Although children with TS are apparently a high-risk population for developing special education needs, only 25% of children who have TS and learning disabilities are identified by school personnel (7).

DESCRIPTION OF TICS

The first tics or symptoms of TS are usually simple motor tics of the head, face, and neck region. ***Simple motor tics*** are rapid, purposeless and repetitive movements of one muscle group, such as eye blinking, shoulder shrugging, squinting, or facial grimacing. In a review of over 2400 patients, Bruun found that 66% reported facial tics as their first symptom. Eye tics were the single most frequent first symptom, occurring in 53% of all patients (4). These simple motor tics are often misdiagnosed by both parents and educators. For example, children with eye blinking tics are often referred for vision examination, children with throat clearing are sent to pediatricians or allergists, and children who brush their hair back from their foreheads are often sent for haircuts. Bruun reports that 13% of her patients reported vocal tics as their first symptom. ***Simple phonic tics*** are repetitive sounds that are not linguistically meaningful. They include throat clearing, sniffing, grunting, squeaking, and coughing.

The first tic of TS may appear suddenly, last a few weeks, and then disappear, only to be replaced a few months later by a different tic. Apart from the variability in the anatomic location of the tics, there is also variability in the frequency and severity of ticcing. This inherent variability is referred to as ***waxing and waning***. Individuals with TS will generally experience bouts of severe and frequent ticcing alternating with periods of total or relative remission. This variability in the frequency and severity of ticcing often creates confusion for educators and parents, who may erroneously conclude that the tics are controllable.

HOW ARE TICS EXPERIENCED BY THE PATIENT?

While most tics are rapid in appearance, many patients report slower (dystonic) tics (29, 33, 34). Many individuals also report a sensory basis for their tics, which they describe as an unpleasant sensation building up in an anatomic region. The unpleasant sensation is temporarily relieved by the expression of the tic. Patients also report that they feel as if there is a voluntary component to the experience. They feel the need to tic building up and they release it (34). The patient's experience that s/he is exerting some choice or volition in releasing the tic may mislead parents and educators into erroneously concluding that a child can really suppress or inhibit the tics. In reality, the child may only be temporarily able to inhibit the tics. As we shall see below, suppressing the tics leads to other problems.

NATURAL PROGRESSION OF THE DISORDER

Studies on TS indicate that the onset of symptoms usually occurs between the ages of 5 and 10 years old, with a mean onset of 7 years (4). Almost every study has found that TS affects males more than females (31). While the male:female ratio in the general population of TS patients is estimated as 3:1, the gender difference is greater in young children and adolescents (8). In young children, the male:female ratio is more on the order of 9:1 (8, 9).

As the symptoms of TS emerge, simple motor tics of the head and neck region are often replaced by more complex tics of the extremities and trunk. **Complex motor tics** are involuntary movements that involve the coordinated sequence or activation of two or more muscle groups. Complex motor tics may involve elaborate sequences such as bending down to touch the ground, or spinning around and jumping. Children with TS may also involuntarily imitate the actions or movements or others (**echopraxia**).

Complex phonic tics represent involuntary linguistically meaningful utterances or expressions, such as repetitive use of phrases such as “you know” or “ooh boy.” Complex phonic tics may also be expressed as entire statements or questions such as “How are you?” Children with TS may also involuntarily imitate the last word said by others (**echolalia**) or the last sound they heard, including nonhuman sounds such as horns honking or brakes squealing. Children with TS may also imitate their own last words, sounds or phrases (**palilalia**). Because many young children intentionally imitate other children or adults, complex tics involving echo phenomena are often misinterpreted as intentional behavior.

Some of the most bizarre and distressing complex tics are the involuntary utterance of expletives or socially taboo words (**coprolalia**) or the involuntary movements of obscene or socially inappropriate gestures (**copropraxia**). Because these unfortunate symptoms have attracted such widespread media attention, they will be discussed separately below.

Table 1 lists a number of the most common tics observed in TS. It is important to note, however, that the list is not complete. Almost any movement or utterance may be a tic in a particular patient. Educators who observe questionable behaviors or utterances in a diagnosed child are encouraged to share their observations with the child’s parents or physician. Such consultation is essential if there is any consideration of attempting to alter the behavior.

For children with TS, symptom severity tends to increase over the first decade from onset of symptoms (36). For about 70% of individuals with TS, the severity of the tics or their frequency will diminish significantly during the late teen years (4, 19, 36). Bruun estimates that 30 - 40% of patients will experience a total remission by late adolescence, 30% or more will experience significant improvement in tic symptoms, and approximately one-third will continue to experience the same severity of symptoms. There does not appear to be any correlation between tic severity in childhood and long-term prognosis (20). The only predictor of moderate or severe tics in adulthood identified to date is the severity of dysfunction in late adolescence. Furthermore, despite the fact that the majority of patients in one sample had experienced significant difficulties when younger, 99% of them had graduated high school and 90% were either employed full-time or enrolled in graduate programs.

While tic symptoms do not necessarily get more severe during adolescence, there is some suggestion that they tend to become more complex and more unpredictable. Parents of adolescents report that they never know from one day to the next what to expect.

Table 1
Tics of Tourette Syndrome*

	<i>Motor</i>	<i>Phonic</i>
<i>Simple</i>	Eye Blinking Shoulder Shrugs Brushing or Tossing Hair Out of Eyes Mouth Opening Arm Extending Facial Grimaces Lip-licking Rolling Eyes Squinting	Throat Clearing Grunting Yelling or Screaming Sniffing Barking Snorting Coughing Spitting Squeaking Humming Whistling
<i>Complex</i>	Pulling at Clothes Touching People Touching Objects Smelling Fingers Smelling Objects Jumping or Skipping Poking or Jabbing Punching Kicking Hopping Kissing Self or Others Flapping Arms Twirling Around Tensing Muscle Groups Thrusting Movements of Groin or Torso Twirling Hair Walking on Toes Copropraxia: Sexually Touching Self Sexually Touching Others Obscene Gestures Echo Phenomena: Others' Actions One's Own Actions Self-Injurious Behaviors (e.g., Biting, Hitting, Picking Skin Or Scabs)	Making Animal-like Sounds Unusual Changes in Pitch or Volume of Voice Stuttering Echo Phenomena: One's Own Words or Sounds Others' Words or Sounds Coprolalia: Obscenities Socially Taboo Phrases

* Note: Any behavior or symptom may have alternative explanations in a child who has TS and other diagnoses such as Obsessive-Compulsive Disorder and/or Attention Deficit Hyperactivity Disorder. For example, any behavior or symptom may represent a complex tic, a compulsive behavior, an impulsive behavior, or a normal voluntary behavior. Differentially diagnosing any one symptom cannot be made without further study or information.

COPROLALIA

Some of the most embarrassing tics of TS may emerge four to seven years after the onset of the earliest tics. If coprolalia or copropraxia emerges, it is usually at age 10 - 13 (41, 45). Both coprolalia and copropraxia are often confused with voluntary preadolescent or adolescent misbehavior.

Almost any obscene or taboo word or remark can become part of a child's coprolalia. Simple obscenities are the most common form of coprolalia. The hallmark of coprolalia is its repetitive, inappropriate, and almost compulsive use during speech even when the child is not angry or upset. Most coprolalia occurs at the beginning of speech or during a transitional phrase. Older children or adults are sometimes able to truncate the obscenity into just the beginning sounds, such as "Fuh" or "Sh," but younger children are usually unable to exert this level of control. Often, the coprolalia is represented as a more complex utterance that combines obscenities, references to genitalia or sexual acts, and/or racial or ethnic slurs. For at least some individuals, the coprolalia seems to be a "mental tic," i.e., there are individuals who report thoughts of obscene words or phrases which they don't actually say out loud.

When TS first began to attract public and media attention, coprolalia was the most dramatic symptom and the one which attracted the most interest. TS was sometimes referred to as the "cursing disease." It is important for school personnel to be aware of the following:

1. Less than 30% of all patients with TS will develop coprolalia as a symptom. Even if it does appear, it is unlikely to persist for very long. It will come and go as other tics do.
2. Coprolalia is not required for diagnosis of TS.
3. The coprolalic utterances do not reflect the patient's true thoughts or feelings.

Because coprolalia can be particularly distracting or disruptive to the class, school personnel may be tempted to ask (or order) the child to leave the class. If parents consent to such contingencies as part of a behavior modification plan developed at the Committee on Special Education (CSE) meeting, then school personnel may apply such agreed-upon contingencies. School personnel should be particularly careful not to implement any "behavior modification" plan without informing the parents in advance and obtaining their consent. There are both legal and educational reasons for this firm recommendation. First, federal law prohibits schools from punishing a child for a symptom of a disability and also protects the child against discrimination on the basis of disability. Punishing a child for a tic is no different than punishing a child who has epilepsy for having a seizure. Second, there is no scientific evidence that behavior modification strategies can really extinguish an involuntary neurologically-based tic. To the contrary, there has been one clinical report that a child's symptoms can be made worse by an inappropriately applied behavioral strategy.

COPROPRAXIA

Copropraxia is the action form of coprolalia, and its most common expression is what is usually referred to as "giving the finger." Again, what distinguishes copropraxia from intentional obscene gestures is its inappropriate display when the individual is not angry. Copropraxia may also be manifest as sexually touching or exposing oneself or touching others in the genitalia.

As with coprolalia, less than 30% of all patients with TS develop copropraxia. Depending on the form of the copropraxia, school personnel may be concerned that the child is

displaying a symptom of possible sexual abuse. Such confusion, while understandable, may lead school personnel to report the family to Child Protective Services (14). While school personnel must comply with the laws regulating mandated reporters, they are advised to consult with the child's treating physician before initiating any course of action. Furthermore, if the child has a complex tic that involves touching others, school personnel should provide added adult supervision at all times and allow a larger buffer space around the child at all times.

For children with copropraxia, balancing the child's needs and rights against the school's responsibility to the other children and staff can be a delicate issue. Because true coprolalia and copropraxia are tics, the first line of intervention will be pharmacological, and indeed, for many patients, adjustments in their anti-tic medication will help reduce or totally suppress these tics. By notifying the child's treating physician and/or parents if copropraxia or coprolalia emerges, the school enables the child to obtain prompt medical intervention and possible relief from mortifying symptoms.

FACTORS AFFECTING TIC SEVERITY

Although the symptoms of TS follow an inherently waxing and waning course, there are some factors that have been identified as producing a worsening of symptoms. Of all of these factors, stress is the single most potent factor exacerbating the symptoms of TS. Some stressors that have been identified in the clinical literature include:

1. Time pressure (particularly time pressure during school tests).
2. Environments or programs that do not provide adequate opportunity to discharge symptoms or dissipate motor activity.
3. Holiday anticipation, birthdays, and other "positive" stressors such as vacations.
4. School re-opening in September.
5. Substances such as caffeine, nicotine, or stimulants.
6. Estrogen and progesterone changes during menstruation.
7. Environmental factors such as allergy seasons or hot weather.
8. Specific school settings where children are expected to sit quietly (such as study hall, library, assembly).
9. Fatigue.

While stress and fatigue tend to produce a worsening of tics, relaxation does not always decrease them. It has often been observed that children relaxing at home watching TV may display a significant number of tics. One possible explanation is that the effort to suppress tics is diminished as the child relaxes. There appears to be a qualitative difference in the child's ticcing in different settings, however. Children ticcing while watching TV or relaxing usually do not seem distressed by the tics. Children often do appear distressed or emotional about the explosive ticcing that is displayed when they come home from school.

It has also been frequently observed that symptom severity abates under conditions where the individual is paying rapt attention or is constructively focused on an interesting or novel task. For some children, self-selected activities or challenging school projects that are geared to their interests may produce improvement in symptoms.

SUPPRESSING TICS

Most individuals with TS can inhibit or suppress tics for varying amounts of time (from just a few seconds to hours). If you think of a tic as a sneeze, you can predict what will happen if the child tries to hold it in or suppress it. Suppressing a tic requires mental and physical energy. Sooner or later, the tic will emerge more explosively. While suppressing tics might be desirable from others' perspective, it is generally not in the child's best interest. Suppression will only lead to more explosive tics and the concentration spent on suppressing tics distracts the child from the task or lesson. Over the course of the school day, children who spend time and energy attempting to suppress tics will also become increasingly frustrated and irritable, which may lead to depression or outbursts of angry behavior. Balancing the child's needs against those of other students who might be distracted can be accomplished by applying some common rules of courtesy and simple modifications. These strategies will be discussed in Part III of this series of articles.

The suppressibility of the tics often creates confusion for school personnel. It is important to note that the child's ability to suppress the tics will vary, as will the severity and frequency of the tics themselves. Even within the school building, there may be observed differences in tic frequency and severity in different activities or settings. Hagin and Kugler (23) compared the frequency of tics in the classroom with the frequency of tics in a one-on-one interview situation. They found that children ticqued significantly less while they were in the classroom, suggesting that the children may be actively engaged in suppressing tics in class. Some children, however, may actually tic less in the one-on-one situation because it is less stressful than the classroom setting. School psychologists and educational evaluators should not assume that the frequency of ticcing they observe in the one-on-one situation is a valid estimate of how much the child is ticcing in the classroom.

A second source of confusion relates to reported differences in symptom severity between the home and school. School personnel frequently report significantly less ticcing in school than parents observe in the home. Since many children consciously or unconsciously attempt to suppress tics in school and only totally release them when they get home to their “safe” environment, such discrepancies in observations are understandable. Occasionally, parents report almost no ticcing at home while school personnel observe more frequent or severe ticcing. In cases of marked discrepancy in ticcing between the home and school, the appropriateness of the child’s program needs to be reviewed to determine if modifications or accommodations are needed to reduce the child’s level of stress in the classroom.

ASSOCIATED DISORDERS AND BEHAVIORAL FEATURES

A significant percentage of children who have TS also have associated (or co-morbid) disorders that are also neurobiological in origin. In a review of 200 pediatric and adolescent cases, the investigators found that 58% of their sample had school problems, behavioral problems, or both (18). Indeed, it is often the associated disorders that play havoc with the child’s education and psychosocial development. Before describing the most common associated disorders, we should note the following:

1. *The presence or absence of behavioral or learning disorders cannot be inferred simply on the basis of observed tics.* May children with severe learning disabilities or impairment display only mild tics in school.

2. *Having TS does not prevent the child from having unrelated learning disabilities, physical disabilities, or independent psychopathology.* Nor does TS protect the child from the ills of our society. To the contrary, because the child who has TS is so often undiagnosed and/or misunderstood, such children may be more likely to become victims. There has been some clinical suggestion that children who have TS and/or Attention Deficit Hyperactivity Disorder but who are neither diagnosed nor treated are more likely to engage in substance abuse later on in life.

Children who have TS and one or more of the associated disorders described below will be referred to as “TS+” throughout the remainder of this article.

ATTENTION DEFICIT HYPERACTIVITY DISORDER

Attention Deficit Hyperactivity Disorder (ADHD) is one of the most frequently noted associated disorders in school-age children who have TS. ADHD is found in 30% of cases of mild TS, more than 50% of cases of moderate TS, and 70 - 80% of cases of severe TS. The symptoms of ADHD may precede the emergence of the tics of TS by two to three years (11, 45).¹

Children who have ADHD appear inattentive, impulsive, distractible, and hyperactive. These children tend to have significant difficulty in a regular classroom. For children with TS-

¹ If school personnel are aware that a child has been diagnosed as having ADHD, they should be particularly alert for tic symptoms. Some children with ADHD who are placed on stimulant medications such as Ritalin® may display tics, but those tics do not necessarily indicate TS. There is no evidence that stimulants cause TS, or that they will necessarily cause an increase in tics in a child with TS.

ADHD, unstructured or less structured settings such as recess, lunch, gym, and the school bus tend to be stressful. Children with impulse control problems are more likely to get into fights and respond to provocation from their peers. For children with TS-ADHD, even lining up in close proximity can lead to problems. The child may find it more difficult to inhibit impulses to touch other children, bump them, or poke them. As the stress increases, the child will be less able to suppress tics, thus increasing the likelihood that the tics will intrude on others. By being aware of this tendency and proactively preventing trouble by allowing a wider “buffer zone” around the child and providing added adult supervision, school personnel can avoid many problems.

While the majority of children who have TS will experience little or no difficulty in school, having TS and ADHD is an almost certain guarantee that the child will require educational accommodations, modifications, and/or interventions.

OBSESSIVE-COMPULSIVE DISORDER

Obsessive-Compulsive Disorder (OCD) is present in a significant percentage of individuals with TS; co-morbidity estimates range from 11% to 90%. One study found that 40% of young TS patients had obsessive-compulsive symptoms (OCS) or full-blown OCD (44). There is some suggestion that the incidence of OCD increases with age. An obsession is a recurrent, persistent idea, thought, image, or impulse that is experienced as senseless or repugnant. A compulsion is the ritualized or stereotypic behavior in which the individual must engage to prevent some event from occurring. An individual with OCD initially tries to resist the compulsion, and usually recognizes the senselessness of the behavior.

In young children, the most frequent compulsive-type behaviors relate to “evening up” (e.g., tug on one ear then tug on the other), symmetry, touching, arranging things in a particular order, and smelling things. Some of the common symptoms exhibited by children with TS are identical to those exhibited by children with OCD: checking (or re-checking a fixed number of times), counting, and rituals involving hygiene. Children with either disorder may also engage in repetitive questioning or seeking reassurance. In children with OCD, repetitive questioning may be reassurance-seeking, but it may also represent a compulsion to hear the response given in a particular way, i.e., the child will keep asking the question over and over again until the answer sounds “just right.”

While ADHD symptoms generally emerge before the tics, obsessive-compulsive symptoms tend to emerge after the tics, and tend to last later into the life span (45). In one clinical study, the investigators reported that boys tend to display more symptoms of OCD than girls and have an earlier age of onset (48). In adults, however, females tend to be more frequently affected than males (37).

In children who have TS+, determining whether a symptom is a complex tic (such as touching or smelling), a compulsive behavior, an impulsive behavior, or a voluntary behavior is often very difficult. One way in which the four phenomena can be differentiated is by the child’s subjective experience. Releasing a tic is generally experienced as producing relief like “scratching an itch.” Engaging in a compulsive behavior is often done to relieve feelings of tension and/or anxiety. Responding to an impulse usually produces immediate feelings of pleasure that are subsequently replaced by guilt and regret (25, 42). Since children often lack the ability to verbalize their subjective experiences, differential attribution is often difficult for school personnel. Therefore, school personnel should consult with the child’s treating physician or psychologist and parents before implementing any behavior modification program.

BEHAVIORAL AND AFFECTIVE DISTURBANCES

While ADHD and OCD are the most common associated disorders, other co-morbid disorders have also been noted in a significant percentage of children with TS. Bruun reports that the symptoms of aggressiveness, hostility, and conduct disorders accounted for a large percentage of patients referred to her (6). While a full description of these disorders would be impossible here, useful discussions can be found elsewhere (10, 12, 38, 39, 40, 44, 46, 50, 51).

1. *Oppositional Defiant Disorder/Conduct Disorder.* Children with Oppositional Defiant Disorder invariably come into conflict with authority figures such as parents and teachers. The first symptoms of oppositional defiant disorder generally emerge in the preschool years. Early intervention is important, as estimates of the efficacy of clinical interventions drop markedly after the child reaches the age of 12.

2. *Anxiety Disorders.* In this category, we include Generalized Anxiety Disorder, panic attacks, and phobias. There is some controversy in the literature as to whether panic attacks and phobias are truly co-morbid with TS or are co-morbid with OCD. Since approximately one half of children with TS have OCD, school personnel should simply be aware that a child might present with these problems. School personnel working with diagnosed children also need to be aware that some of the medications used to treat the tics of TS may produce school avoidance and school phobias as side effects (5, 35).

3. *Self-injurious Behaviors.* This includes biting one's lips, picking at sores or skin, head banging, biting of tongue or cheek, and touching hot or dangerous objects. Some self-injurious behaviors appear to have definite tic-like properties. Other self-injurious behaviors seem to be more related to OCD. Some individuals with TS report that there is a sensory basis for these behaviors, i.e., they have to perform the behavior until they produce a particular body sensation or until it feels "just right." Detailed discussions of self-injurious behaviors can be found elsewhere (39, 40, 50).

4. *Explosive Outbursts of Aggressive Behavior.* These are sometimes referred to as "rage attacks" by parents of such children. The relationship between these attacks and TS is not clear. Some investigators have suggested that they correlate with coprolalia, copropraxia and echo phenomena (39), but it has also been suggested that some subset of impulsive aggressiveness correlates with obsessive-compulsive disorder (46). More recently, Bruun has suggested that for at least some children, explosive outbursts of aggressive behavior may be linked to depression (1994, personal communication). In any event, these "rage attacks" do not seem to be amenable to behavior modification, and pharmacological management in conjunction with psychotherapy or counseling will probably be more effective.

5. *Depression.* Approximately 25% of patients with TS may experience depression at some point. Because depression can produce forgetfulness and difficulty in concentrating, its diagnosis is often overlooked in children who have both TS and ADHD. Some of the medications used to treat TS may also produce dysphoria or depression as side effects.

LEARNING DISABILITIES AND ACADEMIC PERFORMANCE

A number of clinical reports suggest that although children with TS or TS+ seem to follow the same normal curve model for intelligence and I.Q. scores, they are more likely to experience learning disabilities than the general population (1, 2, 3, 21, 22, 26, 27, 28, 42, 43). The most frequent learning disabilities involve graphomotor, fine motor, or visuomotor integration problems, difficulties in organizational skills, difficulties in math computations, difficulties in reading comprehension, and difficulties in written expression (apart from graphomotor problems). In this section, we will briefly describe each type of problem. Part II of this series of articles provides suggestions for school psychologists and diagnosticians who are attempting to perform a comprehensive evaluation, and Part III provides strategies for making accommodations or modifications for some of the deficits noted below.

VISUOMOTOR, VISUOSPATIAL, VISUOPERCEPTUAL PROBLEMS

Children with TS often display problems in handwriting. Graphomotor problems may be due to direct interference from arm tics, but there may be other bases for the dysfunction. In investigations of children with TS, sensory-perceptual impairment and deficits in psychomotor speed were the most consistent findings (1, 2, 3, 24, 47, 49).

Children with fine motor, dexterity, graphomotor, or visuomotor integration problems may be frustrated in their attempts to produce handwritten work, copy material from the blackboard, or record lecture notes. Young children will have difficulty manipulating objects or cutting with scissors. Some children with TS may write neatly when there is no time pressure, but their handwriting may deteriorate quickly under conditions of sustained effort or time pressure. Many children with these deficits will display spatial organization problems. Their use of available workspace may be markedly abnormal, with no apparent use of margins or horizontal lines.

Parents of children with such impairment frequently report difficulties in activities of daily living such as using eating utensils and getting dressed (e.g., tying shoelaces or buttoning clothes). In the author's experience with dozens of children with TS+, the vast majority have required occupational therapy services and accommodations or assistive devices in the classroom.²

Because many of these children have ADHD as a co-morbid diagnosis, graphomotor and spatial organization problems are frequently misattributed to the child's impulsivity. Children who are diagnosed as having TS and who display impairment in the school psychologist's administration of the Bender-Gestalt VMI or Beery-Buktenica should be referred for evaluation by an occupational therapist. This issue will be addressed in Part II of this series of articles.

MATHEMATICAL COMPUTATIONS

² *It is important to note that the children who are referred to the author do not represent a random sample of all children who have TS. They probably do represent a random sample of children with TS+ who are experiencing difficulty in school, however.*

Several studies have identified impairment in written arithmetic (21, 27, 28, 31). Hagin and Kugler (23) reported that 56% of their sample was below expectations in mathematics. A significant percentage of children with TS displays relative deficits in mathematical computations although they may clearly grasp mathematical concepts and handle applied problems well. While Bornstein (1) found that children with more complex tics displayed greater impairment on the written mathematics test of the Wide Range Achievement Test and performed better on mental calculations, different children with TS or TS+ may experience calculational difficulties for different reasons. One child may have problems from being internally distracted by tics and losing his place in his mental calculations, but another child might be more impaired in paper-and-pencil tasks if he can't line up his columns neatly or transpose figures accurately due to the types of problems described in the previous section.

SPELLING

Hagin (22, 23) found that 52% of children with TS had spelling deficits. There is no pattern of deficits that appears to be uniquely associated with TS, however. One possible explanation for the spelling deficits is that children with impaired graphomotor skills tend to write less, and hence, have fewer opportunities to practice their spelling skills.

READING COMPREHENSION

While a number of reports have identified deficits in reading comprehension, two factors need to be considered. The first is that although 58% of children who were given group-administered tests fell below expected values, the group scored within normal expectations when given an individually administered test (23). Second, Comings and Comings found that the distribution of reading scores in their sample of children who did not have ADD was not significantly different from the control children, but there was a significant deficit in a group of TS-ADD children when compared with controls (11). Thus, any statements about deficits in reading comprehension must take associated disorders into account, since they may be more problematic than the TS itself.

For children who have TS+, the source of any deficits in reading comprehension may be a challenge to identify. Children may experience interference due to eye or head tics, or they may be distracted by the need to tic in any part of their body. Children who have OCD may experience interference from unwanted intrusive thoughts, or they may experience interference from nonobservable compulsive rituals. For example, suppose that you had to count all of the times the letter "E" occurred in this paragraph as you were reading it. How much of the material would you be able to process? Finally, children with TS-ADD may experience deficits in reading comprehension due to their distractibility. In some cases, the child may not need remediation for reading comprehension as much as accommodations for the intrusive effects of the disability.

WRITTEN EXPRESSIVE LANGUAGE

Many children with TS or TS+ have significant impairment in written expressive language. Evaluation of their deficits is frequently confounded by their graphomotor problems or impulsivity. Thus, tests of written expressive language that require handwritten samples may provide inaccurate assessment. Many children who have graphomotor problems fail to use

capitalization and punctuation. When asked to critique a sample and/or correct it with respect to capitalization and punctuation, they often have the skill.

Assessment of written expressive language will be one of the most difficult areas to evaluate and to address. If a child appears to have deficits in written expression over and above any graphomotor problems, then the child's oral communication and executive cognitive functioning may need to be assessed. Many parents report that their children's inability to produce a paragraph or paper commensurate with their knowledge is paralleled by their inability to tell a story clearly in sequence. Speech and language pathologists may be an important part of the interdisciplinary team for such children.

EXECUTIVE COGNITIVE DYSFUNCTION: THE DISORGANIZED CHILD

Executive cognitive function includes the abilities of setting goals, monitoring one's own progress in achieving those goals, and appreciating when the goals are reached. Children with executive cognitive dysfunction will generally be unable to meet their responsibilities and will appear totally disorganized (or as the author prefers to label it, "terminally disorganized"). Como (16) and Denckla and Reader (17) provide useful discussions of the neuropsychological testing and functioning of children with TS.

Children who have problems in executive function may have problems with the following tasks: recording homework assignments, packing necessary materials to complete homework, turning in completed assignments, initiating tasks in class, maintaining attention to tasks in class, completing tasks in a reasonable amount of time, shifting from task to task, initiating homework at home, maintaining attention to complete homework, breaking long-term assignments into manageable "chunks," packing completed homework in the schoolbag to return to school, giving parents important notices from the teacher or school, and keeping track of possessions.³ Teachers who are dismayed by the total chaos in the child's desk or locker may take small comfort in knowing that the child's bedroom at home is probably even worse. Parents often lament that they can't even find the child's bed or desk (or floor) under all of the clutter.⁴

Disorganization may be due to neuropsychological dysfunction, but it may also be due to other disorders. As examples, depressed individuals may appear disorganized or forgetful, while children with Oppositional Defiant Disorder may refuse to do what is expected, thereby producing the same outcome -- responsibilities don't get met. The comprehensive evaluation will be essential in determining the source of the child's problems.

³ Children with executive dysfunction are constantly losing their personal possessions, even items that are of great value to them. This is a source of frustration and demoralization for many of them. They can't understand why they can't remember what they have done with things, and they can't understand why people don't understand that they can't remember. They are not being lazy or irresponsible; it is a genuine neuropsychological dysfunction.

⁴ Having entered the bedroom of one such "terminally disorganized" child, one parent asked the child whether any terrorist group had called to claim responsibility. The child gazed around the room, clearly oblivious to the clutter.

THE “TYPICAL” TS+ CHILD

The vast majority of children who have TS go undiagnosed, probably because their symptoms are so mild that the disorder does not interfere with their lives. Many children who have TS without any of the associated disorders described above will do well in the regular classroom, and may need no or few accommodations or modifications. For children who have TS plus one or more of the associated disorders, however, there is a significant probability that they will require more than just accommodations. In this section, we will consider the “typical” TS+ child that the author has encountered in dozens of referred cases over the last two years. Because of the gender differences, the “typical” TS+ child is usually a boy, and indeed, boys have been referred for assistance approximately nine times more often than girls.

While there are individual differences, and TS does not preclude other independent problems, there are striking similarities among the children who have been referred to the Tourette Syndrome Association’s education assistance program. The “typical” TS+ child is described as a child who has relatively mild academic difficulties in school but who has serious organizational deficits, serious peer problems, handwriting or fine motor problems, increasing aggressiveness or oppositionalism, and/or increasing depression or unhappiness. One of the most difficult problems reported is the rejection and humiliation that the children have experienced. One such unhappy referral may give the reader a sense of what many children with TS face:

G. was 10 years old when the author met him. For the last two years, his teachers had made him sit in the back of the classroom so that his phonic tics would not distract his peers. Each day, the teacher began the class by reminding everyone that if G. bothered anyone, they were to let her know immediately. G. had not been invited to any children’s parties in four years, and had not had a single play date in over two years. On retesting, his I.Q. had deteriorated 20 points.

In the author’s discussions with children and adolescents about their school experiences, they frequently express their wish that people would understand that they cannot help what they are doing.

It is important to note that there is no one profile that will describe all children with TS+. While the profile of a boy with TS, hyperactivity, behavioral problems and organizational deficits accurately describes many of the children referred to the author, it is significant to note that there are two other common profiles. The first profile may be described as the child who is overly controlled in school (usually a child with severe OCD) and who is not seen as a behavioral problem because s/he is performing on (and usually above) grade level in academics. This “perfectionistic” child does not pose a problem for school personnel, but may come home and become quite emotional and depressed, and even aggressive. While school personnel might not recognize these children as being in need of services or accommodations, they are.

The third profile is the child who appears to be seriously impaired in language development, and somewhat intermediate in behavioral control and emotional dysregulation. This child will appear to fit into the category of Learning Disabled children, but will have additional needs.

CONCEPTUALIZING TS+

Children with TS+ have a neurobiological disorder that has sweeping effects. Comings suggests that perhaps the best way to conceptualize all of the pieces of the TS+ child is to view TS+ as a disorder of inhibition (10). Motor acts are disinhibited (motor tics), vocalizations are disinhibited (phonic tics), thoughts are disinhibited (obsessions, mental tics), behaviors are disinhibited (impulsions, compulsions, rage attacks, self-injurious behaviors), and affective or emotional states may be disinhibited. While children with TS may have an emotional dysregulation, the basis for the dysregulation is biological in origin. Treating such children as “behavior problems” is not likely to be effective, and the child is not likely to feel understood by (or cooperate with) those who fail to validate the child’s experience of having an internal state that leads to dysregulation in most areas of functioning.

While the picture described above may sound bleak, it is helpful to understand the “up” side or positive expression of TS+. While many aspects of our lives are not enhanced by disinhibition, there are some behaviors or qualities that are enhanced by excessiveness. Many children with TS or TS+ will be intellectually gifted or extremely creative, and obsessive perfectionism may produce a child who produces extremely detailed projects and papers. One child commented that he was thankful for TS because he felt that the “mental play” he experienced enriched his life.⁵ Educators who appreciate that there is a positive expression of TS or TS+ will be able to generate creative solutions to some of the problems children experience from the disorder.

Because approximately 70% of children with TS will experience a significant or total remission of their symptoms by the late teen years, early educational experiences are crucial. If we can find a way to work around the child’s current symptoms and deliver the curriculum while maintaining positive self-esteem, there is a high probability that the child will be able to use those skills later in life. If, on the other hand, we fail to make reasonable accommodations or provide remedial help for deficits, we may produce an adult who will not have the self-esteem and/or skills that s/he needs to be a productive and contributing member of society.

The feelings of both despair and hope that many of these children experience is reflected in the poem, “The Animals Inside Me,” which appears on the next page. The poem was written at a time when the child (a 10 year-old boy with TS+) was on home instruction because he could not function in school. His feelings that his body and his behavior are not under his own volitional control are evident in his characterization of his tics as animals that “make” him do unwanted things and “make” him experience negative emotions. His anger and rage at the “animals” (TS) is expressed in his desire to shoot them; the banana and bandanna are his accessories in his imaginary safari. In the last verse, he expresses his affirmation that somewhere inside him, there is a joyous animal waiting to emerge that represents his true self.

⁵ Unfortunately, children with too much “mental play” tend to have a difficult time focusing on the external world and environmental demands. Their internal “movies” may be so stimulating or creative that they have marked difficulty in responding to the world outside themselves.

The Animals Inside Me⁶

*I have a spider inside me.
 It makes my lips smack.
 I have a spider inside me
 and it makes me feel black.
 His name is Tourette's.*

*I have a kangaroo inside me.
 It makes me jump up and down.
 I have a kangaroo inside me
 and it makes me feel brown.
 His name is Tourette's.*

*I have a frog inside me.
 It makes me warty and mean.
 I have a frog inside me
 and it turns me green.
 His name is Tourette's.*

*I have an eel inside me
 and it makes me slither.
 I have an eel inside me
 and it makes me shiver.
 His name is Tourette's.*

*I have a wild horse inside me.
 It makes me feel like prancing.
 I have a wild horse inside me
 and it's always dancing.
 His name is Tourette's.*

*I have a tiger inside me
 and it makes me growl.
 I have a tiger inside me
 and when I get mad, I go "r-o-w-l!"
 His name is Tourette's.*

*I'm going to shoot those animals.
 I'm going to bring a banana.
 I'm going to shoot those animals.
 I'm going to wear a bandanna.*

*And then the puppy inside me
 will make me happy and play.
 And then the puppy inside me
 won't ever run away.
 His name is Justin.*

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