

Learning Problems and the Student with TS

by Susan Conners, M.Ed., Education Specialist, TSA, Inc.

As the Education Specialist for the Tourette Syndrome Association (TSA) and as an advocate for children with Tourette Syndrome (TS) for 18 years, I have had the opportunity to work with many children with TS and associated disorders. My own experience demonstrates that a very large majority of children with TS have difficulty functioning in school. These children very often have also been diagnosed with Obsessive Compulsive Disorder (OCD) and Attention Deficit Hyperactivity Disorder (ADHD). In addition, they may have significant learning disabilities, quite frequently in the area of Non Verbal Learning Disabilities, e.g. Central Auditory Processing Difficulties, Fine Motor, Visual Motor Impairment and Executive Dysfunction (see glossary). Given all of these disorders, it is not unlikely that life in the classroom will be very difficult for these children.

Red Flags

- Both parents and teachers must be alert to the signs of learning disabilities in children. The most obvious sign is poor academic performance which often includes difficulty in acquiring the basic skills of reading, writing, spelling and math.
- Parents must be aware of obvious signs of frustration and anxiety in their child who seems unable to cope with school. The child could appear to be trying very hard, but not achieving. Teachers misinter-

pret these poor grades as a lack of motivation and interest. In reality, this is the result and not the cause of the problem.

- The child is having difficulty sustaining attention, doesn't seem to be listening, is unable to get an assignment started or finished and is very disorganized. Given three things to do, the child seems only to remember one of the three. As children get older, they may study and study but not retain what they have learned. They have a difficult time taking notes, completing assignments and adequately expressing their thoughts in writing.
- The child exhibits very poor handwriting. Handwriting is sloppy and uneven and looks like it comes from a much younger child. No matter how hard he tries, he has great difficulty copying things correctly from the chalkboard, the textbook, the overhead.
- Any combination of these warning signs can be indicative of a learning disability. This in no way reflects on the innate intelligence of the child. Many of these children have average to above average intelligence, but continue to fail in school.

What is the Problem?

Parents should not simply accept an explanation from school personnel that the child is unmotivated and disinterested or that they are having

“emotional problems.” The true reason why these children are having difficulty in school may be because of a cognitive dysfunction which is not uncommon with children with TS. Some of the most common of these dysfunctions are the ones already mentioned: Fine Motor, Visual-Motor Impairment, Central Auditory Processing Difficulties and Executive Dysfunction. This, of course, does not preclude the child from having other learning disabilities. These disabilities are usually not directly related to the severity of the child's TS tics. Tics, in themselves, can be disruptive to the child's performance as can the mental effort it takes to attempt to suppress tics. This could interfere with reading, handwriting and attention. The other associated disorders of ADHD and OCD can also have a significant impact on attention, concentration and task completion. Yet, the child may still be dealing with significant learning disabilities. Parents are often unaware that these difficulties that their child is exhibiting are actually signs of a learning disability.

How Do We Assess the Problem?

The first step to take if any of these warning signs are present, is to obtain an accurate assessment. You must first address a letter (see sample) to the school principal or the director of special education for your child's school district. The letter should request a thorough psycho-educational evaluation for your child adminis-

tered by the school psychologist, an occupational therapist and possibly a speech therapist. This should cover all areas of possible disability including auditory processing, language processing, memory skills, executive function and fine motor, visual motor impairment. The school may also want to do a **Functional Behavioral Assessment**. Once this letter is written, in most states the school district has 30 days to comply with the request. In all states, this must be done in a “reasonable” amount of time.

It is advisable that the child be tested by an outside neuropsychologist. This can be an expensive process, but is sometimes covered by medical insurance. If this is not feasible and the findings of the school’s testing do not produce the results that you are seeking, you may then request that the school district pay for this outside testing.

Once the testing is complete, you will be invited to attend a meeting of the district CSE (Committee on Special Education) or the IEP Team (Individual Education Program) to discuss the results. As per IDEA (Individuals with Disabilities Education Act) of 1997, the parent is now an equal voting member of the CSE. It is always advisable to bring someone with you to this meeting; a representative from your local TSA chapter or other advocacy group is a suggestion.

What Help is Available?

There are many possible sources of help for your child. Depending on the results of the testing, your child may be classified by the Committee on Special Education for services and placement which should always be in the least restrictive environment. The current appropriate classification for a child with TS is “**Other Health Impaired (OHI)**.” The following placements are available to your child.

- **Regular Classroom Placement with Resource Room Help.** Resource Room is a special tutorial assignment where pupils work on specific problem areas with a special education teacher.
- **Consultant teacher model.** A special education teacher is assigned to your child for a combination of direct and indirect services. This teacher may meet regularly with your child in a “resource room” setting, be present in some of your child’s regular education classes where the most difficulty is being experienced, or may simply be a consultant to your child’s regular education teachers.
- **Self-Contained Classroom Placement.** A separate classroom with a much smaller number of students where a child can take most of his/her classes. Children are often mainstreamed into some regular classes from their self-contained class where appropriate. This placement is usually reserved for children with severe learning difficulties who are unable to cope in the regular classroom. Never allow the school district to place your child in a self-contained classroom simply because of the severity of his/her tics.

Regular Classroom Modifications

Regardless of your child’s placement, a modification plan should always be a part of the IEP. These modifications will be dependent on your child’s specific TS symptoms and learning disabilities. The following are some examples of possible modifications:

- Preferential seating
- Testing in a separate location with time limits waived or extended
- The use of a computer/word processor

- A frequent break out of the classroom to release tics
- Assignments broken into more manageable pieces
- The use of a daily assignment sheet verified by the teacher
- Mandatory in-service on TS for all teachers working with your child

These are just a few examples of classroom modifications which can be of great benefit to the child with TS and associated disorders. For a more complete list, see *Specific Classroom Strategies and Techniques for Students with TS* and *Helpful Techniques to Aid the Student with TS*. These brochures are available from TSA’s online *Catalog of Publications*, or by calling 718-224-2999.

Summary

Children with TS have been known to have a variety of school difficulties. It is difficult to be specific since every child with TS is different, has different tic symptoms and different associated disorders. These difficulties may be related to a single factor, but are more likely to be a combination of problems. These could include tic severity, medications, ADHD and OCD symptoms, executive dysfunction and specific learning disabilities.

The most important thing to remember is that parents must work together with the school to explore the impact of the tics and associated disorders on classroom performance and to explore the strong possibility of learning disabilities. Identifying the problem areas, exploring creative solutions to help reduce stress and feelings of failure is paramount. I strongly encourage you to take advantage of all the wonderful educational materials from TSA’s *Catalog of Publications* and website (<http://tsa-usa.org>) in order to educate yourself

and school personnel about this baffling disorder.

Many diseases kill children in this country and around the world every day. Tourette Syndrome is not a fatal disease, but children die slowly each day from TS. Their spirit is killed; their potential is killed; their self esteem is killed. TS is not responsible. Ignorance is. These children luckily do not appear disabled although it might be better if they did. They bear the outward appearance of a child with a behavior problem: a defiant child, a stubborn child, a bizarre child, an emotionally disturbed child, a spoiled child. They are disciplined for things they cannot control and receive low grades on things they cannot accomplish. They are teased and imitated by other students and yes, sometimes by teachers. Their spirit dies a slow and painful death. Only when the impact of this disorder on educational performance is understood by all concerned can the greatest amount of learning take place.

Glossary

1. Auditory Processing Deficit — The inability to process and assimilate information. When a child has a deficit in this area, he often does not seem to be listening to what is being said. He processes information much more slowly than the average person and does not process more than one or two things at a time.
2. Fine Motor Visual-Motor Impairment — A weakness in fine motor skills which makes handwriting very difficult. Handwriting will be very sloppy, uneven and will appear as if it came from a much younger child. A child with fine motor problems will experience hand cramping and will have difficulty even holding a pen or pencil properly. This impairment also makes it very difficult for a child to

copy things from a textbook, chalkboard or overhead correctly. They will reverse letters, write letters backward and spelling could be particularly problematic.

3. Executive Dysfunction — The inability to self-regulate, plan, sequence, prioritize and organize and be cognitively flexible. The child with executive dysfunction will be very disorganized and forgetful. They will experience great difficulty starting or finishing a task and will constantly move from one uncompleted task to another.

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Sample School Letter

Sample letter for parent to address to either the school principal or the coordinator of the Special Education Department.

Dear _____,

My child, _____, has recently been diagnosed with Tourette Syndrome by Dr. _____. Tourette Syndrome is a neurological spectrum disorder which is almost always accompanied by other neurological disorders. He/She has thus also been diagnosed with Attention Deficit Hyperactivity Disorder and Obsessive Compulsive Disorder. I have observed the impact that all of these disorders are having on his/her academic performance and social emotional well being. I have also learned from TS literature that a very large number of children with TS also exhibit learning disabilities especially in the area of non-verbal learning. These disabilities very often include central auditory processing difficulties and fine motor/visual motor impairment.

I am therefore requesting that my child be observed and tested by the school psychologist as the first step in seeking from the Committee on Special Education a classification of Other Health Impaired. Given the high percentage of children with TS who do have these accompanying disorders, I am also requesting both an occupational therapy and speech evaluation. I understand that once this written request has been received, these evaluations must be started within thirty school days.

I am including a letter of diagnosis from the treating physician which also discusses the urgent need for the completion of all of the above requested evaluations and educational pamphlets from the Tourette Syndrome Association to be shared with my child's teachers and the school psychologist. In the interim, I will be more than happy to meet with school personnel working with my child to discuss what behaviors he/she may be exhibiting in the classroom as a result of this diagnosis and what educators can do to assist.

Thank you for your prompt attention to this matter. I look forward to hearing from you soon and to working together with school personnel to provide an optimum learning environment for my child.

Sincerely,