

The IEP for Students with Tourette Syndrome: an Educator's Handbook

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

Introduction

The IEP creates an opportunity for teachers, parents, school administrators, related services personnel, and students (when appropriate) to work together to improve educational results for students with disabilities. The IEP is the cornerstone of a quality education for each child with a disability.

To create an effective IEP, parents, teachers, other school staff—and often the student—must come together to look closely at the student's unique needs. These individuals pool knowledge, experience and commitment to design an educational program that will help the student be involved in, and progress in, the general curriculum. The IEP guides the delivery of special education supports and services for the student with a disability. Without a doubt, writing—and implementing—an effective IEP requires teamwork.¹

Students with TS are very frequently classified by the IEP Team Special Education Services and are therefore entitled to an IEP. The appropriate classification for students with TS is under the category of *Other Health Impaired (OHI)*. Many times, the lack of information about TS available to school personnel becomes a stumbling block to establishing that this disorder is indeed impacting on the student's academic performance.

This document will be divided into three parts:

- 1) Validating that the student's TS is impacting on educational performance and that he/she is therefore eligible for special educational services under IDEA;
- 2) Educating yourself about TS;
- 3) Identifying what needs to be included in the IEP to insure the appropriate learning opportunity for the student with TS.

¹ Reprinted from OSEP (Office of Special Education Programs) *A Guide to the IEP*

PART 1

The Impact of TS on Educational Performance

Before a student qualifies for special education services under IDEA, it is required that he/she be evaluated.

This evaluation consists of a series of psycho-educational tests administered by either the school psychologist and/or a special education teacher. This testing, as we know, is not the sole determining factor in qualifying a child for services. According to IDEA, an evaluation must consist of all of the following:

- Special medical concerns addressed by the treating physician
- Interviews with parents and school staff
- Information from parents
- Specific tests which must include all areas related to the suspected disability

Many children with TS do not qualify for classification based on the results of psycho-educational testing alone. They may indeed have a learning disability, but in an area that may not have been assessed. More importantly, their disability will very likely be based on the impact of the symptomology of TS, ADHD, OCD and any other associated neurological disorders on classroom performance. **These are the questions that you need to ask yourself:**

- Has the treating physician been consulted to determine the nature of this student's symptoms?
- Have the parents been interviewed as to specific symptoms and problem areas that they are seeing at home?
- Has the IEP Team looked at a portfolio of the student's work?
- Has the student been administered tests in the following areas?
 - 1) Fine Motor/Visual Motor Impairment (Usually administered by an Occupational Therapist)
 - 2) Central Auditory Processing

- 3) Language Processing
- 4) Memory Skills
- 5) Executive Function

Extensive research and experience have shown that these are all common areas of learning disabilities sometimes associated with children with TS. They are often overlooked when the child is tested. If the school does not routinely test for these disabilities and/or does not have access to these specific tests, it may be necessary to have the child tested outside the school system preferably by a neuropsychologist.

The student's treating physician can actually write a "prescription" for these tests and state why. The Tourette Syndrome Association, Inc. can provide the school with a wealth of information verifying the overwhelming presence of these disabilities in children with TS.

If the child is having behavior problems at school, has a Functional Behavior Assessment (FBA) been done? An FBA may be necessary even if behavior problems are not present at this time.

Behavioral issues sometimes surface with students with TS. There are a multitude of reasons for this. First and foremost, we must look at the level of frustration that children with TS live with. They have movements that cannot be controlled, noises that they cannot stop which are creating social embarrassment, teasing by other children and yes, even discipline from teachers who do not understand the nature of their disorder. These movements and vocalizations also interfere with what they are trying to accomplish. If the child also has ADHD, impulsivity is a major issue which is often misinterpreted as bad behavior in the classroom. They are also very easily over stimulated by a noisy, chaotic environment such as they will encounter in the cafeteria, the school bus, crowded hallways between classes, to name a few. If OCD also enters the picture, these children will have a very difficult time transitioning from one activity to another and letting go of an issue, which may seem to be quite insignificant to us. The anxiety caused by a compulsion that cannot be acted on might also cause a behavior problem to occur.

Better that we modify the environment for these students and not place them in situations that we know their neurological system cannot handle. Better that we teach them how to make a "graceful exit" from a situation. That we can analyze the antecedent to the behavior issue, so that it can be prevented the next time. Thus, a Functional Behavior Assessment is imperative for children with TS and associated disorders.

A very important fact to remember is that the child with TS can be classified for special education services

even if he/she is not "Learning Disabled." Tourette Syndrome is a medical condition and therefore currently qualifies under the classification of "Other Health Impaired (OHI)." A learning disability does not have to be present for classification. Certainly all suggested tests should be administered to test for a learning disability, but one does not have to be present for special education services to be rendered.

Once the appropriate testing requested has been performed, it is time to look at all the ways in which the symptoms of TS and associated disorders interfere with education and performance. It is nearly impossible to list every TS symptom and how it interferes in school, but I will list some very specific examples which can be used to illustrate this point which can then correlate to the student in question.

Tic Symptoms

- An eye rolling or eye blinking tic could make it very difficult for a child to read or write.
- A finger tic could interfere with writing and make it difficult to even hold a pencil.
- A hand jerking tic could make writing, taking notes, etc. very difficult.
- A head shaking tic could cause headaches and make concentration impossible.
- Obvious vocal and motor tics cause great embarrassment in the classroom and create social isolation and stress both of which impact on performance.

OCD Symptoms

Symptoms of Obsessive Compulsive Disorder are often the most difficult to assess and understand. OCD is often the hidden part of TS. I call it "tics of the mind." Children don't talk about their OCD symptoms for fear of people thinking that they're crazy and you can't usually see OCD like you would notice the tics of TS. Here are some examples of how OCD can interfere with classroom performance.

- A student with an obsession to count words in every line that she reads was unable to keep up with note taking and all the writing required to complete assignments.
- A student with a germ obsession could concentrate only on when he would be able to wash his hands. He was washing his hands 70 to 80 times a day, thus missing much of his classes. The anxiety that this was causing was making it impossible for him to concentrate on his work. A student may be afraid to "breathe" germs if a teacher or aide gets too close.

- A student who needed to have a perfectly sharpened pencil was sharpening his pencil 20 times every class period.
- A student with a symmetry obsession who needed to constantly erase his written work was falling behind in all his assignments and was unable to complete tests on time.
- A young girl with OCD had a very difficult time transitioning from one activity to another and was always thought to be stubborn and uncooperative.

ADHD Symptoms

ADHD is probably the most misunderstood associated disorder of TS. Children with ADHD are often viewed as disruptive, lazy, irresponsible, immature, unmotivated and disinterested. They do not invoke the empathy from teachers that a child with a more obvious physical disability would. ADHD is rarely interpreted as the disability that it is. I often relate the story of a close friend's son who was recently critically injured in a car accident. He sustained a traumatic brain injury to the frontal lobe of his brain. This once organized, high functioning honor student and athlete suddenly was having difficulty with the simplest of tasks. His attention span was very short, he could not retrieve words that he always knew, he had become very impulsive and seemed to lack the ability to plan, organize, sequence or understand the consequences of his actions. ADHD results from deficits in the frontal lobe area of the brain. How easy it is now for me to understand the medical, neurological nature of this disorder. When his mother approached the CSE for services for him, no one batted an eyelash. He was provided with everything he needed and more. Kids with ADHD are not at all unlike this boy. The only difference is that his was a sustained injury and theirs was always there. The results are the same. I urge you to think of this story over and over again in the hopes that it will instill in you a better understanding of ADHD. Below are examples of how ADHD interferes with classroom performance:

- Children with ADHD have a very short attention span so concentrating for long periods of time is very difficult for them.
 - They find it very difficult initiating an assignment and staying on task. They rarely complete assignments on time.
 - They are innately very disorganized children who even when they complete assignments often lose them before they can be turned in. They lack executive function in the brain.
- They find it difficult to stay with any task for an extended period of time.
 - They often come to class with the wrong materials and/or without necessary classroom supplies.
 - They are easily distracted by external stimuli so they miss major parts of the lesson including the assignment. They constantly lose points for not turning things in that either they have done and lost or claim to know nothing about.
 - They find it impossible to break work down into more manageable parts and therefore long range assignments and projects are never completed.
 - They are hyperactive, fidgety and impulsive in the classroom and are constantly getting into trouble for talking out of turn, not raising their hand, being out of their seat.
 - They become very easily over-stimulated in chaotic, non-structured environments such as the school bus, the cafeteria, the playground and the hallways between classes.

Fine Motor Visual Impairment

Students with TS frequently also experience a disability in the area of fine motor visual motor impairment. In simple terms, this means that handwriting is very difficult for them. Their hands cramp very easily, they have great difficulty forming letters, staying on the line, making letters all the same size and keeping margins. The result is handwriting that is very messy and difficult to read. Children with this problem will also find it very challenging to copy things from an overhead, chalkboard or textbook to their paper. They will reverse letters and copy problems and assignments incorrectly. Spelling is especially problematic. The impact that this disability would have on a child's performance in school is easily understandable.

Summary of Part 1

A significant number of children with TS are diagnosed with one or more of the above mentioned associated disorders. Given the impact of all of these disorders on education, it's not difficult to comprehend why these children struggle in school and why they need special education services. It is critical that the child's treating physician and/or the outside neuropsychologist address a letter to the IEP Team indicating which of the above disorders are also a part of the child's diagnosis and how these disorders are interfering with school achievement.

PART 2

Educating Yourself

Below is a list of excellent brochures available through TSA, Inc. This information should be read well in advance of the testing process and the CSE meeting to determine the child's eligibility for services.

Brochures Available Through TSA, Inc.

Tourette Syndrome in the Classroom

Learning Problems and the Student with TS

Specific Classroom Strategies and Techniques for Students with TS

TS and the School Psychologist

Videos Available Through TSA, Inc.

A Regular Kid, That's Me

Teaching Children With TS: A Resource for Educators

TSA Educators' Curriculum in CD format

visit <http://tsa-usa.org>

PART 3

Writing The IEP

Contents of The IEP for a Student with TS

The current performance section of the IEP seems cut and dry, simply a report on how the child is performing in school. But, remember that "current performance" also includes how the child's disability affects his or her involvement and progress in the general curriculum. This is rarely done, because, for the most part, the impact of TS on performance is not understood. IDEA 2004 now states that the improvement of academic achievement as well as functional performance must be emphasized within a child's IEP. This is where the recommended TSA brochures and the letter from the treating physician will be needed. This is where specific tics and obsessions should be noted and how they impact on classroom performance. *It is also very important that the IEP be flexible because of the waxing and waning nature of the symptoms.* What is an interfering tic or compulsion today may not be the same in a month's time.

Annual Goals for students with TS can be difficult to write if the true nature of the disability is not always understood. The goal should never simply restate the disability. For example, a goal for a student with TS

ADHD/OCD and Executive Dysfunction should not read:

Goal: *The student will improve organizational skills.*

Objective: *Through the use of an assignment pad, the student will be responsible for preparing and completing assignments and test preparation materials by due date.*

Organization (Executive Dysfunction) is the child's disability. It's easy to say that he will improve organizational skills, but not possible without outside assistance. This goal for a child with all of these disorders is as silly and unreasonable as this one for a child with a serious vision impairment would be. It is also very important to note that IEP goals must be *measurable*. The parameters must be defined.

Goal: *Student will improve vision.* A more appropriate wording for this goal would be would be:

Goal: *Given teacher assistance the student will improve organizational skills.*

Specifically, each teacher will verify with initials each assignment recorded, and resource room teacher or assistant will meet with student the last 5 minutes of each school day to help organize materials needed to take home.

Objective: *Student will be responsible for preparing and completing all assignments and projects by due date 80% of the time.*

Here are some other examples of good IEP goals for students with TS. Each of these goals would then need to be qualified in measurable terms. (Time frame, accuracy, consistency, etc.)

- Given the use of a computer for all written work, the student will complete written assignments neatly.
- With teacher assistance, student will improve time management skills. (Define teacher assistance.)
- Student will improve self-advocacy skills by letting teachers and parents know when he is experiencing difficulty.
- With teacher assistance, student will break down long range assignments and projects into smaller more manageable parts. (Define teacher assistance.)

Special Education and Related Services

This part of the IEP again is critical. This is where all of the environmental adaptations, direct services, assistive technology, positive behavior supports, educational modifications and supplement aids and services should be listed. The following is a list of likely related services that a child with TS and associated disorders will need.

- Preferential seating (classroom and school bus)
- Frequent breaks to release tics

- A designated place to go if tics are very difficult
- Testing in a separate location
- Time limits extended or waived for tests or oral testing
- Modified assignments
- All homework assignments verified by teacher
- Class notes provided
- Use of graph paper to help line up math problems
- No penalty for spelling errors
- Leave each class 2 to 3 minutes early to avoid crowded hallways
- Leave last class 4 to 5 minutes early to organize materials with assistance
- All long range assignments/projects broken down with teacher assistance into smaller parts
- Extra set of textbooks at home
- Provide student with basic classroom supplies when forgotten rather than penalize
- Use of a computer for notes and all written tests and assignments
- Directions repeated and clarified
- Printing, keyboarding and scribing are acceptable for written work
- Mandatory in-service for all school personnel involved with this child at the beginning of year

Direct services most often include counseling, occupational and speech therapy. Each of these services can be very important to the child with TS for the reasons that we will state.

Occupational Therapy is especially necessary when the child in question has been diagnosed with Fine Motor Visual Motor Impairment and/or Sensory Integration Difficulties. The OT can work with the child to help improve fine motor skills, but more importantly to assist the student with alternatives to handwriting which will never be easy for him/her. A child with this problem needs to master computer skills which will be his life-line to success. Another very important role of the OT with children with TS is to assist with the management of sensory and stress issues.

Speech Therapy is very beneficial for the child with Central Auditory Processing Difficulties.

Counseling Services can be critical. The majority of children with TS experience low self-esteem due to the bizarre nature of their symptoms and their lack of academic success. They are teased, made fun of, imitated and often punished for symptoms they cannot control. Counseling and social skills training can be crucial to their well-being. Counselors will play a very

important role in the lives of these children helping them to live with, accept and cope not only with their symptoms, but also with everyone's reaction to their symptoms.

Special Factors to Consider

If the student's *behavior* interferes with his or her learning or the learning of others, the IEP team will consider strategies and supports to address the child's behavior. This is not uncommon with children with TS and associated disorders. This is where a Functional Behavioral Assessment is extremely important. TSA, Inc. now has a publication available on the TSA website entitled *A Workbook for Conducting a Functional Behavioral Assessment and Writing a Positive Behavior Intervention Plan for a Student with Tourette Syndrome* which is designed to lead school personnel through the process of conducting an FBA for a child with neurological disorders such as TS, ADHD, OCD, etc. Very frequently, the behavior of children with TS is simply a manifestation of the neurological disorder and/or the way in which the school system deals with it.

Placement

Decisions on placement must be made according to IDEA's least restrictive environment requirements. The majority of children with TS are educated in a regular classroom with special education services and/or environmental modifications. Just as any other child with special needs, children with TS may require a more restrictive environment depending on the severity of their learning disabilities and ADHD. A very important point to remember is that **no student with TS should be removed from a regular classroom environment simply because of the severity of their tics.**

After The IEP is Written

When the IEP has been written, parents must receive a copy at no cost to themselves. The IDEA also stresses that everyone who will be involved in implementing the IEP must have access to the document. This includes the child's:

1. regular education teacher(s);
2. special education teacher(s);
3. related service provider(s) (for example, speech therapist);
4. any other service provider (such as a paraprofessional) who will be responsible for a part of the child's education.

Each of these individuals needs to know what his or her specific responsibilities are for carrying out the child's IEP. This includes the specific accommodations, modifications, and supports that the child must receive, according to the IEP.

Other Important Things to Remember

It is very important to make sure that one individual within the school is in charge of coordinating and monitoring the services the student receives. In addition to special education, the student may be receiving any number of related services. Many people may be involved in delivering those services. Having a person in charge of overseeing that services are being delivered as planned can help ensure that the IEP is being carried out appropriately. Usually this person is the child's special education teacher, but it does not have to be.

Summary of Part 3

Much of the information provided in this brochure may seem overwhelming to teachers. I would like to summarize by reiterating the most important points to remember when working with a student with TS.

1. The IEP document is the cornerstone of the child's educational program. It is vital that it be a **cooperative** effort between the parent, special education or regular classroom teacher, and other school personnel.
2. Teachers as well as parents should always make every effort to approach the process with an open mind. Conflicts that occur between school and parents are often due to the lack of good information that the educators have had access to. I taught for 15 years in a public school before I had ever heard the word *Tourette Syndrome*. At the end of my 15th year, I was diagnosed with TS. There is still no requirement for

persons enrolled in teacher training programs to learn about these disorders. IDEA 2004 enhances the preparation, professional development and support for special educators and other school personnel working with students with disabilities to ensure that these educators possess the necessary skills and knowledge to provide instruction to students. I urge you to avail yourself of the wonderful written materials, videos and curriculums that the Tourette Syndrome Association has at your disposal and use them to educate yourself and others about this misunderstood disorder.

3. Always remember the story of my friend's son with the traumatic brain injury and hopefully that will give you a better understanding of the neurological basis for this disorder.

Suggested TSA, inc. Materials to Provide for Educators

Brochures

Tourette Syndrome in the Classroom

Learning Problems and the Student with TS

Specific Classroom Strategies and Techniques for Students with TS

TS and the School Psychologist

Videos

A Regular Kid, That's Me

Teaching Children with TS: A Resource for Educators

TSA Educator's Curriculum (CD version available)

A Teacher Looks at Tourette Syndrome

These materials are available by calling TSA, Inc.
or online at the TSA website.

Copyright © 2003 revised 2005

Permission to reprint this publication in any form must be obtained from the national
TOURETTE SYNDROME ASSOCIATION, INC.

THE AUTHOR

Susan Conners, M.Ed., is national TSA's Education Specialist. She taught French for thirty-three years. Ms. Conners has TS, is the President of TSA of Western New York and has served on the national TSA Board of Directors as the First Vice Chair. She was for many years, the Chair of the TSA Education Committee. She was a lead author of the TSA Education Curriculum and has written several useful articles on educational accommodations for students with Tourette Syndrome. Ms. Conners is in great demand as a speaker, and travels across the United States and around the world presenting information on TS to educators, families, clinicians and other interested audiences. Susan has been a multiple presenter at the National Association of School Psychologists Annual Convention in Toronto and has spoken at the U.S. Department of Education and at the national conference of Children/Adults w/Attention Deficit-Hyperactivity Disorder (CHADD). TSA continues to mount her exciting presentations on "Tourette Syndrome in the Classroom & School" when invited by schools, TSA chapters or committed funding sources. A video of her informative, yet poignant and humorous training presentations has been produced by TSA for sale and distribution. The video will be an effective adjunct to training programs and IEP planning sessions.

ADDITIONAL TSA RESOURCES

Videos & Vignettes

AV-9 After the Diagnosis . . . The Next Steps

Produced expressly for individuals and families who have received a new diagnosis of TS. This video was developed to help clarify what TS is, to offer encouragement, and to dispel misperceptions about having TS. Features several families in excerpts from the Family Life With TS A Six-Part Series who recount their own experiences as well as comments from medical experts. Narrated by Academy Award Winner Richard Dreyfuss. 35 min.

AV-10a Clinical Counseling: Towards an Understanding of Tourette Syndrome

Targeted to counselors, social workers, educators, psychologists and families, this video features expert physicians, allied professionals and several families summarizing key issues that can arise when counseling families with TS. Includes valuable insights from the vantage point of those who have TS and those who seek to help them. 15 min.

AV-11 Family Life With Tourette Syndrome . . . Personal Stories . . . A Six-Part Series

Adults, teenagers, children, and their families . . . all affected by Tourette Syndrome describe lives filled with triumphs and setbacks . . . struggle and growth. Informative and inspirational, these stories present universal issues and resonate with a sense of hope, possibility, and love. 58 min.

AV-12 A Teacher Looks at Tourette Syndrome

Susan Conners, M.A., TSA Education Specialist is very much in world-wide demand for her helpful and inspiring in-service training programs. Filmed at an all day TSA Educators Conference, she introduces teachers to what it is like to have TS in the classroom. She gives her techniques to help students learn best, and helps teachers be most effective and informed. Aspects of ADHD, OCD and other related conditions are covered. Susan's years of teaching experience, personal insight and abundant humor make for compelling viewing. You get both full hour and half hour versions designed to be shown at teacher training sessions, chapter meetings, educational and clinical conferences. Features a personal introduction by actor-writer Polly Draper. 90 min.

An up-to-date Catalog of Publications
and Videos can be obtained by contacting:



Tourette Syndrome Association, Inc.
42-40 Bell Boulevard ■ Suite 205
Bayside, New York 11361-2820
Tel 718-224-2999 ■ Fax 718-279-9596
ts@tsa-usa.org ■ <http://tsa-usa.org>