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# Educator's Guide for **Developing Plans for Students** with Tourette Syndrome

Pamela Malley, MA, CCC-SLP, and Kathy Giordano, Tourette Association Education Advisory Board

# **Education Plan Process**

Tourette Syndrome (TS) can be a challenging diagnosis and have a major impact on the education process. Using effective supports is critical in helping students with TS reach their fullest potential. However, since symptoms may be different for each individual student, as well as fluctuate and cycle over time, developing an appropriate IEP or 504 Plan requires creativity and flexibility.

The purpose of this document is to provide a sampling of suggestions to get you started when developing an education plan for your student. This list is not all-inclusive; some of these suggestions may work for one student but not for others; they may work for a student and suddenly no longer be effective. Because of the complex and often changing nature of symptoms, there is no "one size fits all" program, strategy, or technique that will be successful for all students with TS at all times. Using the suggestions in this document as a guide for developing unique and creative strategies/techniques is the most beneficial approach for the challenges students with TS face on a daily basis.

This document may be used two ways. First, this can simply be used as a reference guide for strategies that might be explored when helping students with TS. It might just be a "go-to guide" for you to keep on your reference shelf and applied to many students. However, this document was also developed with a second option in mind: to be used as a workbook to be completed for an individual student. For this latter option, you may want to make a copy of this document for use with each student with TS. The copy could be circulated among all of the student's teachers for input prior to meetings, even those teachers who may be unable to attend the meeting. Each teacher could check off appropriate strategies and/or

write comments in the appropriate sections, so relevant input from everyone working with the student can be considered, thereby developing a more comprehensive education plan.

#### Before developing an effective support plan, there are a few important factors to keep in mind:

The student is an important part of the team and should be included in as much of the planning as possible. If the supports do not make sense or are not considered helpful to the student, then he or she probably will not use them and the plan will not be effective. Additionally, students are more likely to respect a plan which they helped to develop.

Communication is key for the following reasons:

- · Communication with family members is important in developing a collaborative relationship that is essential to the success of students with TS.
- · Members of the team need to communicate about the effectiveness of the plan and modify it when necessary. Any factors which might impact the student should be shared among team members. For example, medication changes may result in new or different symptoms and the team should be made aware when these changes occur.
- The team should monitor strategies to ensure they do not increase anxiety or other symptoms.

Creativity is essential in identifying strategies which might be most helpful to your student. Each student is unique and may benefit from a strategy you may never have tried, or thought to try, with this or other students. Therefore, it is important to have a discussion with the student regarding what he or she believes might be helpful. Pay close attention to his or her thoughts on why strategies may or may not help because the student's insights can be instrumental when tweaking or developing strategies.

The following strategies and suggestions are organized according to diagnoses or symptoms to give you a starting point. It's important to remember that there can be crossover of symptoms between diagnoses, so suggestions in one category might be helpful for your student even if he or she does not have that particular diagnosis. Again, be creative, and if it works, use it! If it stops working, don't be discouraged. TS can be a baffling

disorder and symptoms can change over time; therefore, IEP and 504 plans also tend to change over time and require ongoing revision.

#### 504 Plan or IEP: Which is best for a student with TS?

Because every child living with this diagnosis has a unique profile of symptoms, strategies and supports must be tailored to meet his or her specific needs. It is important to anticipate the different levels of need based on his or her symptoms.

Some children with TS have only mild tics which have no impact on their learning. These children may never require any supports in school. However, these same children may have mild tics but are impacted significantly by some of the related difficulties. Also, it's not unusual for a student with TS to start off with mild symptoms but then have a change or increase in symptoms in later years. In this case, the student may begin to require additional supports over time in order to continue to be successful in the classroom.

Other children may have severe tics and coexisting conditions, such as Attention Deficit Hyperactivity Disorder (ADHD) and Obsessive Compulsive Disorder (OCD), from an early age. These children may struggle with all aspects of school, from academics to making friends, and require extensive accommodations and modifications in order to succeed. When this is the case, a decision must be made to determine if the child would benefit from accommodations & modifications, in which case a 504 plan may be sufficient. However, it's not unusual for a student to require special education supports from an occupational therapist, speech pathologist, counselor, paraprofessional/aide, resource room and/or consultant teacher. When these services are necessary, an Individualized Education Plan (IEP) may be more appropriate.

#### Things to consider before the meeting

• When discussing "behavioral" aspects of a student's profile, using the word "symptom(s)" is preferred to the word "behavior(s)." The word "behavior" may give rise to negative connotations which imply that the student's symptoms are intentional and purposeful. The word "symptom" more accurately suggests that the student has a neurological disorder which is manifesting in a certain manner.

- Use of the word "symptoms" to refer to the features of TS may also assist in modifying the environment from one of negative consequences, to a more positive/proactive approach which is more effective in managing symptoms in a classroom environment.
- Tourette Syndrome is a disorder of disinhibition and suggestibility. Given that symptoms are often "suggestible", reminding a student to suppress tics or symptoms is often counterproductive. By reminding the student to NOT do something, one might actually cause the symptom to occur MORE frequently. The student then gets in trouble because the perception is that the student's behavior is purposely oppositional and defiant. Reminding a student to stop doing something also brings unwanted attention to the student, which may then raise anxiety, and result in a more dramatic display of symptoms. This can apply to all symptoms associated with TS, even those which are not "typical tics."
- · Students with TS may have difficulty inhibiting emotions, thoughts, vocalizations and inappropriate actions. These may also be worsened with repeated reminders to stop doing something.
- · Educating staff, teachers, professionals, peers, and the student about Tourette Syndrome is a critical component in understanding and accepting the student. This is also necessary in order to develop an appropriate education plan designed to meet his or her individual needs. The Tourette Association has developed an Educator's In-service, available at http://www.tourette.org/EducationInservice/Online.html, which can be given by a professional from your school.
- The Tourette Association also offers a free DVD titled, TS in the Classroom, School, and Community. Contact us if you'd like a copy. This includes video of a presentation to educators by a member of the Tourette Association Education Advisory Board and could be shown at your school if a member of your staff is not comfortable giving the aforementioned in-service.
- Educating the student about his/her symptoms is important for self-esteem, the ability to explain them to others, and self-advocacy. Therefore, including this in the education plan can often be helpful.
- The impact symptoms have on a student does not necessarily correlate with severity level; just because a student has mild symptoms, one cannot

- assume that the student is not embarrassed or negatively impacted by them.
- It typically is not helpful to downplay the impact symptoms have on the student. Identifying and developing strategies to help the student manage symptoms which he or she perceives to have a social or academic impact is equally as important as managing those symptoms which are perceived to have a bigger impact by the classroom teacher(s).
- Inventory of symptoms: Keeping an ongoing list on the computer and updating it as needed may help to identify cycles, patterns, and to determine what supports may or may not be effective. The following is a sample chart one might use to track symptoms:

Description of Symptoms Easier Situations Difficult Situations
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#### **Tourette Syndrome**

Consider accommodations for all written work when
writing is difficult (see sections on Strategies
for Writing Problems and Written Language Disorders).
Consider additional adult support during unstructured
time.
Provide positive and proactive supports specific to the
student's social and/or academic skills
deficits.
Be creative; this list is not all-inclusive and your team
may identify a new or unconventional
strategy that is effective for your particular student.
Develop a graph or chart, with the student, so the
student can visually monitor the effectiveness
of a specific strategy.
Other:
[a .
Comments:
Possible Strategies for Tics:
•
Planned ignoring is the preferred strategy for tics; do
not call attention to them or ask the student
to stop.
Allow student to leave class early to avoid crowded
hallways.
Set up a signal for student to use when there is a need
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symptoms to assist the student in managing them in a more socially acceptable manner. For example, if student has spitting tic, encourage him or her to spit into a tissue. Or, if student is touching others inappropriately, encourage him or her to wrap arms around books when walking through hallways. \_\_\_ Arrange a Tourette Association educational in-service for the entire school. \_\_\_ Invite a young presenter from the Tourette Association Youth Ambassador Program to talk to your students about what it is like to live with TS. More information can be found at http://www.tourette.org/aPeople/Youth/YouthAm.htm 2 \_\_ Other: Comments:

#### **Attention Deficit Hyperactivity Disorder and Executive Function Disorders**

Students with TS frequently have the related disorders of ADD, ADHD and Executive Function Disorders. These may be as or more disruptive to the educational process than issues related to tics.

Possible Strategies for ADHD/Executive Function Disorders: \_\_\_ Maintain structure in the classroom so the student knows expectations, yet be flexible to allow for creative supports. For example, the student might be allowed to stand while working or take periodic breaks to move around the room between assignments. Limit unstructured time; keep a folder of fun activities on hand so student always has something to do or have a list of appropriate activities the student can choose from during down time. \_\_ Use visual supports: \_\_\_ Provide an example of the expected outcome, such as a finished project or example of a math solution, to demonstrate what the student is trying to accomplish. Provide a photograph of the expectation (e.g., what a clean locker should look like or what the student looks like when he or she is dressed and ready for school).

\_\_\_ Teach note-taking skills appropriate for the student's

writing, auditory comprehension,
attention, and language abilities.
Teach use of highlighter to help the student identify
important information.
Teach use of headings, topic sentence, etc. to identify
key points.
Teach use of lists to keep track of materials,
assignments, etc.
Establish a code word or hand gesture to cue the
student to refocus or get back on task.
Allow student to move frequently throughout the day;
send student to water fountain, on
errands, etc.
Allow student to stand at desk, sit on large exercise
ball, move, wiggle, chew gum, etc. while
working. This can improve focus and concentration;
whereas forcing a student to "sit still" or
"look at you" may actually reduce focus because attention
is shifted from school work to
maintaining a behavior that is difficult or unnatural for the
student.
Consider quality vs. quantity, when possible:
Shorten assignments: primary goal is to master the
material so assign enough material
for student to learn a skill but do not over-drill.
Give one paper or assignment at a time. This
accommodation can be difficult as student gets
older; a consultant teacher may be more helpful at higher
grades to help manage assignments
and teach the student to prioritize.
Provide a second set of textbooks to be kept at home.
Keep an extra supply of materials (pens, pencils,
paper, etc.) for the student to borrow if
needed; make arrangements for the parent to replenish
the supply, if necessary.
Teach time management skills:
Teach the "sweep of time": use erasable marker to
color a clock face and mark the
amount of time student has to complete task.*
Use a visual timer or set an alarm so the student knows
how much time is allowed to
complete a task.*
Set reasonable goals: "In 15 minutes, you should have
8 math problems finished."*
Designate the amount of time for each task on a "To
Do" list.*
*These may increase anxiety for a student who also has
OCD; modify or omit if these are

not helpful.
Schedule:
Teach student to make and use schedules.
Post schedule in prominent places, such as on a
notebook and inside locker door
or on a desk, for easy reference.
Divide long-term assignments into smaller segments
with separate due dates (chunking);
schedule check–ins with the teacher at each due date to
monitor progress.
Develop reminder systems:
Leave homework with a specified adult to distribute to
appropriate teachers or to oversee
the student turning in assignments to appropriate
teachers.
Have the student or designated adult call or email
assignments home at end of each class
or end of day.
Teach student to make and use "To Do" or check lists.
Utilize technology for reminders, such as smart phones,
Pads or electronic calendars.
Teach student to prioritize tasks
Assign a "homework buddy" for student to call if
questions about assignments or due dates
come up at home.
Organization: Develop a system that works for this
student.
Keep separate folders for "To be Completed" and
Completed" homework.
Color code books and notebooks according to subject,
then use corresponding color on
schedule and "To Do" lists. For example, all math materials
and assignments are coded
with yellow covers, highlighters, etc.
Assist with organizing locker or desk on routine basis.
Be specific about who will help the
student with this and exactly when/how often it will occur.
Assign a consultant or resource room teacher to the
student in order to help the student
manage current workload while teaching life-long
strategies. List specific strategies in
the student's education plan.
Other:
Comments:

Obsessive Compulsive Disorder or Obsessive Compulsive **Behaviors** 

OCD or OCB are related disorders which may also occur in students with TS. Compulsive symptoms may be easily recognized, but some students with TS are impacted by interfering obsessive thoughts that are more difficult to recognize. These students may appear to be inattentive or daydreaming, but may actually be struggling with obsessive thoughts that interrupt the ability to focus.

Possible Strategies for OCD/OCB:
Because obsessions and compulsions will be unique to each student, it is especially important to brainstorm effective strategies which may work for each student's symptoms. Below are examples to help you identify some possibilities:
If a student erases frequently and strives for perfection in writing, allow him or her to use
a computer, speak answers into a tape recorder, or have someone transcribe responses.  If student has a germ obsession, keep antibacterial
wipes or gel readily available.  If student needs sharp pencils, keep several sharpened.
pencils available or encourage use of a mechanical pencil.
If student cannot initiate a task because he or she obsesses about where to begin, mapping may be helpful.
If student becomes overwhelmed by number of different tasks, give one assignment at a time
and put others in a "To-do-later" folder.  Identify a code word or signal to indicate need for break or to inform teacher of obsessions or compulsions.
Test in separate location so student does not feel it necessary to rush or keep up with other students.
Provide bathroom passes for day; either unlimited use or a set number, depending on what works best for student.
Avoid physical and verbal triggers which escalate OCD symptoms.
Post class schedule in clear location if student needs to know what will happen next.
If a student becomes 'stuck', attempt to distract him or her to redirect focus to a more
desirable topic. Changing the environment or engaging the student in physical activity can also

help the student to move past obsessions or compulsions.
Signal the student several times before a transition (ex.
"We have 5 minutes until we go in from
recess.", "We have 3 minutes until we go in from recess.",
"We have 1 minute until we go in from
recess.")
Assign a trusted adult to aid the student when needed.
Assign a back-up for the trusted adult in case the
primary adult becomes unavailable.
Use of Cognitive Behavior Therapy in collaboration
with outside professionals can sometimes
be of assistance; this treatment would be developed and
overseen by that professional.
Other:
Comments:

#### **Learning Disabilities**

Students with TS can also have learning disabilities. A thorough evaluation by a qualified diagnostician to determine the nature and severity of the learning disability and how it negatively impacts the student with TS is critical so that appropriate interventions can be provided. Identification of the student's learning strengths is equally valuable, as the best strategies often utilize the student's strengths to overcome difficulties. Strategies will vary depending on nature and severity of the learning disability; many of the strategies listed throughout this document can be helpful for these students. In addition, the student may also benefit from speech pathology services if the underlying causes of learning difficulties are due to language and/or cognitive deficits.

#### **Writing Problems**

Students with TS may also demonstrate difficulties with handwriting for a multitude of reasons. For some, tics of the hand or arm may interfere with the physical ability to write. For others, they may have difficulty forming letters or maintaining legible writing. These students might have neat handwriting at the beginning of the day or at the beginning of an assignment, but fatigue quickly and cannot maintain legibility. They then lose points for "sloppy work" or cannot read their notes when studying at home. Other students struggle with writing because they cannot organize their thoughts to write them on paper. Evaluation by an occupational therapist and/or assistive

technologist is recommended in cases where the student is having physical difficulties with writing; evaluation by a speech pathologist is recommended in cases where the student cannot organize thoughts to express themselves coherently in writing (see Written Language Disorders, below). These therapists will develop a treatment plan based on evaluation results and can also share strategies to compensate for these problems until progress is noted with treatment. Students with ongoing writing difficulties may benefit from assistive technology, so it is also important to be familiar with new technology which might be beneficial.

#### **Possible Strategies for Writing Problems:**

It is preferable that evaluations by an Occupational
Therapist, Speech Pathologist and/or Assistive
Technologist be conducted before choosing strategies.
Teach keyboarding early if it appears that handwriting
difficulties will be ongoing.
Use of computer at home and in class to compensate
for handwriting.
Use a scribe to take notes.
Provide a copy of class notes and study guides.
Allow the student to tape record lectures, to do lists, or
anything that other students need to
write down.
Make a copy of assignments or problems for the
student rather than require the student to
copy them.
Encourage the student to use graph paper in math to
ensure that problems are copied and
aligned correctly.
Shorten or reduce written assignments.
Teach the student to use an index card or ruler to help
keep track of place when reading
or copying.
Accept oral reports or responses.
Accept homework responses typed on the computer or
transcribed by an adult.
Other:

#### Comments:

Written Language Disorders:

As previously stated, some students with TS have difficulties getting thoughts from the brain onto paper or into a computer. This can be due to word finding problems, deficits with thought organization, executive function or attention issues, or other language based

problems. In these cases, evaluations by a speechlanguage pathologist or other professional are recommended to identify exactly what is the underlying cause of the writing deficit and determine a treatment plan.

Comments:

Sensory Integration/Processing Disorder Some students with TS may demonstrate differences in the ways sensory input is processed. When Sensory Integration or Processing Disorder is evident, evaluation by an Occupational Therapist trained in these disorders is necessary. The OT will prescribe an individualized "Sensory Diet" or plan based on the evaluation results. The OT will educate teachers and other professionals on how to effectively implement the plan so the student's needs are met throughout the day. Communication between the entire team and family is critical to ensure that the plan is being followed correctly and is effective across environments. The Tourette Association offers a video about these OT services which can be viewed at http://www.tourette.org/ZTSOT/content.html.

Possible Strategies for Sensory Integration Disorder: Again, it is preferable that an OT makes recommendations for strategies based on evaluation results. \_\_ Use of a headset to reduce auditory input and distractibility (with or without music). \_\_\_ Allow the student to chew gum or suck on hard candy/lollipops. \_\_ Use of a weighted vest or blanket. Use of an exercise ball or bean bag intermittently during the day or instead of a chair. \_\_\_ Use of brushing, deep pressure, massage, drumming, or other tactile stimulation. \_\_\_ Allow the student to leave class early to avoid overcrowded and noisy halls. \_\_\_ Use of movement, such as walking, sitting in a rocking chair, swinging, etc. \_ Giving the student work to expend energy, such as sharpening pencils, moving desks or chairs, or carrying books. \_\_\_ Allow student to spend time in a sensory room at scheduled intervals or whenever necessary. \_\_ Other:

Comments:

Pragmatic Language Disorder/Social Skills Impairment Some students with TS, regardless of intellectual abilities, struggle with social skills deficits. These can be related to impulsivity, executive function deficits, or pragmatic language disorders. These students often benefit from social skills training, which can be taught by the counselor or speech pathologist after careful evaluation is completed. This evaluation needs to be conducted through observation of the student's social skills in a variety of naturalistic settings (structured and unstructured), parent and teacher interviews, and direct interaction with the student. Treatment involves teaching skills and strategies first in small groups and then in more naturalistic settings such as the classroom, playground or lunchroom. Skills are learned through a variety of activities such as role-play, social stories, scripts, and problemsolving activities. Once the student is successful in using skills in small groups, it is critical that the teachers and family help the student use them in other environments so the student's success generalizes to outside situations and the skills become more natural for him or her.

Strategies which might be taught by counselor or Speech and Language Pathologists include:

\_\_\_ Teach student to "Hit your pause button" or "Rewind and try again."

\_\_\_ Teach skills for requesting turns, items, or information.

\_\_ Teach scripts for various situations through social stories.

\_\_ Teach skills to start and maintain a conversation.

\_\_ Teach rules for appropriate body space, eye contact, and physical contact.

\_\_ Teach time and place rules.

\_\_ Teach anger management strategies.

\_\_ Teach strategies to self-regulate behavior.

\_\_ Other:

Possible Strategies for Social Skills:

#### Managing "Behavior"

Comments:

Some students with TS struggle with behavior issues for a variety of reasons. Developing a hypothesis regarding why specific and interfering behaviors occur is essential in developing a positive and proactive behavior plan. The Tourette Association has written a Workbook for

Conducting a Functional Behavioral Assessment and Writing a Positive Behavior Intervention Plan for a Student with Tourette Syndrome, available on this disk as well as at the The Tourette Association store (http://store.tsausa.org/e126.html). This guide clearly outlines best practices for assessing and managing behaviors/symptoms in students with TS.

When developing a behavior plan, remember that behavior is communication. When "behaviors" occur, they frequently provide clues regarding an underlying skills deficit which is actually causing the behavior to occur. If you can identify the needed skill and teach it, the behavior will often extinguish. Teaching these skills is often much more effective than using consequences or punishments because the student is learning to do things differently and in a more successful or meaningful manner. Teaching skills gives the student the tools they need to do things differently and can have life-long and positive results. Extinguishing behaviors through consequences or punishments may not have lasting effects because the student is not learning the strategies necessary to manage symptoms of this complex disorder. In fact, using consequences may often increase behaviors due to the suggestibility of TS (described above), the frustration of being punished for symptoms and the resulting anxiety.

#### Recommendations for Managing "Behavior":

- Remain calm, both physically & verbally.
- Praise the student often for appropriate behaviors: encouraging positive behavior is often more productive than reprimanding symptoms or behaviors.
- Ignore symptoms/behaviors when possible.
- · Incorporate transitions: provide time to shift gears between classes, tasks, difficult times of day, etc.
- · Avoid negative motivators, such as debates, sarcasm, put downs, or power struggles.
- Choose your battles carefully!
- · Avoid the word "no" or remind student that it is not "no" forever, it is just "no" for now.
- · Understand motivators; carefully examine why rewards sometimes 'work'
- · Avoid embarrassing the student.
- Include the student in problem-solving strategies.
- · Give the student the words he or she could use to express a message more appropriately ("Next time, it might sound nicer if you say, '....'".)

- · Try to identify why the student is struggling: what about the situation is making this so difficult or overwhelming for the student? Ask the student how you can help; provide a written list of strategies if student cannot provide suggestions
- Modify one element of the situation or task at a time until you understand what is negatively affecting the student.
- · Demonstrate willingness to hear and understand the student's perspective; their perception is their reality and this insight often reveals valuable information about why they are struggling.
- · Show respect: let the student know you are on his or her side.
- · Put yourself in their shoes: recognize how difficult and exhausting this must be for them.
- · Remember that invisible symptoms (obsessions, compulsions, distractibility, inattention, etc.) can be more disruptive than tics.
- · Recognize that you WILL make mistakes and it is ok to discuss them with the student; it's important that they know you are attempting to understand and that you model appropriate behavior when you are wrong.
- · Do NOT take behaviors personally.
- · Resist generalizing because every student is different. Comparing two students with TS may not be helpful because although symptoms may appear similar, there may be different underlying causes.
- Symptoms vary and change over time, so your plan needs to adjust according to your student's needs.
- · Avoid assumptions.
- Remember the only thing consistent about TS is the inconsistency.

Comments:

### A concluding thought...

While the overall goal is for the student to be as independent as possible in utilizing strategies, support is essential to a student's success as he or she works toward independence. Do not assume that supports can be removed as soon as success and independence are observed. Gradual weaning off of supports and continued monitoring of progress are critical in ensuring continued success and independence. If supports are removed and a student starts to regress, put them back in place immediately to avoid or reduce negative consequences.

## **Related Resources**

- Classroom Behavior Management Strategies for Children with Tourette Syndrome
- Classroom Strategies and Techniques for Students with Tourette Syndrome
- Education In-service Understanding TS and its Effects on Learning
- Red Flags: Identifying Common Education Difficulties with TS
- Resources for the Classroom