

NAVIGATING THE SYSTEM

**A MINI GUIDE FOR SMOOTH SAILING
WHEN ACCESSING EDUCATIONAL SERVICES
FOR THE T.S. CHILD**



Helping Children and Changing Lives

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1) To start the school year positively, communication is essential.

- Provide concise information at the beginning of every school year for every teacher your child has contact with, including cafeteria personnel, coaches, and bus drivers. Info should be available prior to the first day of school.
- Recommendations for an effective packet include:
A colorful folder: a Q & A brochure from the National TSA office, a fact sheet from TSA Texas, and a one page or less synopsis of your child and his symptoms entitled “All About <Your Child’s Name>.” Avoid information overload.

(see enclosure #1 – “All About...”

- Make early contact with all teachers prior to start of school through email or notes to introduce yourself and offer support.
- Arrange an informal meeting with all teachers to reinforce your child’s needs as early as possible in the school year, preferably before school starts. Bring snacks. Usually meeting is scheduled before or after school.
- Make teacher care packages:
Provide a container filled with pencils, pens, Kleenex, stickers, paper, glue, candy, etc. for each of your child’s teachers. Your child will often arrive at class without supplies, due to intrinsic disorganization.

2. Assume the school knows little.

- **You** must be the expert and know specifically what your child needs and why.

3. Your child must have an educational need to receive services and/or a documented disability that impacts on functioning.

- Low or failing grades are not necessary to determine need.

4. Access appropriate services through Special Education (Other Health Impairment) or Regular Education (Section 504). Either designation is acceptable; the key is acknowledgment of appropriate educational intervention in writing.

- **Never** allow the district to access services for a T.S. child with the label E.D. (emotionally disturbed).
- OHI is a medical consideration and the form to receive this classification must be signed by an M.D.
- The OHI form is an important tool. It can serve as a prescription pad for services your child needs.

- Remember to discuss your child's needs with the M.D. so he will include them on the form. It becomes a legal document.

(See enclosure #2)

5. The purpose of accessing Special Education (Other Health Impaired) services is to design an Individual Education Plan (IEP) that specifically meets the needs of your child or to access Accommodations under Section 504 that specifically meet your child's needs.

The ARD (Admission, Review, Dismissal) process is the vehicle necessary to institute and implement an IEP, BIP, and to access related services.

- It is comprised of a multi-disciplined committee that includes (nominally) a teacher from regular and special education, a representative from the school district other than the child's teacher (usually an administrator), the child's parent(s) or guardian(s), and the child, when appropriate.
- May include any other individuals or professionals deemed appropriate by either the parents or the school district.
- An ARD may be held at the request of either the parents or the school district and as often as necessary.
- Ample notice must be given to the parents prior to the ARD date.
- The school district must not take undue time to comply with a parent's request for ARD.
- A parent can disagree with the consensus of the ARD committee. The committee then recesses for ten school days and works to reconcile the differences.
- Be sure to include ongoing evaluation dates for strategies agreed upon during the ARD meeting, ideally every six to eight weeks. These should be staffing / conferences, not necessarily ARD meetings.
- Be sure the minutes of the meeting are read and are correct and that you understand the documents before you sign a statement of agreement.

6. Designing an appropriate IEP (Special Education) should include the following elements:

- A. Assessment

It is critical that current data on levels of academic ability and performance be available for consideration since there is a high incidence of learning differences and giftedness among TS children.

Notes on educational testing by the school district:

- You must be assured the test administrator has a demonstrated expertise with special needs and has experience testing TS children.
- Schools currently have 60 days to complete testing and 30 days to respond with results.
- Testing must be modified at least in the following ways:
 - Frequent breaks
 - No time constraints
 - Administered in small segments and in a non-stimulating environment.
- May need other modifications such as answers transcribed or questions read.
 - As a general rule, do not allow psychological testing by the school district. TS kids almost without exception appear ED (emotionally disturbed).
 - If the school district feels strongly, tell them you will agree to allow an expert in the field to perform the assessment. (The TSA of Texas has a list of appropriate providers.)

B. Information describing TS symptoms, especially as they affect school performance:

- Should be updated at least every six weeks and teachers notified immediately if a new tic or OCD behavior is evident.

C. Information relating to medications and how they affect school performance:

- Should be updated every six weeks and teachers and school nurse notified immediately if medication changes occur.

D. Academic and non-academic strengths and weaknesses—capitalizing on strengths

E. Flexibility

- Since symptoms wax and wane and change over time with no measure of predictability, performance and behavior will vary possibly on an hourly / daily basis.

F. Long and short term goals

G. Related Services

TS kids often need a multi-disciplinary approach to meet their educational needs.

- Occupational therapy (OT)
Can help with the mechanics of handwriting
- Assistive technology (AT)
Can provide key boarding programs and even computers (in extreme situations)
- Auditory Processing and Speech and language
Provides help not only with stuttering, but with speech atypicalities such a regulating volume, talking in a “baby” voice, etc.
- Counseling
Can work on issues of self-esteem, peer relationships, social skills.

H. Degree of participation in regular education

- 99% of all students with TS should be in regular classroom with modifications including access to content mastery or the Resource room for extra help and / or for testing purposes.
- Even those with very loud vocal or physically disruptive tics can be “skyped” into the regular classroom.
- *A self-contained classroom is almost never appropriate for a TS child.*

I. Specific academic accommodations

- Academic modifications do not necessitate modifying the core of the curriculum, hence no “S” designation on the report card or in records
- Common Modifications/Adaptations:
 - Decrease all paper and pencil tasks
 - Preferential seating
 - Copy of notes provided by teacher / NCR paper
 - Shorten writing assignments or oral assignments without changing content
 - Use of scribe

- Use of graph paper
 - Use tape recorders, calculators, and computers when necessary
 - Oral testing
 - No timed testing
 - Extended time for testing
 - Frequent breaks
 - Extend time to complete assignments
 - Safe place to discharge tics or emotions
 - Allow frequent movement in classroom
 - Special homework plan:
 - Bi-weekly communication via email generated by parent (Tu/Thur)
 - Trapper Keeper or special homework folder
 - Weekly assignment sheet of homework and test dates
 - Set of textbooks to keep at home
- Common Behavioral Adaptations
 - Contained classroom is not necessary nor appropriate to implement.*
 - A. Planned ignoring – tics
 1. Tics will worsen if attention is focused on them (increasing anxiety)
 2. Pass to Nurse for a short time if tics are overwhelming or disruptive
 - B. Use calm, quiet voice for directives and corrections (child is neurologically over stimulated; quiet voice will help refocus)
 - C. Transition time both physically and for directives
(Allows brain to engage and disengage from tasks)
 - D. Stepwise directives and rules
 - E. Provide structure and clear understanding of expectations with flexibility for waxing and waning of symptoms
 - F. Provide increased supervision in unstructured settings, i.e., lunch, P.E. and recess
 - G. Quiet area to regroup/gain control when over-stimulated
 - H. Use positive reinforcement

- I. Do not apply immediate consequences (whenever possible) after escalated behavior has occurred. Wait until child has calmed before disciplining. (Will avoid continued or rapid re-escalation.)
7. **Designing a Behavior Intervention Plan (BIP) is usually necessary for most TS students due to the impact of ADHD, OCD, or other behaviors on academic performance.**
- TS students usually experience a high degree of academic frustration, which can translate into inappropriate behavior. If academic accommodations are appropriate, a BIP may be unnecessary.
 - Designing an appropriate BIP should include the following:
 - A. Assessment
 - Usually done through a Functional Behavioral Assessment
 - Must be done by individual with experience observing TS children
 - Can also be done with a private psychological assessment as a primary vehicle for information
 - B. Long and short term goals and objectives
 - The ultimate goal should always be to teach self-management and social compensatory skills, and to move the child to the norm.
 - Never allow the TS child to harm self or others.
 - Do not punish for involuntary behaviors.
 - Should target behaviors most troublesome educationally, with a plan to circumvent and / or extinguish.
 - Should be pro-active to prevent potential problems from escalation to melt down.
 - C. Classroom Intervention Implementation Directives
 - Must include implementation strategies for teachers
 - Follow BIP
 - Be proactive – address issue before escalation

- The actual steps to be taken when a problem occurs should include addressing positive reinforcement strategies, consequences and person(s) implementing. The interventions are most effective if implemented in a pre-designated order of which the student is cognizant.
- Include input from student; when correctly prompted can be surprisingly insightful.

D. Discipline Contingency Plan

- Should be included to insure related behaviors are documented and planned for both before and if trouble occurs. Related behaviors are disciplined differently by law.

(see enclosure – 504 Equal Access)

8. Section 504 of the Americans with Disabilities Act (Accessing Services under Regular Education)

- A law of Equal Access. Anyone with documented disability qualifies (educational need not necessary)
- Statute protects Civil Rights of individuals with disabilities in programs that receive Federal financial assistance from the USDE. Includes public school districts, institutions of higher education, as well as state and local educational agencies
- Provides equal opportunity for success
- Levels the playing field so students with disabilities can have “equal access” to all education programs
- Has no entitlement

1. Eligibility

- Must have disability that substantially (truly) limits a major life activity
 - E.g., walking, seeing, speaking, caring for oneself, learning
- NOT “significantly” or “severely” limits
- “Regardless of their intelligence”
- Can be found eligible if student is “unable to fully demonstrate their ability”
- The original law states: “No otherwise qualified individual with a disability in the United States....shall solely by reason of her or his disability be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance....”
- The Americans with Disabilities Amendments Act of 2008 clarifies the original intent by stating: “*The effect of these changes is to make it easier for an individual seeking protection under the ADA to establish that he or she has a disability*”

within the meaning of the ADA.” The Act “emphasizes that the definition of disability should be construed in favor of broad coverage of individuals to the maximum extent permitted by the terms of the ADA and generally shall not require extensive analysis.”

- This involves all school functions, including academics, after-school activities and non-academic school activities.
- 2008 Amendment included eating, sleeping, standing, lifting, bending, reading, concentrating, thinking and communicating. (Not exclusive)
- Tic suppression affects ADHD and/or OCD
- Tics interfere with reading, writing
- Verbal and written dysgraphia

2008 Amendment “*clarifies that an impairment that is episodic or in remission is a disability if it would substantially limit major life activity when active.*”

Tics wax and wane and change over time with no measure of predictability and many tics are hidden.

Appropriate to have 504 Plan even if symptoms interfere inconsistently or may be absent at time of meeting.

“Major life activities, as defined in the Section 504 regulations at 34 C.F.R. 104.3(j)(2)(ii), include functions such as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working. This list is not exhaustive. Other functions can be major life activities for purpose of Section 504. In the Amendments Act Congress provided additional examples of general activities that are major life activities, including eating, sleeping, standing, lifting, bending, reading, concentrating, thinking and communicating.”

Two additions of significant importance for students with Tourette’s syndrome:

Reading

Numerous symptoms of TS and related disorders substantially limit the activity of ‘reading.’ A few examples are: numerous tics, eye blinking, head jerks, processing delays, obsessive/compulsive symptoms, arm movements, attention deficit disorder, counting words, etc.

Communication

1. **Oral communication:**

Many students with TS have vocal tics that can substantially limit verbal communication, making it less productive and/or socially inappropriate.

2. **Written Communication:**

A great number of students with TS have tics and/or dysgraphia which substantially limits their ability to write and therefore to ‘communicate’ in a written fashion. A scribe, notes provided, access to word processors, and other accommodations and modifications may be necessary, depending on the unique needs of the child, in order to provide ‘equal access’ to an education.

An impairment may limit only one life activity and still be considered a disability. Many students with TS have symptoms that interfere with reading, writing, concentrating, thinking and/or communicating, but the student is still able to maintain good grades. Students cannot be denied because they are passing, maintaining good grades or even earning high grades.

The following clarifying statement from the Amendment is important for students with TS: *“An individual with an impairment that substantially limits a major life activity should not be penalized when seeking protection under the ADA simply because he or she managed their own adaptive strategies or received informal or undocumented accommodations that have the effect of lessening the deleterious impacts of their disability.”*

If a student’s symptoms are being managed by medication, with specific strategies or undocumented supports, he can still qualify for a 504 Plan. Additionally, when his ability to communicate, read or learn is substantially impaired but he is able to maintain high grades due to working with an after-school tutor or spending an extraordinary amount of time and effort on homework, he may still qualify for a 504 Plan.

Mitigating measures can no longer be used as a reason to deny eligibility, with the exception of eyeglasses or contact lenses. Medications to manage symptoms are mitigating measures that cannot be used to deny a student a 504 Plan.

Re-evaluation

Re-evaluations must be provided periodically and in a manner similar to IDEA re-evaluations and must occur prior to a significant change in placement. Terminating or significantly reducing a related service and transferring a student from one type of program to another would all be considered as a significant change in placement.

9. Social issues are prevalent among TS children and should be carefully addressed each year.

- Difficulty making and sustaining friendships and embarrassment from symptoms may be greatly alleviated with an in-service program for classmates.
- Involve the TS student in peer mentoring program such as “Circle of Friends.”
- Involve the TS student in social skills training at school.
- Use counseling as a related service to work on issues of friendship, social skills, and self-esteem.
- Appropriate role models, i.e., regular education students, are critical to the TS child’s normal growth and development.

10. Tools for Smooth Sailing

A. Knowledge

1. Know what your child needs and how to implement.
2. Know the process – how to access services.
3. Know your rights.

B. Support

1. Bring a positive and supportive “attitude.” Most educators truly want to help your child.
2. Consider bringing refreshments to the ARD, to staffings, or after school. Often teachers miss meals to attend meetings.
3. Remember to express appreciation and to offer your assistance.

C. Understanding

1. The educational process is fluid and ongoing. Be prepared for mistakes to be made.
2. Monitor the process diligently.

D. Communication

1. Communicate frequently, daily if necessary, through email or a case manger.
2. **MOST IMPORTANTLY**, remember the greatest success is achieved when the parents and the school district work as a team.

Additional sources:

<http://ed.gov/about/offices/list/ocr/504faq.html>

<http://www.access-board.gov/about/laws/ADA-amendments.htm>

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