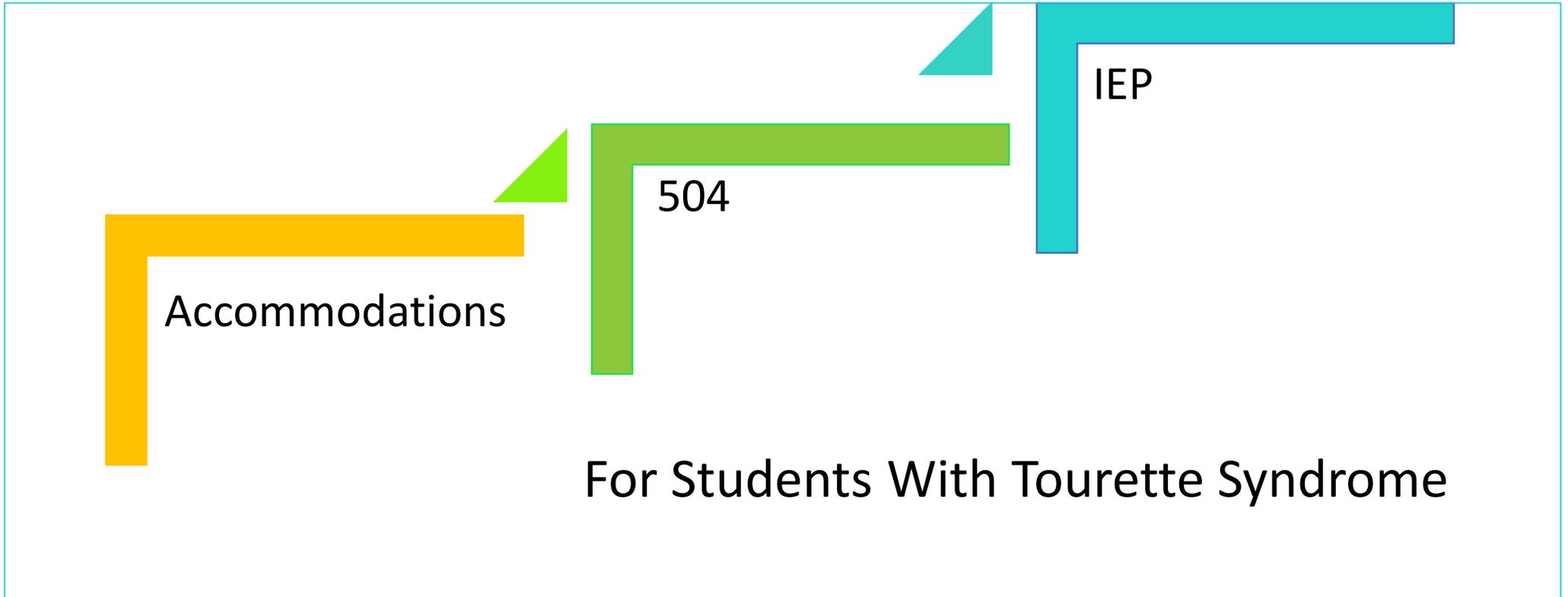




Tourette Association of America

Awareness. Research. Support.



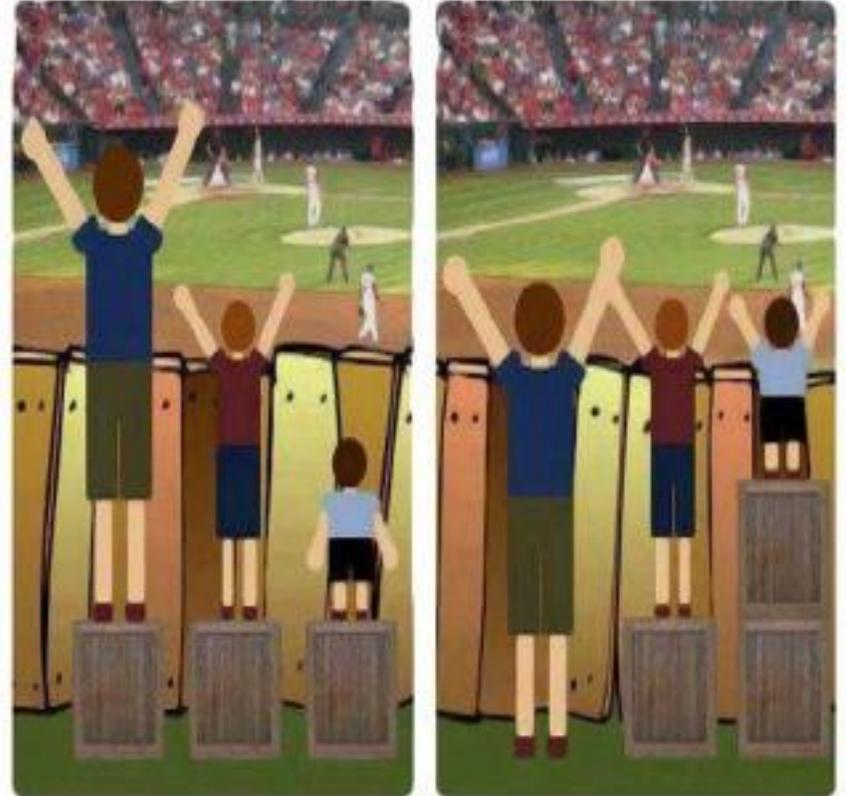
For Students With Tourette Syndrome

Margery Henning, TAA Education Advisory Board



Rehabilitation Act of 1973 Section 504

- Civil rights law
- Protects individuals with disabilities from discrimination
- Ensures children with disabilities have equal access to an education...similarly to students who **do not** have disabilities.
- Can provide modifications and accommodations





Common Explanations for 504 Denial

- Child received high scores on evaluations
- Child:
 - Is Passing
 - Getting Good Grades
- We have students who have much worse disabilities
- We don't have to provide the BEST education.....





Is Student Demonstrating True Ability?

Section 504 states that students may be eligible:

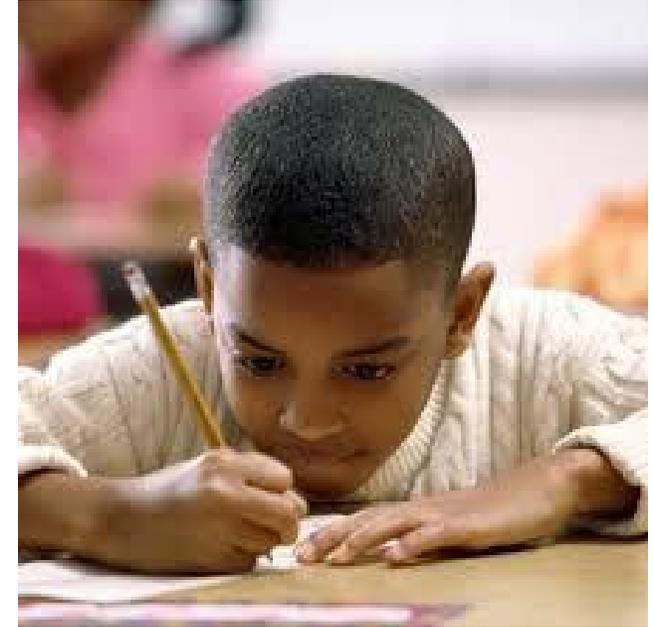
- *“regardless of their intelligence”.*
- if the disability results in students being *“unable to fully demonstrate their ability”.*



Eligibility – under Section 504

If the physical or mental impairment results in a:

1. substantial limitation of
2. one or more *major life activities*





'Substantial' vs 'Significantly'

The *ADA Amendment Act of 2008* restores the **original** definition of disability intended by Congress

The disability "*substantially*" (*actually, truly*) limits a major life activity

Instead of "significantly" (of utmost importance) limits a major life activity



2008 Amendments & Major Life Activities

Major Life Activities:

Include functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.

In the Amendments Act additional examples of general activities that are major life activities, including eating, sleeping, standing, lifting, bending, reading, concentrating, thinking, and communicating.

This list was never intended to be exclusive.



One Major Life Activity Impacted

An impairment may limit only one major life activity and still be considered a disability.

For example, a student will be considered to have a disability if his/her impairment substantially limits communicating, even if it does not substantially limit learning.



Inconsistent Symptoms

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

TS is the poster-child for EPISODIC



The 2008 Amendment

“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.”

ADA Amendment Act 2008



The 2008 Amendment:

“The effect of these changes is to make it easier for an individual seeking protection under the American’s with Disabilities Act (ADA) to establish that he or she has a disability within the meaning of the ADA.”

ADA Amendment Act 2008



Symptom Management

“..an individual with an impairment that substantially limits a major life activity should not be penalized when seeking protection.... 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”

ADA Amendment Act of 2008





How to Request 504 Plan

- Read
 - TS is More than Tics
 - Educator’s Guide for Developing Plans for Student with TS
 - Identifying Common Educational Difficulties
- **Submit a letter** requesting a meeting to put a 504 plan in place and to discuss required accommodations or modifications
 - List all the areas of concern that need to be evaluated
- Well before the meeting share 504 Facts and **one** of the above with highlights for symptoms that impact your child
- Keep in mind that Educators do not learn about TS in college
- They also may not be familiar with the laws and will assume if a child is passing, they do not qualify



Common items for 504 Plan

- Extra time to complete work/tests
- Separate Location
- Reduced homework, when possible
- Access to a computer
- Seating
- Sensory Plan... Chewing gum/candy; water bottle; sour spray
- Get Drink - movement
- Speak with Safe person as needed
- Access to assistive technology



Common Accommodations for 504 Plan

- Notes provided
- Can be creative...
 - Away from heat source
 - Challenging classes scheduled at student's optimum time of day
 - Eat some place other than cafeteria
 - Specific writing utensil
 - Doodle



What to do if Denied

- Request a written explanation
- Ask for additional evaluations/assessments
- If additional information is available, ask for another meeting
- Contact your area Office of Civil Rights



Difference between 504 and IEP

504

- Civil Rights Law, Ensures equal access
- Provides modifications and accommodations
- Does not require special education services
- Fewer safeguards

IEP

- Individuals with Disabilities Act (IDEA), requires public schools to provide an individualized educational program = Special education services
- Requires assessment in all areas related to suspected disability
 - Health, vision, hearing, social/emotional, general intelligence, academic performance, communication skills, motor skills
- Educational performance must be impacted
- Eligibility is not restricted to child's academic performance



Individuals With Disabilities Education Act (IDEA)

“Section 1400(d)

The main purposes are:

.....to ensure that all children with disabilities have available to them a **free appropriate public education (FAPE)**, that emphasizes special education and related services designed to meet their unique needs and **prepare them for further education, employment and independent living**” and “to ensure that the rights of children with disabilities and parents of such children are protected.....”



Common “Explanations” for IEP Denial

1. Child received high scores on evaluations
2. Child:
 - Is Passing
 - Is not failing
 - Is getting Good Grades
3. We have student who have much worse disabilities

You can request another meeting but
Make sure you have NEW information





High Cognition & No Need to Fail



In an April 17, 2015 Memo to all State Directors of Special Education, the Office of Special Education Programs (OSEP) wrote:

“It remains the Department’s position that students who have high cognition, have disabilities and require special education and related services are protected under the IDEA and its implementing regulations.”

[300.101\(c\)](#) Children advancing from grade to grade. (1) Each State must ensure that FAPE is available to any individual child with a disability who needs special education and related services, even though the child has not failed or been retained in a course or grade, and is advancing from grade to grade. (IDEA)



§ 300.324 Development, review, and revision of IEP.



Development of IEP—

- 1) General Process in developing each child's IEP,
 - A. The IEP Team must consider—
 - 1) The strengths of the child;
 - 2) The concerns of the parents for enhancing the education of their child;
 - 3) The results of the initial or most recent evaluation of the child; and
 - 4) The academic, developmental, and **functional needs of the child.**



Functional Needs (Discussion re 2004 IDEA)

- (Commentary in the Federal Register, page 46661) –

"It is not necessary to include a definition of "functional" in these regulations because we believe it is a term that is generally understood to refer to skills or activities that are not considered academic or related to a child's academic achievement. Instead, "functional" is often used in the context of routine activities of everyday living."

See more at: <http://www.wrightslaw.com/howey/iep.functional.perf.htm#sthash.y2EPwi3h.dpuf>

- ❖ NEW EVERY STUDENT SUCCEEDS ACT – changed “Core academic subjects” to “Well-rounded education”



IDEA 2004 Federal Regulations



Explanation for including TS in IDEA:

"We believe that Tourette Syndrome is *commonly misunderstood* to be a behavioral or emotional condition, rather than a **neurological condition**. Therefore including TS in the definition of OHI (Other Health Impaired) may help correct the misconception of TS as a behavioral or conduct disorder and prevent the misdiagnosis of their needs."



Steps for Appropriate IEP

- Review IEP Essentials for Parents <http://tourette.org/pubsonline/E-128DD.pdf>
- To initiate the IEP process, submit a **written** request for a complete Psycho-Educational Evaluation Assessment – TAA Website: Getting Help at School http://tourette.org/Education/getting_help_at_school.htm
 - Request that every area of suspected disability be included
 - Sec. 300.304(c)(4) The child is assessed in all areas related to the suspected disability, including, if appropriate, health, vision, hearing, social and emotional status, general intelligence, academic performance, communicative status, and motor abilities;
 - Common Indicators of related disorders; TS is More than Tics (Written Language; Executive Function Skills; Pragmatic; Sensory; Processing Delays, etc.)
- Review Evaluation/Assessment with person who provided test



Teacher input

- Use report cards, notes, conversation:
- Reports of
 - Attention problems
 - Refusal to work
 - Avoidance
 - Social interactions
 - Defiance
 - Refusal to comply with directions/requests
 - Behavior issues

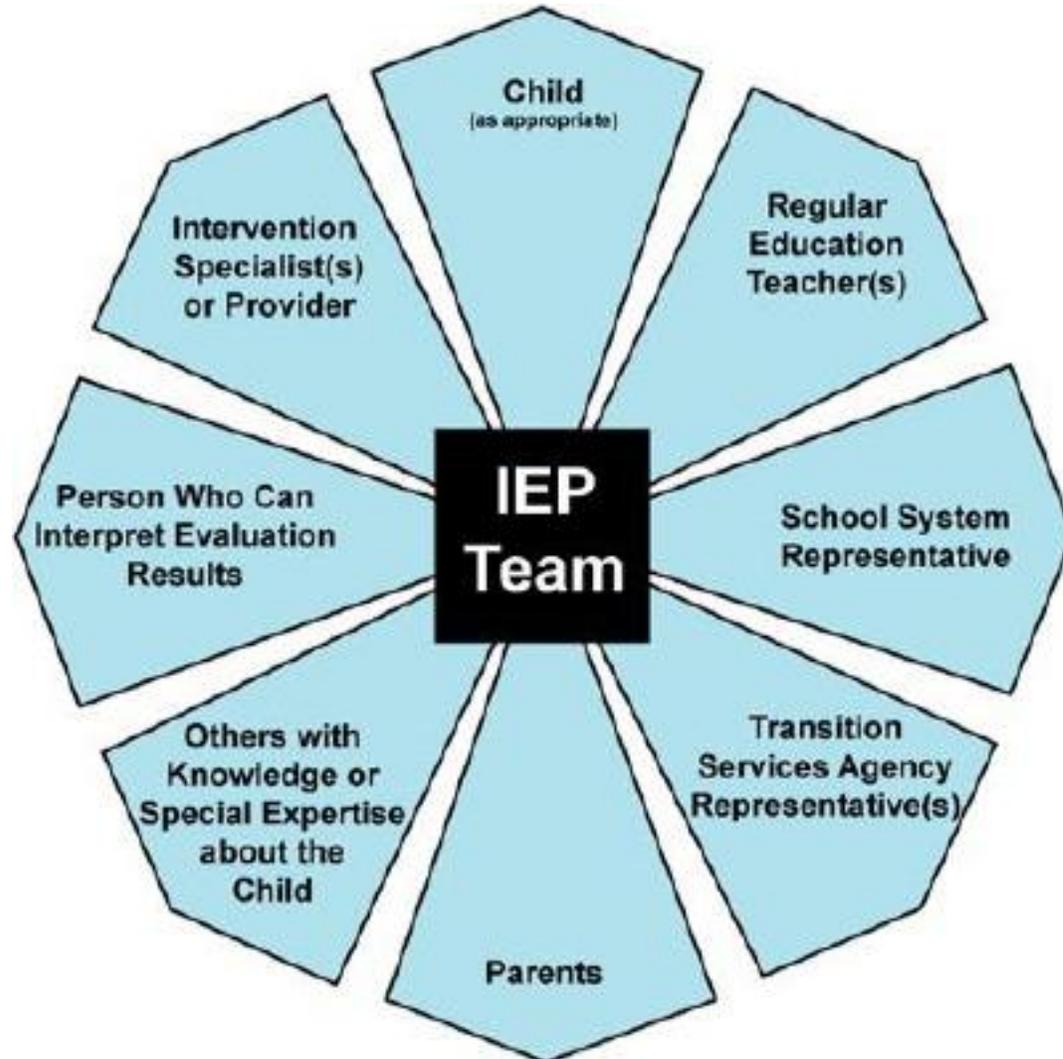
I recognize these can be upsetting but use it as evidence that supports are necessary and it's not just an overly anxious/pushy parent –

Hint: Think of yourself as an attorney gathering evidence



IEP TEAM

- At least 1 Gen Ed. Teacher
- At least 1 Spec. Ed. Teacher
- Person who provides services
- Parent
- Child – (Advantage/Disadvantage)
- Any one with expertise or knowledge about Child





Tips for Meetings

- Be Prepared –
- They may ask you to begin the meeting/They may ask you to wait until others have reported
 - Script if needed or bullet points – you WILL forget important points
 - If not first, listen to what others are saying as impersonally as possible
- Take notes
 - statements you agree – demonstrates your willingness to be part of team effort
 - statements you disagree – provide examples if possible why you disagree



More Tips

- Bring someone with you to take notes and to listen unemotionally
- Tape recorders
 - Only under extreme circumstances
 - you know you will be getting an attorney or advocate to help you
 - if you don't have someone to take notes and you explain that because of your own issues with ADD you will want to listen to this again or share with spouse
 - IMPORTANT: Tell them ahead of time because they will want to have one as well
- Emotions
 - Anger – try to keep in check; if necessary, take a breather
 - Tears – not always a bad thing as long as they indicate your love and concern for your child



More Tips

- Try not to interrupt but take notes that you can refer to
- Bring documentation from TAA website
 - a copy for everyone present
 - as few as possible
 - Tourette Syndrome and Dysinhibition;
 - Identifying Common Education Difficulties with TS ;
 - Educator's Guide for Developing Plans for Students with Tourette Syndrome
 - Awareness Flyer



More Tips

- If Possible, summarize meeting
- Discuss any action steps
 - Know who will be responsible for ensuring these happen
 - Ask for a Date that these will occur
- When Possible – Thank people for their continued support/time
- If there is the need for a follow-up meeting, ask to set the date
- Send a letter of thanks (again when appropriate) including summary of what you believe was decided



IEP Accommodations/Modifications (few examples)

- Extended time
- Test in separate location
- Allow movement
- Copy of notes provided
- Phone picture of homework
- Check backpack end of day
- Seating
 - Front
 - Back
 - Away from Window
 - Near Door
- Access to Computer
- Reduced homework (when possible)
- Doodling allowed
- Sensory items/strategies
- Leave class early/late
- Lunch options
 - Eat separate location w/friends
 - Eat then go to library/music/gym
- Alternative to bubble filling



All of these could be on a 504 Plan as well



Special Ed Services

few examples, typically not on 504 Plan- but could be

- Work with Consultant/Resource Teacher
 - Manage current workload – may include working with teachers as well
 - Teach strategies for managing work load
 - Organization strategies – beginning and end of day
- Work with Speech Pathologist
 - Pragmatic Language
 - Executive Function Skills
 - Social Skills
- Work with School Psychologist/Counselor/Social Worker
 - Directly from bus
 - Access during Day
 - Scheduled times
 - Social Skills
- Work with Occupational Therapist
 - Provide INDIVIDUALIZED Sensory Plan
 - Executive Function Skills
 - Assistive Technology



If Denied

- Request a written explanation specifying why & what is necessary
- Request, in writing, additional evaluations/assessments (if appropriate)
- When you have additional information, request another meeting (EX: new meds; new symptoms...)
- Accept a 504 Plan as the first step toward an IEP
- If extremely serious:
 - Ask for mediation
 - Ask for an impartial hearing
 - Most people require an attorney. This is a major step and can cost a lot of money. In some states, if you lose, you need to pay for school's attorney.
 - Contact local agency for assistance (Parent Information Centers; Protection and Advocacy; Learning Disability Assoc.; ARC and others)



Tourette.org Resources

- ❖ Identifying Common Education Difficulties (Brief)
- ❖ Tourette is More than Tics: Understanding Behavior Challenges and Related Issues (long)
- ❖ Classroom Strategies
- ❖ Educators Guide for Developing Plans for Students with TS - preparation & during meeting
- ❖ Eligibility for 504 Plans
- ❖ 504 Plan Fact Sheet
- ❖ IEP Essentials for Parents
- ❖ Education Rights for Students with TS
- ❖ Audio with Power point Topics http://tourette.org/Education/audio_presentTSA.htm
 - How to Prepare for an IEP or 504 Plan Meeting Parts 1&2
 - Education Rights every Parent Should Know
 - Much more.....



A Few More Resources

- ❖ Wrightslaw <http://www.wrightslaw.com/>
- ❖ The ADA Amendments Act of 2008 <http://www.access-board.gov/about/laws/ada-amendments.htm>
- ❖ US Office of Special Education Site (excellent) <http://idea.ed.gov/explore/home>
- ❖ Frequently Asked Questions About Section 504 and the Education of Children with Disabilities <http://ed.gov/about/offices/list/ocr/504faq.html>
- ❖ “Parent Advocacy Brief” about the Act and Section 504 by the National Center for Learning Disabilities.
<http://www.ncld.org/images/stories/Publications/AdvocacyBriefs/UnderstandingADAAA-Section504/UnderstandingADAAA-Section504.pdf>