

# Tourette and Tics

The LSSP role for 504 or  
Special Education

## Learner Objectives:

1. Integrate the student's diagnosis of Tourette or tic disorders with the school service model through the use of 504 or Special Education.
2. Utilize the role of the LSSP in partnership with parents, teachers, and the student.
3. Understand the uniqueness of each student and how that impacts development of the FBA, BIP, and service plan.
4. Have resources at the ready for Monday morning.

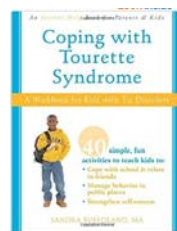
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## Professional background

- LSSP – M.A. Univ of Houston- Clear Lake
- Diagnostician – M.Ed. UH Main campus
- Teacher – General Ed. and Special Ed. SUNY
- In home trainer and Evaluator
- Parent – daughter diagnosed 1998
- Tourette Association of America volunteer and trainer- 1996 to present
- Support group leader
- Author – two publications

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## Coping with Tourette Syndrome



**A Workbook For Kids  
With Tic Disorders**  
New Harbinger Publications  
2008

## Tourettes and Tics Toolbox

- Differentiate criteria for Tourettes, tic disorders, and related conditions
- Identify tics
- Document tics
- Roles: Consultation/Accommodations
- Resources: community, FBA, BIP, IEPs
- Know where your resources are for parents, teachers, schools, and children

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## DSM-5 Tic Disorders:

- Tourette's Disorder
- Persistent Motor or Vocal Tic Disorder  
Specify: with motor tics only  
with vocal tics only
- Provisional Tic Disorder
- Other Specified Tic Disorder- reason
- Unspecified Tic Disorder – no reason

## Tourette's Disorder

- have **BOTH** multiple **motor** tics (for example, blinking or shrugging the shoulders) **and vocal** tics (for example, humming, clearing the throat, or yelling out a word or phrase), although they might not always happen at the same time.
- have had tics for **at least a year**. The tics can occur many times a day (usually in bouts) nearly every day, or off and on.
- have tics that begin **before** he or she is **18 years of age**.
- have symptoms that are not due to taking medicine or other drugs or due to having another medical condition (for example, seizures, Huntington disease, or postviral encephalitis).

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## What is commonly referred to as Tourette Syndrome, Tourettes, TS?

A complex neurobiological disorder with a spectrum of tics and associated behaviors

3-4 Male to 1 Female

.05% to 1% of the population

Handout

**TOURETTE SYNDROME**  
Tics are just the tip of the iceberg

Tourette Association of America

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Also available in...

图雷特综合症  
抽搐症仅是冰山一角

- Chinese
- French
- Spanish

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- ***“The only thing that is consistent about Tourettes is the inconsistency of symptoms and related issues. Students may perform well one day and then perform poorly the next day.”***
- ***Kathy Giordano, Tourette Association Educational Specialist***

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**Other tic and OCD related disorders**

<b>P.A.N.S.</b>	<b>P.A.N.D.A.S.</b>
<ul style="list-style-type: none"> <li>• Pediatric</li> <li>• Acute-onset</li> <li>• Neuro-psychiatric</li> <li>• Syndromes</li> </ul>	<ul style="list-style-type: none"> <li>• Pediatric</li> <li>• Auto-immune</li> <li>• Neuro-psychiatric</li> <li>• Disorders</li> <li>• Associated with</li> <li>• Streptococcal infection</li> </ul>
Not linked to Strept	

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## P.A.N.D.A.S.

- Identified by medical doctors
- Lingering reluctance to diagnose within medical community – controversial
- currently no conclusive diagnostic blood or neurological tests to be relied on.
- There is a temporal relationship between a streptococcal infection and the abrupt onset and exacerbation of OCD and tics
- Common treatment – antibiotic series

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### PANS is defined by the following criteria:

Abrupt, dramatic onset of OCD or severely restricted food intake; symptoms are not better explained by a known neurologic or medical disorder; and the addition of at least 2 of the "accompanying" symptoms:

- Anxiety
- Emotional lability and/or depression
- Irritability, aggression and/or severely oppositional behaviors
- Behavioral (developmental) regression
- Deterioration in school performance
- Sensory or motor abnormalities
- Somatic signs including sleep disturbances, enuresis or urinary frequency

The onset of PANS may start with infectious agents other than strep. It also includes onset from environmental triggers or immune dysfunction.

### PANDAS is defined by the following criteria:

Clinical diagnosis of PANDAS includes 5 criteria:

- Presence of significant obsessions, compulsions and/or tics
- Abrupt onset of symptoms or a relapsing-remitting course of symptom severity
- Prepubertal onset
- Association with streptococcal infection
- Association with other neuropsychiatric symptoms (includes any of the PANS "accompanying" symptoms)

<http://www.pandasnetwork.org>

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## Can LSSPs diagnose Tourette Disorder, Tic Disorders, PANDAS, PANS?

- NO..... but they can be crucial in documenting the onset of tics that may lead to an earlier diagnosis
- They can identify evidence of tic and OCD disorders in the context of a psychological
- They can report tic symptomology in the context of a written observation or consultation
- They can and should use an FBA as an appropriate educational tool that drives the BIP and Behavior IEP- informational and appropriate

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## Tics

### • Motor:

- - Simple
- Ex. Blinking, grimacing
- - Complex
- Ex. Kissing, pulling at clothes, touching

### • Vocal – Phonic:

- - Simple
- Ex. Throat clearing, simple sounds
- - Complex
- Ex. Words, echolalia, role playing 2 people

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## Incidences of Tics

- Within school age children:
- **1 in 100 boys**
- **1 in 300-400 girls**

Based on data from the Texas Tourette Association

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## Function of Tics vs OCD vs Self-stim

### TICS

- It's like an itch
- You have to scratch it to stop thinking about it.
- Example: touching right index finger to nose

### OCD

- It's an action you have to do to relieve **anxiety**
- Example: Touch something 3 times

vs

### SELF STIM

- Do it when over or under stimulated to get sensory feedback
- Example: pinching self

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## Which are these? Tics, OCD, or Self Stim?

- Excessive blinking
- Re-writing a word over and over to get it right
- Checking and rechecking the front door lock
- Flushing toilet and watching water go down drain
- \* Licking pencil
- \*Punching self in stomach
- \*Singing the same commercial over and over
- \* Repeating lines from movies
- \* Rocking back and forth

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## Tools for tic documentation for LSSPs

- Anecdotal
- Checklists
- Formal observations
- Interviews

Are there items on formal rating scales?

- Yes – minimal items
- But – accidental assumptions about some items that lead to other diagnosis such as AU, ODD

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## Evidence on rating scales?

- MHS: Conners Comprehensive Behavior Rating Scale – CBRS self report

- item 21 “ I make sounds that are hard to control (like clearing my throat or sniffing)
- item 95 “I have muscle twitches that are hard to control (like blinking a lot or jerking my head)

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## Conners 3

- Teacher Conners 3:
  - 19. Fidgeting
  - 45. Is constantly moving
  - 71. Is noisy and loud when playing or using free time
  - 98. Fidgets or squirms in seat
  - 99. Restless or overactive

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## Pearson BASC-3 Teacher ages 6-11

- Speaks out of turn during class
- Has trouble staying seated
- Disrupts the schoolwork of other children
- Has poor self-control
- Acts without thinking
- Cannot wait to take turn
- Acts out of control
- Does strange things/acts strangely
- Picks at things like own hair, nails, or clothing
- Babbles to self
- Seems odd
- Annoys others on purpose
- Engages in repetitive movements

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## Pearson BASC-3 Parent ages 6-11

- 30 Engages in repetitive movements
- 32 Is overly active
- 73 Has poor self control
- 93 Fiddles with things while at meals
- 99 Is in constant motion
- 114 Disrupts other’s activities
- 115 Acts strangely
- 122 Says things that make no sense
- 145 Does strange things
- 171 Does weird things

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## Autism Spectrum Rating Scales

- **Unusual Behaviors scale:**
- Have a strong reaction to any changes in routine
- Use an odd way of speaking
- Repeat certain words or phrases out of context
- Insist on doing things the same way each time
- Flap hands when excited
- Need things to happen just as expected
- Twirl, spin, or bang objects
- Repeat or echo what others said

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## Other Tools for identification of tics

- Checklists – handouts
- **Formal checklist**
- **Clinical Observation form**
- **V1=verbal tics**
- **V2= motor tics**
- Multiple checklists/observations are key

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Formal checklist in handouts.

**Questionnaire**

LSSP: \_\_\_\_\_  
 Name of observer: \_\_\_\_\_  
 Dates observed: Beginning \_\_\_\_\_  
 Ending \_\_\_\_\_

Checklist of range of symptoms: Place an X on the symptoms you have observed.  
 This is not a diagnosis. This is simply an observation of symptoms.  
 No person has all symptoms.

SIMPLE MOTOR TICS	Place an X if Present	Place an X if Present
Eye Blinking		Kicks
Grimacing		Finger Movements
Nose twitching		Jaw snaps
Lip pointing		Tooth clicking
Shoulder shrugs		Frowning
Arm jerks		Tensing body parts
Head jerks		Rapid jerking
Abdominal tensing		Other
<b>COMPLEX MOTOR</b>		
Hopping		Rolling eyes to ceiling
Clapping		Holding funny expression

2 pages

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Clinical Observation form

**Systematic Observation Form - TS symptomatology**

Name: \_\_\_\_\_ Date: \_\_\_\_\_ Teacher/Subject: \_\_\_\_\_  
 Time Invol: \_\_\_\_\_ Class/Act: \_\_\_\_\_  
 Observer: \_\_\_\_\_ Approval (I): \_\_\_\_\_ Disapproval (X): \_\_\_\_\_  
 Special Variables: V1= verbal tics, V2= motor tics  
 Approval Behavior: \_\_\_\_\_  
 Peer Interaction: \_\_\_\_\_ Comments: \_\_\_\_\_

Method of Presentation	Interval	Target Behavior	Peers
	1	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	2	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	3	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	4	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	5	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	6	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	7	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	8	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	9	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	10	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	11	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	12	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	13	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	14	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	15	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	16	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
	17	= N GP PC DT V1 V2 = N GP PC DT V1 V2	
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	26	= N GP PC DT V1 V2 = N GP PC DT V1 V2	

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Clinical Observation example

*Notes/tics are reported by doctor + parents*

**Systematic Observation Form – TS symptomology**

Name: Johnny P Date: 9-15-18 Teacher/Subject: Mrs. Smith  
 Time used: 3:30-4:00 Class size: 23 Class Activity: Reading  
 Observer: S. Buffalano Approval (I) \_\_\_\_\_ Disapproval (X) \_\_\_\_\_  
 Special Variables: V1= verbal tics V2= motor tics  
 Atypical Behavior: \_\_\_\_\_  
 Peer Interaction: Full class instruction Comments: student seated in the last row by door

Time interval: 10 seconds

Method of Presentation	Interval	Target Student	Peers
1	0	N	OP
2	0	N	OP
3	+	N	OP
4	+	N	OP
5	+	N	OP
6	+	N	OP
7	+	N	OP
8	+	N	OP
9	+	N	OP
10	+	N	OP
11	+	N	OP
12	+	N	OP
13	+	N	OP
14	+	N	OP
15	+	N	OP
16	+	N	OP
17	+	N	OP
18	+	N	OP
19	+	N	OP
20	+	N	OP
21	+	N	OP
22	+	N	OP
23	+	N	OP
24	+	N	OP

*Direct teaching instruction*  
*Involuntary sounds*  
*Moving feet in seat/room*  
*on floor*  
*talking to self - repeating words*  
*looking around*

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Totals

Total		Total	
T	N	OP	PC
100	100	100	100

**Summary of Observations:**

Target Student: On Task: 41% Peers: On Task: 75%  
 Making Noise: 15% Making Noise: 2%  
 Out of Place: 12% Out of Place: 1%  
 Physical Contact: 0% Physical Contact: 0%  
 Off Task (general): 23% Off Task (general): 22%

V1= verbal tics: 15 V2= motor tics: 17  
*in a 25 minute period*

KEY:  
 += On Task

N = Noise: Any sounds created by the child which distracts either another student or the teacher from the business at hand. The noise may be generated orally (including "talk out" or unintelligible sounds) or nonvocal noises (tapping pencil or snapping fingers).

OP = Out of Place: Any movement beyond either explicitly or implicitly defined boundaries in which the child is allowed movement. If the child is seated at his desk, then movement of any sort out of seat is "out of place".

PC = Physical Contact: Any contact with another person or another person's property which is unacceptable to that person. Kicking, hitting, punching, leaning, breaking, and taking are categorized as physical contact.

OT = Off Task: Any movement off of a particular activity which does not fall into one of the three categories. "Moving around," "staring into space," etc. are included.

V1= Possible verbal tics observed  
 V2= Possible motor tics observed

Descriptions of tics observed:  
 Verbal - repeating words to himself, clearing throat, whistling  
 Motor - moving back and forth, snapping head/neck, moving feet in a pattern

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## Qualitative evidence

- Observations - # of tics per 30' period
- Checklists

Write up- see handouts for examples

- Interviews:
- - **Parent Interview worksheet**
- - **Student – Interview** & informal checklist

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## Student Interview & testing

1. Reassure student that he/she is allowed to move around, make noises and take breaks during your time with them.
2. Watch for suppression techniques:
  - - sitting on hands
  - - putting arms in shirt or folding legs into chair
  - - coughing and masking
3. Continue to observe throughout testing

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## Student interviewing cont.

- If tics have been verified with parent and it is OK to discuss with student: only then do you discuss tics with student in interviews
- identify what tics are
- Use [pp 16-17 from workbook](#) see next slide

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EXCERPTS FROM COPING WITH TOURETTE SYNDROME  
WORKBOOK PAGE 16

### Introduction:

When Ethan's doctor first explained about tics, ... he explained that there are two kinds of tics: vocal tics and motor tics. Vocal tics are sounds, like sniffing or coughing. Repeating words or lines from a movie are also vocal tics. Motor tics involve movement, like blinking or jerking. Ethan thought about his own tics, and he realized that they were different at different times...

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page 17: Directions

Tics are sounds or movements that you do over and over and have a hard time stopping..  
Use a highlighter to mark tics that you have had.

- |   |   |
|---|---|
| <ul style="list-style-type: none"> <li>• Sounds (Vocal Tics)</li> <li>• Clearing your throat</li> <li>• Humming</li> <li>• Sniffing</li> <li>• Smacking your lips</li> <li>• Kissing</li> <li>• Clicking your tongue</li> <li>• Grunting</li> <li>• Whispering</li> <li>• Hawking</li> <li>• Spitting</li> <li>• Blowing raspberries</li> <li>• Coughing repeatedly</li> <li>• Repeating words</li> <li>• Whistling</li> <li>• Cursing</li> <li>• Barking</li> <li>• Imitating others</li> <li>• Other _____</li> </ul> | <p><b>Movements (Motor Tics)</b></p> <ul style="list-style-type: none"> <li>Blinking</li> <li>Moving your eyebrows or nose</li> <li>Making faces</li> <li>Moving your shoulders</li> <li>Putting your arm out</li> <li>Bending over</li> <li>Hopping</li> <li>Jumping</li> <li>Shaking, jerking, or rolling your head</li> <li>Pulling at your clothes</li> <li>Smelling</li> <li>Tensing your muscles</li> <li>Kicking</li> <li>Biting</li> <li>Cracking your knuckles or joints</li> <li>Touching other people</li> <li>Touching things</li> <li>Other _____</li> </ul> |
|---|---|

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### Does TS get delayed as a diagnosis? YES -----Derailed diagnosis

- Blinking – ophthalmologist
- Throat clearing – ENT
- Head shaking – head shave by the barber
- ADHD – often first diagnosis
- Echolalia and those similar to PDD
- Shaking/motor – suspicion of seizures
- Tantrums and RAGE – exorcism?

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### Let's meet some kids with Tourette at camp

- <http://www.tourettetexas.org/camp/>
- Produced by Baylor College of Medicine in Houston, Texas- a Tourette Association of America's Center of Excellence
- 12 minute video

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### Video TS Camp

- Produced through Baylor College of Medicine
- <https://www.bcm.edu/healthcare/care-centers/parkinsons/videos/tourette-syndrome-up-close>

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### Coprolalia

- Relative to age and might include racial slurs: "butt" for 4 yr old child; X rated movie line for adult
- Different for every individual, inconsistent, change periodically, wax and wane and are increased by stress.
- The inconsistency of a child with Tourette to inhibit the use of inappropriate behaviors and statements adds to the difficulty of understanding the symptoms of this disorder.
- The following is an example of coprolalia that may be misinterpreted as purposeful:

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## Coprolalia Example:



- A student with Tourette is being disciplined for what the teacher thought was said in a disrespectful manner. The teacher reported that every time she said that the class was going to have a test or homework, the girl would say “damn it.”
- While this is certainly inappropriate for the student to say this, it may be a symptom of Tourette. Indeed, many of the students may have been thinking the same thing, but they were able to inhibit these thoughts.
- The student with TS was not able to inhibit blurting out inappropriate statements that appeared to be purposeful. Perhaps the event of taking a test heightened her stress, contributed to her inability to inhibit, and made her tics worse.

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## Disinhibition: no mental brakes

- Examples of disinhibition might include excessive silliness, sassiness, uncensored and/or inappropriate comments, emotional outbursts, contextual swearing, explosive anger, or oppositional defiance.
- Inappropriate statements or behaviors can result from an inability to consistently apply “mental brakes” – the child cannot consistently stop himself from expressing thoughts or displaying actions that most students have the ability to control.

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## Comorbidity

Attention Deficit Hyperactivity – 50-60%

Obsessive Compulsive Disorder - 30 -50%  
Coprolalia (obscene or inappropriate words)–  
8 to 10% of those with Tourette

Copropaxia (obscene or inappropriate actions) –  
up to 6% of those with Tourette

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## Comorbidity:

- Learning Disabilities – 20-30%
- Autism Spectrum Disorders – not a rule out
- Mood Disorders – 30 - 40%
- Anxiety Disorders including OCD – 30-40%
- Other Disorders- various  
- Trichotillomania, Intermittent Explosive Disorder, Conduct Disorder

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## What is “Tourette Syndrome Plus?”

- Typical Complex Cases:
- Tourette +OCD + ADHD
- Tourette + ADHD + LD
- Tourette + OCD + ADHD + Depression
- Tourette + AU + ADHD
- Tourette + ADHD + Bipolar
- Tourette + OCD + Bipolar

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## R.A.G.E.



**R.A.G.E. = Repeated  
Anger  
Generated  
Episodes**

More Tourette PLUS co-morbid diagnoses = more likely to have R.A.G.E.

**If Tourette only then < 10% likelihood that they will have anger control problems**

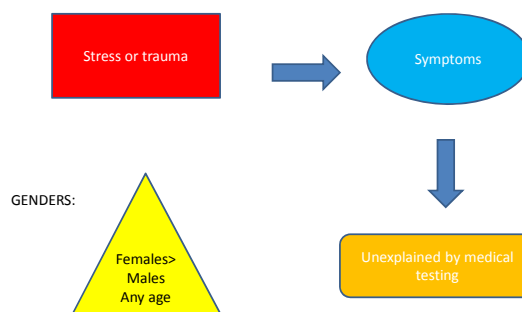
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## Less frequent but concerning- **Conversion Disorder**

- A physiological condition as a reaction to a neuro or psychiatric condition.
- Example: sudden weakness, dropping to the ground, paralysis, stroke like on one side of the body, seizures/like, impaired vision, impaired hearing, loss of sensation
- Can come on suddenly and remain for months

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## Conversion disorder sequence



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## Conversion disorder treatment

- Neurologist- rule out causes
- (Often first seen in Emergency Room)
- Waiting it out if short term
- Psychotherapy
- Physiotherapy/PT/Chiropractor
- Hypnosis
- Key to all treatment? Being believed and creating trust between patient & doctor or therapist treating
- Can be resolved

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## LSSP roles with tic disorders

- Recognize or report suspicion of a diagnosis
- Provide documentation for outside physician and assessments
- Be a liaison for all through 504/IEP
- Educate -**Tourettes and Associated Behaviors Information Sheet**
- FBAs and BIPS and Behavior IEPs
- Psychological services: direct and consult
- Direct the plan until others are ready
- Re-evaluate the plan as needed

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## LSSP roles for the student

- Understand the impact of what you have discovered and act
- Observations and interviews
- Advocate for the child
- Counseling
- Information/Consultation
- Teach them to advocate for themselves
- Smile a lot and be positive

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## LSSP roles for the parents

- Support and connect with resources
- Schedule check ins regularly- whether the news is good, not so good, or average
- Encourage them to access community camp and support groups
- Be the contact person until others are educated enough to do it.
- Be encouraging of their efforts.

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### When do physicians consider medications?

- If symptoms are functionally disabling and not remediable through non-drug interventions
- Targeting specific symptoms
- Balanced against potential side effects
- There is not one single medication that is helpful to all individuals with Tourettes.
- Examples: all these students have Tourettes
- Tic-suppression medication for patient A-
- OCD medication for patient B- SSRI
- ADHD medication for patient C- stimulant or not

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### Treatment Medications: TICS

- Abilify (aripiprazole)- First FDA approved drug specifically for Tourette. Others for tics include: Haloperidol (Haldol) and pimozide (Orap) but some side effects are concerning.
- High blood pressure medications- guanfacine or clonidine are used off label: moderately effective in reducing tics and are better tolerated.

Ecopipam- a new class of research drugs for tics  
Dopamine 1 receptor antagonist will be further researched after some initial trial successes.

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### Treatment Medications: TICS plus

- MONOTHERAPY – just one medication that covers two or more problems
- TARGETED COMBINED PHARMACOTHERAPY- 2 or more medications simultaneously for tics +  
GOAL: use lower doses of each to reduce side effects, booster effects of the combination therapy  
Example: clonidine and dextroamphetamine

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### TREATMENTS: Not medications

- Deep Brain Stimulation for severe tics
- Comprehensive Behavioral Intervention for Tics (CBIT)
- Habit Reversal Therapy- small number of tics
- Therapy to address stress and management of disorder
- P.A.N.D.A.S. treatment with long term antibiotics
- Nutrition changes like adding or increasing Omega-3, Magnesium, B6; avoiding caffeine; addressing food sensitivities that already exist like lactose, food dyes, and gluten
- Lifestyle changes- exercise, yoga

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## What is CBIT?

- Comprehensive Behavioral Intervention for Tics
- Highly structured therapy in a **specially trained therapist's** office on a weekly basis: 8 sessions over 10 weeks, but can be longer or shorter
- 3 components:
  - (a) training the patient to be more aware of tics,
  - (b) training patients to do competing behavior when they feel the urge to tic, and
  - (c) making changes to day to day activities in ways that can be helpful in reducing tics.

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## New research



- The Tourette Association of America has awarded \$21 million to about 450 projects across 16 countries
- New medications
- Deep brain stimulation
- Identify genes and gene variations that cause rare forms of TS, increase the risk, and link to OCD
- Established global collaborations and resources
- Ongoing novel and promising treatments: medical cannabis, dental orthotic devices, home-based therapies

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## Quality of Life

- Trade off of symptoms and side effects
- Which condition is having the most impact on the quality of life?
- Mysterious side effects and reactions- example: Haldol and Risperdal
- Years of drug experiments
- Medication is sometimes an unreliable variable
- Therefore – it is not about the medication, it is about the management of the resources and accommodations

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## Example for 9 year old “Brandon”



### Outside medical professionals

- Pediatrician
  - Psychiatrist
  - Psychologist
  - Neurologist
  - Urologist – enuresis is also common
- Note: this child grew up to have of an off label medication side effect of enlarged breasts and received a double mastectomy at age 18.

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## 14 yr old female “Susan”

### Outside medical / professionals

- Pediatrician
- Psychiatrist
- Psychologist
- Speech pathologist – stuttering tic
- Certified Nutritionist
- Algebra Tutor
- Dental specialist due to unusual medication side effect to her teeth dentin- resulting in 8 crowns at age 16

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## Services for students with TS

- General Education + Intervention Tiers
- 504 with Accommodations + Intervention
- Special Education as OHI – preferred eligibility
- Special Education as ED- rarely eligibility
  - 1. with other co-morbid diagnoses  
(severely emotionally disturbed due to internalizing disorder of anxiety or depression)
  - 2. temporarily until formally diagnosed

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## The **Golden** Rules

- ***Avoid academic frustration***
- ***Utilize appropriate accommodations***
- ***Teach compensatory strategies***

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## Important Changes Regarding Eligibility for 504: since 2008

There was a ruling that added the following:

1. Additions to the major life activity list
  2. Episodic and Inconsistent Symptoms are recognized and still eligible
  3. Disability can impact only one major life activity without needing to impact a 2<sup>nd</sup>
  4. Management of Disability and mitigating measures do not make a student ineligible
- Ex. Medications reduce symptoms.

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## The Role of Educators

- **Often students with TS do not understand what triggers their behaviors. Ask their parents about triggers and:**
  1. Ignore tic symptoms.
  2. Be alert to possible triggers.
  3. Provide accommodations and modifications.
  4. Acknowledge the student, separate from the symptoms.
  5. Work with the student to develop and practice appropriate accommodations and supports.

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## The role of educators continued

- **Asking a student** what can be done to help him or her be successful, instead of asking why he or she is not successful often aids teachers in developing appropriate supports. This can also help establish an atmosphere of teamwork between the student and the educators; the student can take ownership of a positive and proactive intervention plan.
- **Asking parents** what can be done to help their child

Finn's story



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## Accommodations and Recommendations

See **handouts**:

- **Accommodations/Adaptation of School Environment**
- **Report Recommendations and Behavior Intervention Plans- 2 pages**
- **Individual Education Plans for Tourettes and Tic Disorders: start with the FBA download**

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FREE DOWNLOAD  
Tourette.org



### **A Workbook for Conducting a Functional Behavioral Assessment and Writing a Positive Behavior Intervention Plan for a Student with Tourette Syndrome**

Includes ADHD, Obsessive Compulsive Disorder, Executive Dysfunction & Sensory Integration Issues

by Kathy Giordano B.A., TAA Education Specialist, and Members of the TAA Education Advisory Board

The Individuals with Disabilities Education Act (IDEA) requires that a Functional Behavioral Assessment (FBA) be conducted and a (positive) behavior intervention plan (PBIP) be developed whenever the behavior of a student interferes with the ability of that or other students to learn. This assessment is conducted exclusively to provide information which will assist in developing positive and proactive interventions and supports to be implemented by the school district. The ultimate purpose of these interventions is to limit the likelihood of the behaviors re-occurring by providing accommodations, teaching skills and/or strategies that are written into a positive and proactive behavior intervention plan (PBIP).

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## CONTENTS

1) Overview of Functional Behavioral Assessments	p. 2-4
2) FBA Worksheet	p. 5-6
3) FBA Summary Worksheet	p. 7-8
4) Positive Behavior Intervention Plan Worksheet	p. 9-15
5) Vignettes	p.16-21
6) Resources	p. 22

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## Functional Behavioral Assessment

**FBA**s – Tics are not voluntary.

Therefore, you can't punish a neurological disorder.

Telling a student that their behavior is not appropriate is not helpful if the behavior is a manifestation of his disability.

Educators are not always aware of the symptomology of Tourette and the associated disorders that often accompany. It is therefore not unusual to misinterpret symptoms of the disorder as behavioral problems rather than the neurobiological symptoms that they are.

Your observations, documentation, and newly trained knowledge are vital for your FBAS.

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## IEPS

- Behavior IEPs – Tics are not correctable. Therefore you don't put "reducing tics" on an IEP.
- Reminding people with tics to inhibit their need to complete a tic is not helpful and generally will increase the need to have the tic because they have been reminded of it.
- Behavior plans should never address tics. However, if the tic is self-injurious or very socially inappropriate, environmental changes and supports may be necessary.

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## COUNSELING AND CONSULTATION:

### *Coping with Tourette Syndrome: a workbook for kids with tic disorders*

- 40 activities
- Grades 2-8 with low readability
- Written for therapists or parents to do with kids
- Narrative stories for each introduction to students
- Active worksheets following each story

- [www.newharbinger.com/coping-tourette-syndrome](http://www.newharbinger.com/coping-tourette-syndrome) \$13.99 download

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### *Coping with Tourette Syndrome: a workbook for kids with tic disorders*

Designed for use with

- LSSPs
- Counselors
- Mental Health Professionals
- Licensed Professional Counselors
- Parents

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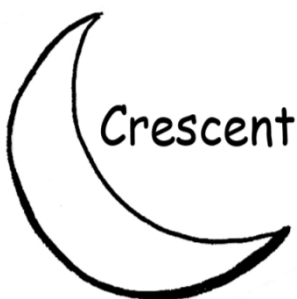
### *Coping with Tourette Syndrome: a workbook for kids with tic disorders*

- Unique approaches for school and home

Moon analogies for symptom communication, tic identification, co-morbid conditions, school and community activities, middle school transitioning, self-advocacy, social skills, study skills

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### **Moon Analogy: Crescent moon**



**When my TS is like a crescent moon, I have fewer tics and I feel happy most of the time.**

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### **Half Moon**



**When my TS is like a half moon, I feel frustrated. It is hard for me to finish my schoolwork and my chores at home.**

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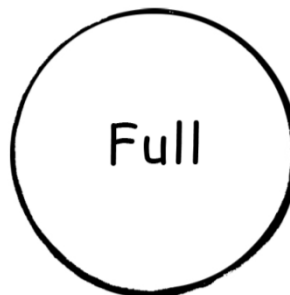
Three-quarter moon



**When my TS is like a three-quarter moon,** it is hard for me to handle. I worry more, and I need more help from my parents and teachers.

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Full moon



**When my TS is like a full moon,** I feel like saying, "Forget it!" I get angry, so I talk with my counselor more often. I need help from grown-ups to explain to other kids what is happening.

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**Moon analogy activities**

**As the adult completes the activities with the student with TS, he or she can gain direct insight into the intervention needed. With this collaboration, they can better identify those Full moon days and create collaborative school team plans.**

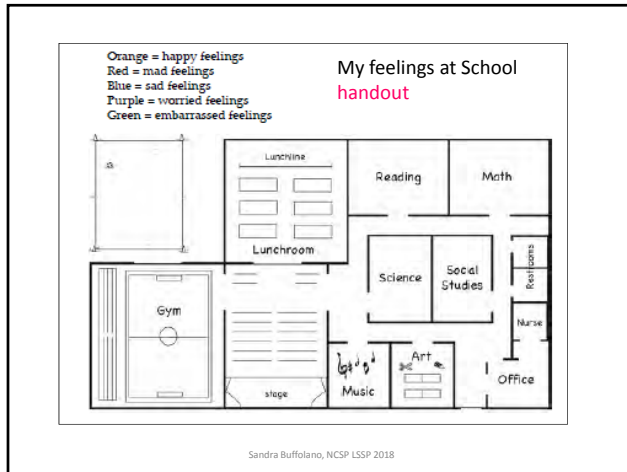
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**Moon analogy activities**

- As the student gains understanding of their personal four phases of the moon, they are asked to address comorbid conditions and to plan ahead for their TS phases.

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40 different activities for school  
and home  
Tourette Simulation GAME



- ### Tourette Association of Texas Services
- In-service programs for professionals, students, parents, and community
  - Consulting
  - Educational programs, conferences, and conventions
  - Dissemination of information – packets, brochures, website
  - Reference library
- Sandra Buffolano, NCSP LSSP 2018
- REFERRALS:
- Physicians
  - Therapists
  - Community services
  - State and county agencies
  - Sources of financial aid
  - Sources of legal aid
  - Support Groups: 9 in TX
  - Katy, Woodlands, Galveston areas

- ### Tourette Association of Texas Services
- Advocacy:
  - Educational and legal empowerment
  - Counseling:
  - Lay Counseling
  - Professional counseling
  - Special funding:
  - Assistance Fund
  - Direct Client Services
  - Educational Scholarship Fund
- Weekend children's camping program for the last 15 years
  - du Ballon Rouge
  - Newsletter email
  - Crisis Intervention
  - 281-238-8096
  - Tourettetexas@aol.com
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## A Camp for kids with Tourette in Texas

- Camp du Ballon Rouge- the red balloon
- Annual weekend in the Spring- 15 years!
- Friday, March 1 thru Sunday, March 3, 2010



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TouretteTexas.org

281-238-8096



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## NATIONAL

- Tourette Association of America
- National website: [tourette.org](http://tourette.org)
- Newsletters for all ages, teacher resources, school psychology resources, handouts, DVDs, books, links, newly diagnosed, clips
- Physician referrals, parent and teen resources, support groups, Facebook

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## What's good to have from Tourette.org?

- The FBA/BIP workbook
- Articles for teachers and administrators:
  - - Tics in the Classroom: An Educator's Guide
  - - Tourettes: Resources for the Classroom
  - - Bullying issues
  - - Educator's Guide for Developing Plans for Students with Tourette Syndrome

Various videos including:

- How to Prepare for a Successful School Year

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## Discussion: Q and A

1. What did you learn that surprised you?
2. Can you think of at least one student you already know that needs to be considered for tics or Tourettes?
3. Who should receive training about tics?
4. What resources do you need to share?

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## Conclusions

- **Challenge** – find those one to five students in each of your schools that can now use your expertise.
- **Use these resources** for students with Tourette, PANDAS, tic disorders and other populations.

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## Resources:

- Tourette America- [tourette.org](http://tourette.org)
- <https://tourette.org/resource>
- TouretteTexas.org
- Additude magazine and Facebook page
- You tube Video: Tourette Syndrome Tic Resource Video
- Baylor College of Medicine video: Tourette Syndrome Up Close
- TLC programming: Raising Tourettes
- <http://www.pandasnetwork.org>
- <https://www.youtube.com/watch?v=MKaA5gGdXag> conversion disorder
- *Coping with Tourette Syndrome: A workbook for kids with tic disorders* [www.newharbinger.com](http://www.newharbinger.com) or amazon

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## Tic Resource Video

- Tourette Syndrome Tic Resource Video
- 10 minutes  
<https://www.youtube.com/watch?v=XjgIfoSIFqQ>
- <https://www.youtube.com/watch?v=XjgIfoSIFqQ>

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