Understanding Tourette Syndrome
And Effective Interventions

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Our Mission Is To Identify The Cause Of, Find The Cure For And Control The Effects Of Tourette Syndrome
“I Have TS but TS Doesn’t Have Me”
"Every adult needs a child to teach. It's how adults learn."

Frank Clark
“Don’t ever tell THEM what you like, because they will either make you earn it or they will take it away”

Young boy
“75 Watts” – documentary can be viewed at drumechoes.com
“CHILDREN DO WELL IF THEY CAN”

“If a child is NOT doing well, there may be a Universe of explanations”.

“If they CAN’T, then it is the job of the adults to figure out why so that they CAN.”

Dr. Ross Greene “The Explosive Child”
Major Life Lesson

We Cannot FIX! – They are not Broken!

BUT we MUST
Teach them
Strategies to
Manage
Symptoms

Tool Box!
TOOLBOX

• Strategies & Techniques = Manage Symptoms
  o Are we looking at the ‘uniqueness’ of every child?
  o Are we considering the complexities of the situation?
  o Are we relying on old tools or are we open to using new tools?

✓ Example of Tools: Computer; Email Homework assignments; Doodle; Music; Sensory diet; Leave class briefly; After school HW; chunking assignments; Mapping, Giving assignments to school secretary, etc.
Tourette Syndrome (TS) • Neuro-biological disorder • Genetic • Involuntary • More common than once thought • Symptoms involve both motor and vocal tics • Due to the nature of TS, symptoms will vary from person to person
The Nature of Symptoms

- Naturally wax and wane
- Change in appearance and frequency
- Change in severity and intensity
  - May worsen during adolescence
- Can sometimes be suppressed for short periods of time
  - But suppression may cause unanticipated and undesirable consequences

Important:

- The Only thing consistent about TS is the Inconsistency
“We believe that Tourette syndrome is commonly misunderstood to be a behavioral or emotional condition, rather than a neurological condition. Therefore including Tourette syndrome in definition of other health impairment may help correct the misperception of Tourette syndrome as a behavioral or conduct disorder and prevent the misdiagnosis of their needs.”
Motor Tics

• Simple Motor Tics
  – Eye blinking, grimacing, nose twitching, leg movements, shoulder shrugs, arm and head jerks, etc.

• Complex Motor Tics
  – Hopping, clapping, throwing, touching (self, others, objects)
  – Holding funny expressions, sticking out the tongue, kissing, pinching, tearing paper or books, etc.
Vocal Tics

• Simple Vocal Tics
  – Whistling, coughing, sniffling, screeching, animal noises, grunting, throat clearing, etc.

• Complex Vocal Tics
  – Linguistically meaningful utterances
    • Coprolalia (racial slurs, inappropriate language), repeating words/phrases

• Speech Atypicalities
  – Unusual rhythms, tone accents, intensity of speech, stutter-like, immature voice

Do Not Need To Swear
Prevalence of Related Disorders

- Obsessive Compulsive Disorder: 25 -50%
- Non-OCD Anxiety Disorders: 30-40%
- Attention Deficit Hyperactivity Disorder: 50-60%
- Mood Disorder: 30-40%
- Learning Disabilities 20-30%
- Written Language Deficits: Extremely Common

Cathy Budman, MD
“YOUR EXPLANATION OF A BEHAVIOR LEADS DIRECTLY TO HOW YOU RESPOND TO IT.”

DR. ROSS GREENE, Ph.D.
Once upon a time, A man whose ax was missing
Suspected his neighbor’s son.
The boy walked like a thief,
Looked like a thief, and
Spoke like a thief.
But the man found his ax, While digging in the valley,
and the next time, He saw his neighbor’s son,
The boy walked, looked, and
Spoke like any other child.

Lao-tzu
“Setting an example is not the main means of influencing another. It is the Only means.”

Albert Einstein
Negative Perspective of Behavior
(the child IS a problem)

Our thoughts:
- mean
- disrespectful
- deliberate

Our feelings:
- angry
- threatened

Our behaviors:
- punish
- offer ultimatum

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Positive Perspective of Behavior (the child **HAS** a problem)

thoughts

unhappy
discouraged
frustrated

behaviors

support
courage
help

feelings

concern
empathy

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“Information is not Knowledge, 
Knowledge is not Wisdom, 
And 
Wisdom is not Foresight. 
But 
Information is the first essential step 
To all of these.”

Arthur C. Clark
“Typical” Strengths

TOURETTE SYNDROME

Charm

Sensitive

Athletic

Focused

Distractable

Humor

Music

Creative

Writing

ART

Science

Creative
“Typical” Related Issues

TOURETTE SYNDROME

Tics

OCD

Anxiety

Handwriting

Sensory

Social Skills

ADHD

LD

Impulsive

Executive Dysfunction.

Disinhibition

Gifted

Sleep

Autism Spectrum
Intellectual disabilities can disguise intelligence.

Disabilities can also disguise intelligence.
Environmental Factors May Impact TS Symptoms

- Stress
- Anxiety
- Excitement
- Fatigue
- Holidays
- Illness
- Vacations
- Hunger
- Life & School Transitions
“ANXIETY IS ALWAYS THE ENEMY OF INTELLIGENCE.”

“The minute anxiety arises, intelligence closes to search for anything that relieves the anxiety.”

Joseph Chilton Pearson
“Meltdown”

A cumulative effect – Rick LaVoie

“Vase” overflows and reaction frequently
Undesirable!

Question: How do we reduce “vase” so less likely to overflow?
“A condition in people with primary neurological disorders that limit a person’s ability to use his inhibitory process and learned inhibitory skills.”

“The individual experiences involuntary behaviors that include contextual swearing, free-associative comments, emotional outbursts, rage, infantile behaviors……..”

Rose Woods

“Dysinhibition Syndrome”
Impulsivity

“REDUCES ABILITY TO INHIBIT BEHAVIORS”

Mental Brakes Malfunction
What to do for anxiety & OCD symptoms

Strategize with student creative ‘solutions’
- To-do-later folder
- Copropraxia – poker chips

- Develop Plan with student – Everyone sign
  - Number of bathroom passes for the day
  - Remove trigger (bend over near student; fire alarm)
  - Write lock combination
  - Schedule in various places
  - Trusted Adult
  - Back-up for trusted adult

- Cognitive Behavior Therapy

Be aware of whether strategy is increasing anxiety
Dysgraphia

• Characteristics may include
  – Slow and laborious writing
  – Hand and finger cramping
  – Sloppy handwriting, e.g., uneven spacing, irregular margins, and inconsistent lettering
  – Inability to copy correctly from book to paper or board to paper
  – Inability to transfer thoughts onto paper

• Can be addressed with the use of computer technologies
How Does Having TS Really Impact Performance And Learning?
What to do About Dysgraphia

• Get evaluations for LD or dysgraphia
  – Use OT and AT services as needed

• Give extra assistance in class
  – Use a scribe, provide class notes, study guides

• Be proactive with assistive
  – Research frequently changing computer software
  – Teach keyboarding early
  – Use of computer at home class
  – Breaks? Scheduled/As needed
SENSORY INTEGRATION
(difficulties processing sensory input)

- Can affect any senses and cause anxiety
- Common indicators are:
  - Sensitivity to sudden touch, the feel of certain fabrics and tags
  - Inability to tolerate texture of certain foods
  - Sensitivity to certain smells, sounds
  - Sensitivity to bright or fluorescent lights
  - Experiencing “sensory tics” e.g. picking at scabs; biting nails, scratching, hurting or hitting self
  - Difficulty - over stimulating environments such as the school bus, cafeteria, gym, hallways, etc.
  - Need for increased sensory input - Running into things purposefully, frequent hugs, painful actions
  - Excessive chewing on clothes, or objects
Executive Functioning Difficulties

- The term “executive functioning” refers to mental processes involved in goal-directed activity.
- Unorganized with:
  - Time
  - Products of any kind (homework, clean room, possessions)
  - Materials
  - Thoughts
- Deficits with:
  - Short term planning
  - Long term planning
- Consequences – are not processed consistently
- Live in the moment

Frontal Lobe impacted; Result = “Output Failure”

Consultant Teacher to Help Manage Work Load & Teach Strategies
Oppositional Defiant Disorder (ODD) NOT a Diagnosis

“Chronically Inflexible”
Dr. Ross Greene

Could be: Means of Communication

We Need to Look for Underlying Reason instead of making assumptions
What Can Be Done for Defiance

- FBA & PBIP
- Discover WHY
  - Inability to complete task?
  - Environmental agitators?
  - Wrong Motivator?
  - Exhaustion?
  - Full Vase?

- Develop a Plan to Provide
  - Supports
  - Accommodations
  - Modifications
IDEA 2004 requires that an FBA be conducted and a behavior intervention plan be developed whenever the behavior of a student interferes with the ability of that or other students to learn.
Definition of FBA

Functional behavioral assessment is the process of determining why an individual engages in challenging behavior and how the behavior relates to the environment.

DOES NOT HAVE TO BE COMPLICATED, EXPENSIVE OR TIME CONSUMING
What is objective of FBA?

• The purpose of a Functional Behavior Assessment is to understand the structure and function of behavior in order to teach and promote effective strategies, techniques and alternatives as well as knowing when it is better to use planned ignorance of the “behavior”.

• Use to Write Positive & Proactive Behavior Intervention Plan
When to Request an FBA

• Behavior referrals, detentions, etc.
• Dropping grades
• Child seems depressed
• Child doesn’t want to go to school
“For any true, complex problem there is always a simple solution which is succinct, brief and ………”

WRONG!!”

Richard Lavoie
Effective FBA’s Don’t Make Assumptions

• Assumptions:
  Attention Seeking; Manipulative;
  Avoidance; Rude, Purposely Disruptive

• Think Outside Box
  • George & Gladys
  • Joe & Sue
  • Man & Cabin
  • 11th grader with backpack
"If you do what you have always done, you’ll get what you’ve always gotten."

Think Outside The Box
For Those Skeptics

Eight
  Five
    Four
      Nine
        One
          Seven
            Six
              Ten
                Three
                  Two
WHAT CAN WE DO FOR THE STUDENT PRIOR TO THE BEHAVIOR INSTEAD OF WHAT DO WE DO TO THEM AFTER THE BEHAVIOR HAS OCCURRED?
Suggestions

- Remain Calm physically & verbally
- Reduce Stress - Anxiety
- Provide time to shift gears (transition)
- Avoid debates, sarcasm, Put Down, Power Struggle
- Choose your battles carefully!!!!!!
- Avoid the word “no”
- Remember the only thing consistent is the inconsistency
- Don’t Take Symptoms Personally
Suggestions

• Allow Movement (doodling, gum chewing, etc)
• Promote hands-on activity
• Support Personnel
  – Study skills
  – Organization strategies & support
  – End of Day check in or Beginning or Middle or......
  – Begin HW; Ensure assignment written down; Email self
  – Assist in Managing Workload/assignments
  – Chunk materials
  – Experiment with strategies
  – Meet with team to assist with understanding difficulties, supports, Strategies & Time/Task Management
Old Adage – In order to be successful, we must work hard!

In order for some students to be successful; they must first experience success.
Most Important

• Trusted person on student Side not on his/her back
• Believe Them – their perspective IS their reality
• Recognize symptoms:
  – Wax & wane
  – May appear purposeful
  – Overflow Vase
  – Maybe suppressed – not necessarily good
  – Tourette is MORE than Tics
• Student needs to know someone believes in him/her
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I want to learn and do well in school!

Will you help me?

Thanks!