HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

Where the world comes for answers

Understanding ADHD in Individuals with Down syndrome

Assessment, treatment, and supports

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Introductions

- Sabrina Sargado, MD: Developmental Behavioral Pediatrician
  - Developmental Medicine Center, Down Syndrome Program
- Cara Soccorso, PsyD: Child Psychologist
  - Newton Neuropsychology Group

Disclosures

- No financial disclosures

Objectives / Goals

- Review neurodevelopmental profile and common behaviors associated with individuals with Down syndrome
- Discuss ADHD criteria: signs and symptoms
- Review considerations for ADHD in DS
- Review steps for evaluation
- Discuss treatments, therapies, and supports

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Down Syndrome Program

Neurodevelopmental Profile

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- **Cognition:**
  - Mild to moderate range of Intellectual Disability
  - Functional skills may be higher, communication skills may be lower
  - Nonverbal stronger than Verbal
- **Long Term Memory:**
  - Explicit / Declarative: Selectively impaired
    - Memory for facts, concepts, events/experiences
  - Implicit / Procedural: Less impaired, relative strength
    - Incidental Learning, memory of skills and tasks
- **Working / Short-Term Memory:**
  - Selective weakness in processing and remembering verbal / auditory information
  - Relative Strengths in processing visual-spatial information

Neurobehavioral Profile

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- Fewer adaptive behavior problems compared to those with other cognitive disabilities
- Noncompliant behavior and difficulty with task persistence are commonly seen
- Often characterized by having strong-willed or stubborn temperament
- May use social distraction as a means of avoiding tasks

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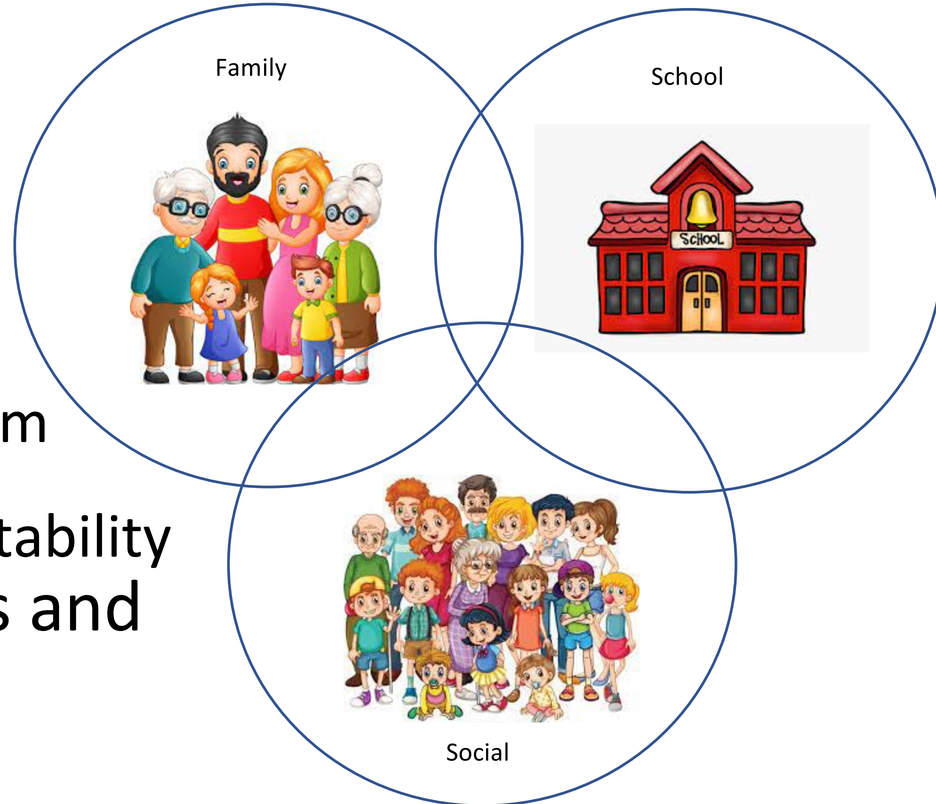
Environmental Factors

- Family:
  - functioning / stress
  - Parent-child relationships
- School
  - Educational setting
  - Appropriateness of curriculum
  - Fit with teacher
  - Level of consistency / predictability
- Strength of social networks and support systems



The Brain Controls Behavior

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Where the world comes for answers

Frontal
- Motivation
- Expressive language

Executive Functioning:
- Attention
- Problem solving
- Impulse Control
- Organization / Planning
- Judgement

Brainstem
- Alertness
- Sleep

Occipital
- Vision / Visual Processing

Parietal
- Visual attention
- Integration of senses

Temporal
- Hearing
- Receptive Language
- Memory
- Emotion

Cerebellum
- Balance
- Motor memory / planning
- Learning

Baumer, 2019

Case 1

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Attention Deficit Hyperactivity Disorder (ADHD)

Where the world comes for answers

Symptoms and/or behaviors that have persisted ≥ 6 months in ≥ 2 settings.
Symptoms have negatively impacted academic, social, and/or occupational functioning.
In patients aged < 17 years, ≥ 6 symptoms are necessary; in those aged ≥ 17 years, ≥ 5 symptoms are necessary.

INATTENTION

- Fails to give close attention to details
- Difficulty sustaining attention
- Does not seem to listen when spoken to
- Does not follow through on instructions/quickly loses focus
- Difficulty organizing tasks
- Avoids, dislikes, or is reluctant to engage in tasks with sustained mental effort
- Loses things necessary for tasks or activities
- Forgetful in daily activities

COMBINED

HYPERACTIVE/IMPULSIVE

- Fidgets with/taps hands or feet/wiggles in seat
- Leaves seat in situations when expected
- Runs or climbs in situations when it's inappropriate
- Unable to play or engage in leisure activities; uncomfortable being still for extended periods of time
- Talks excessively
- Blurts out answers before a question is finished
- Difficulty waiting his/her turn
- Interrupts or intrudes on others

DSM-5 *

ADHD criteria (continued)

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- **D. There is clear evidence that the symptoms interfere with, or reduce the quality of, social, academic, or occupational functioning.**
- **E. The symptoms do not occur exclusively during the course of schizophrenia or another psychotic disorder and are not better explained by another mental disorder (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, Personality Disorder, Substance Intoxication or Withdrawal)**
- **Specify if: In partial remission**: When full criteria were previously met, fewer than the full criteria have been met for the past 6 months, and the symptoms still result in impairment in social, academic, or occupational functioning

DSM-5

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Indications for Co-occurring Diagnosis

- Results in significant impairment in learning, socialization
- Dangerous behaviors / Associated with aggression, injury, destructiveness
- Behaviors occur across multiple environments

Related Challenges

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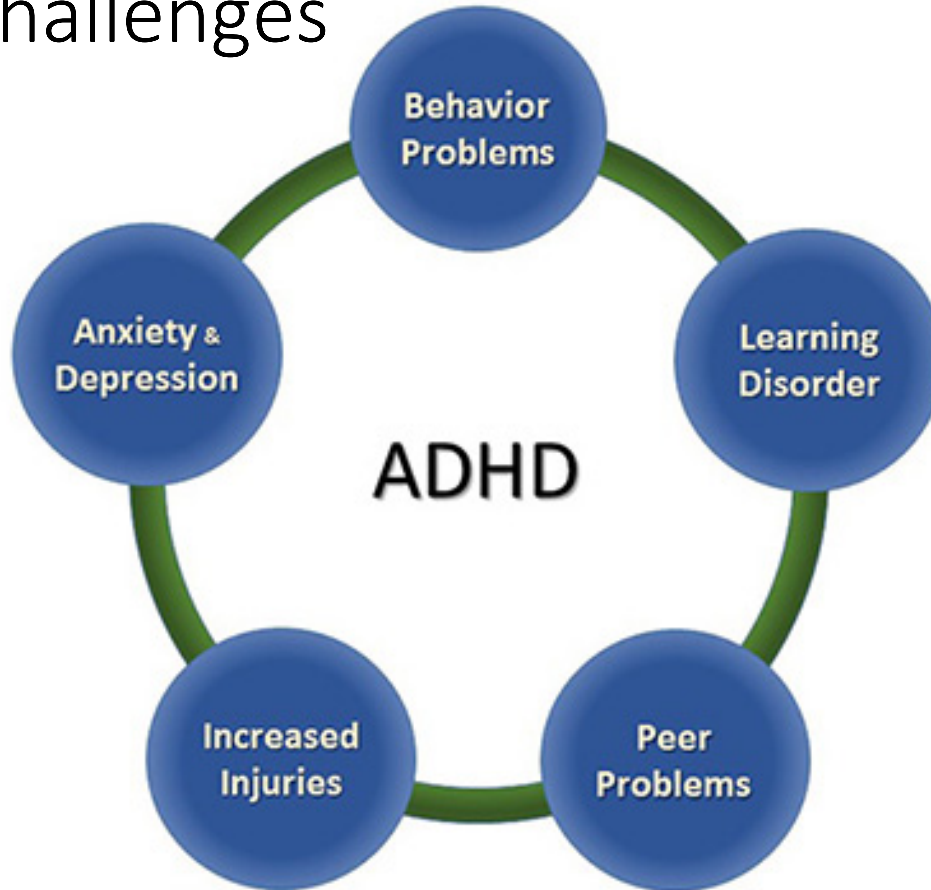

CDC, 2022

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Incidence of ADHD in DS

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- Frequency of ADHD in DS is not known with certainty
  - Incidence has been found to be up to 43.9% (Ekstein et al., 2011)
  - 20% (Dykens et al., 2015)
  - 34% (Oxelgreen et al, 2016)
- More common in young children with DS than children in general population

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Case 2

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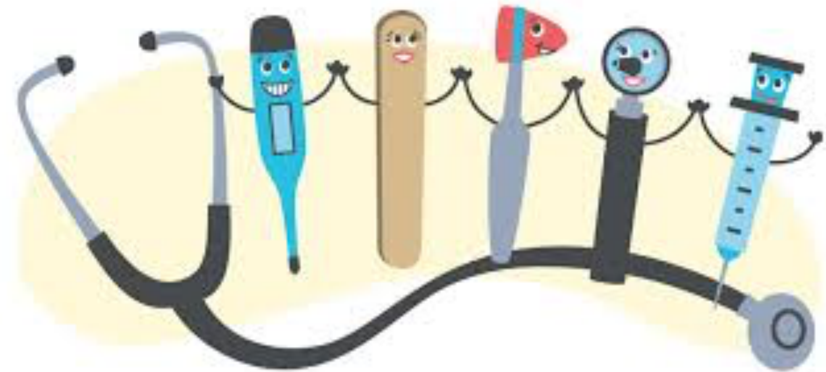
What else can it be?

- Medical Problems in individuals with DS
  - Vision Problems – in 60-80 %
  - Hearing Problems – in 75%
  - Obstructive Sleep Apnea/ OSA/ sleep problems – in 50-79%
  - Thyroid Problems – 50% by adulthood
  - Celiac Disease – 1-5 %

M.Bull et al., 2022

Evaluation

- Check Vision
- Audiology Evaluation
- Sleep Study
- Thyroid function tests
- Check for celiac disorder
- Thorough History and Physical Examination



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What else can it be?

- Mental, Emotional, Behavioral:
  - Anxiety
  - Depression
  - Learning Disorders
  - Language or Communication Disorders
  - Trauma
  - Inappropriate classroom placement or supports

Considerations for ADHD in DS

- Consider individual's developmental level
  - Hyperactivity, impulsivity, and inattention: appropriate for his or her developmental level?
- Communication challenges
- Educational placement/supports/services
  - Schedule, curriculum, no routine
  - Distractions: audio, visual
- Mood, fear, anxiety, physiological states (hungry, tired)
- Behaviors only occurring at certain times of day
- Behavioral issues

Other Common Behavioral Challenges

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- Oppositionality
- Defiance
- Aggression
- Non-compliance
- Irritability, Agitation
- Restlessness
- Anger, Mood swings
- Disruptive
- Destructive
- Tantrums
- Flopping
- Wandering

30% of children with DS may have diagnosable behavior condition

*May be extreme in duration and / or frequency .

**Can pose significant safety risk.

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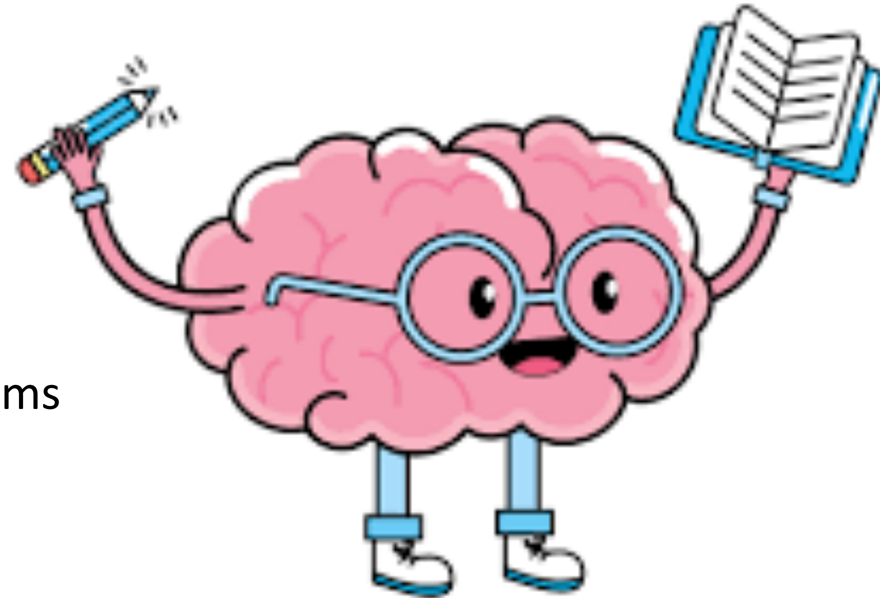
Where the world comes for answers

Psychological Evaluation

- Psychological evaluation
  - Cognitive
  - Academic
  - Language
  - Motor
  - Social-emotional skills
- Rule out other potential causes of symptoms
  - Anxiety
  - Mood disorders
  - Disruptive behaviors
  - Mismatched levels of supports
  - Inappropriate educational setting



Supports and Services

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Home-Based/Treatment Supports:

- Home-based or Center-based ABA Therapy
- In-Home Behavioral Therapy (IHBT)
- Cognitive Behavioral Therapy (CBT)
- Counseling
- Private Services
  - ST, OT, PT
- Many others…

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Supports & Services

School-Based Supports:

- Speech and language therapy
  - Total communication approach
- Occupational therapy
- Physical therapy
- Functional Behavioral Assessment
  - Reinforcer Assessment
- Behavioral supports/accommodations
  - Positive behavioral supports, ABA therapy, etc.
- Extended school year

Case 3

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ADHD Treatment

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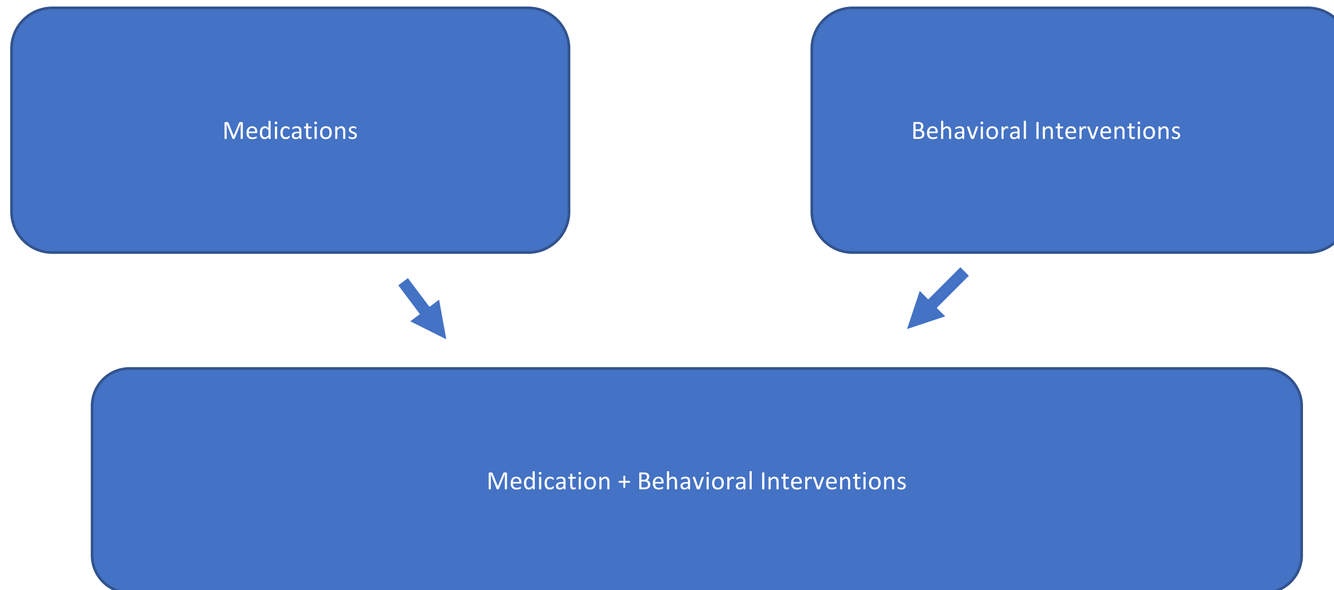
- 3 evidence-based treatments:



Medications

- There is scientific evidence about pharmacologic treatment of ADHD

- We are learning more about pharmacologic treatment of *ADHD in individuals with Down syndrome*

  - Case reports, expert experience
  - Clinical trials/Studies that have been done and are ongoing

Medications: Things to remember before starting

1. It is part of a Treatment Plan – which includes Behavior Supports and accommodations
2. We have to be clear about what we are treating/targeting
3. Medications do NOT teach skills
4. Medication can help an individual access educational and behavioral strategies early
5. Start low, go slow
6. Monitor for effects and side effects

Medication

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Where the world comes for answers

- Stimulant Medications
  - Examples are Adderall, Ritalin a Concerta
- Non Stimulant
  - Guanfacine
    - Trial with ADHD +DS
  - Clonidine

Behavioral Therapy

- Behavioral specialist
  - Behavior therapist, cognitive behavioral therapist, BCBA
- Parent training
  - Time-limited therapy teaching parents strategies for managing child's symptoms of ADHD
- Behavioral planning at home & school
  - Help establish behavioral plans in both settings
- Finding a therapist:
  - https://www.abct.org
  - https://www.psychologytoday.com/us/therapists
  - https://www.findatherapist.com
  - School and current providers may also have suggestions for local supports

Other suggestions/accommodations

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- Token reward system for target behaviors
- Preferential seating near teacher
- Frequent praise and positive attention
- Clear explanations of classroom rules and expectations
- Frequent breaks, including motor breaks
- Maximize outdoor time and gross motor activity
- Shorter work periods
- Daily Report Card (DRC)

Who else can help ?

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- School Teacher
- School Psychologist
- Primary Care Provider/Pediatrician
- Psychologist in the community
- Behavior therapist/therapists
- Other familiar care providers

Resources

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- Attention Problems in DS
- Finding a therapist:
  - https://www.abct.org
  - https://www.psychologytoday.com/us/therapists
  - https://www.findatherapist.com
- Resources, Advocacy, Education:
  - https://chadd.org
- Daily Report Cards:
  - https://www.additudemag.com/daily-report-card-to-improve-adhd-classroom-behavior/
  - http://www.healthyinfo.com/consumers/ho/ADD.daily.report.card.pdf
- Books:
  - Taking Charge of ADHD: The Complete Authoritative Guide for Parents by Russell A. Barkley, PhD