



NEW ENGLAND
NEURODEVELOPMENT, LLC

SUPPORTING POSITIVE BEHAVIOR IN CHILDREN AND TEENS WITH DOWN SYNDROME: THE RESPOND BUT DON'T REACT METHOD

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Founder, New England Neurodevelopment, LLC

David Stein, 2019

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BRIEF BACKGROUND

- The year, 2002
- My job, “Child Behavior Specialist”
- My training, a degree in clinical psychology and child development
- My success rate, TERRIBLE

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REMEMBER: THIS IS HARD WORK AND NOBODY HAS 100% SUCCESS. OUR GOAL IS NOT PERFECTION, IT IS IMPROVEMENT.

BEHAVIOR



TIME

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AS PARENTS AND PROVIDERS, WE HAVE TO KEEP OUR EYES ON THE LONG-TERM PRIZE AND REMEMBER TO TAKE CARE OF OURSELVES



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EPIDEMIOLOGY

HOW COMMON ARE BEHAVIOR PROBLEMS IN CHILDREN WITH DS?

- ~30% of children with DS have diagnosable behavior condition
- 10% of typically developing children have diagnosable behavior condition, meaning children with DS are 3X more likely
- Many more present with common behavior problems that can still get in the way, even without a diagnosis
- Behavior problems in childhood predict the same in adulthood
- Behavior problems in adults with DS can interfere with living in the LRE, working, and having a social life.
 - We need to intervene!

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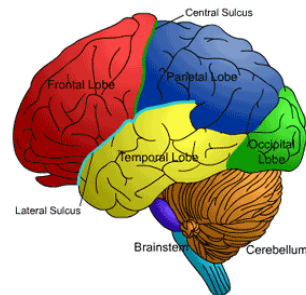
McCarthy, 2008
Cuskelly & Dadds, 1992

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ETIOLOGY

WHY DO CHILDREN WITH DS HAVE BEHAVIOR PROBLEMS?

- Brain Differences
 - Reduced growth in the frontal lobe
 - Smaller brain stem and cerebellum
 - Problems in the temporal lobe and hippocampus



Nadel & Fidler, 2007

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WELL THAT'S A NICE PICTURE...
BUT WHAT DOES THAT MEAN?

*THE CONSEQUENCES OF BRAIN
DIFFERENCES IN DS*

- Social
 - Often hyper-aware (remember this for later) and hyper-engaged
 - Hyper-aware can also mean hypersensitive*
 - “Social-Emotional Radar”
 - “Aggressive social problem solving”
- Language
 - Stronger receptive vs. expressive
 - Difficulty with articulation and formulating ideas → frustration!

Nadel & Fidler, 2007

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THE CONSEQUENCES OF BRAIN DIFFERENCES
IN DS, CONTINUED

- Information Processing & Memory
 - Stronger visual, less robust verbal processing
 - Challenges with encoding and consolidation, prefer repetition
 - The world is ever-changing, and scary?
- Motivation Differences
 - Challenges in intrinsic motivation
 - Greater frustration, over time, can lead to greater avoidance
 - Or...”Gas in the tank” theory
- Executive Functioning
 - May not see the stop signs (e.g., impulsivity)
 - May struggle to plan a behavior and/or consider its consequences

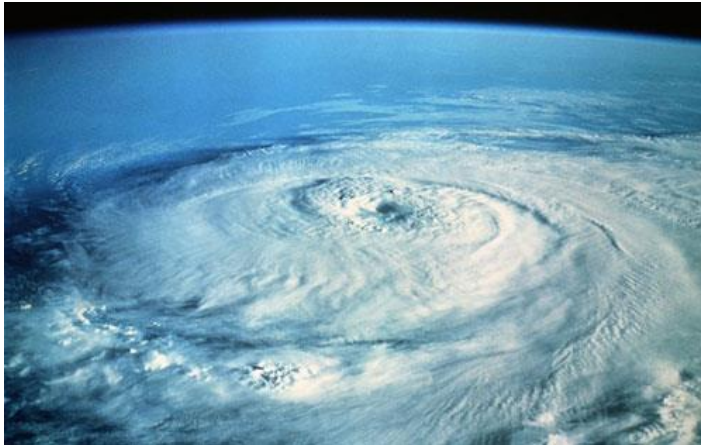
Nadel & Fidler, 2007

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WE LIVE IN A COMPLEX WORLD WITH LOTS OF DEMANDS,
LANGUAGE, AND OTHER SOURCES OF FRUSTRATION.

THIS IS A PERFECT STORM FOR CHILDREN WITH DS TO BE
FRUSTRATED IF NOT WELL-SUPPORTED AND UNDERSTOOD.



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SO NOW THAT WE KNOW WHY BEHAVIOR
PROBLEMS SHOW UP, WHAT CAN WE
DO ABOUT THEM???

The BIG Picture

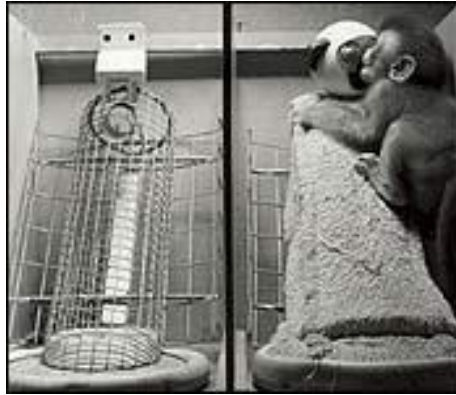
1. **Child-Parent Relationship**
2. Behavioral Principles
3. Functions of a Behavior
4. POSITIVE Behavior Strategies
5. Focusing on and leveraging strengths
6. Effective Discipline

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THE RELATIONSHIP

Harry Harlow, 1959



When you don't know what to do,
consider what is best for your
relationship.

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What to do about behavior.

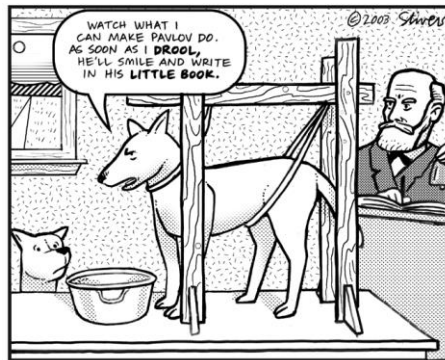
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THE BASICS OF BEHAVIOR- EASY TO UNDERSTAND, VERY HARD TO DO.

- “Reinforce” what you want to see more of.
- Do NOT reinforce what you want to go away.



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HOW DO WE REINFORCE GOOD BEHAVIOR?

- Attention!
 - Notice the behavior and react to it (“Hawthorne Effect”)
 - The “MAGIC” of Weight Watchers...
 - Even more effective for highly sociable individuals
- Praise!
 - Comment on the behavior and have a little party



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HOW DO WE REINFORCE GOOD BEHAVIOR? CONTINUED

- Token Economy...
 - Sounds much fancier than it is
 - Pick a few goals, build a structure, reward them
 - KEEP IT SIMPLE- “Explain it to me.”
 - Complex ≠ effective.
 - It’s not only for children, it’s a reminder for adults
- Why do token economies work for those w/ DS?
 - We are supporting the unique brain profile by using:
 - Visuals
 - Repetition
 - Motivators
 - *Attention* for positive behaviors

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A SAMPLE TOKEN ECONOMY

THE “APPLE” APPROACH– *SIMPLE IS ELEGANT*



	Bath Time	Pajamas	Brush teeth	Prize!
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				

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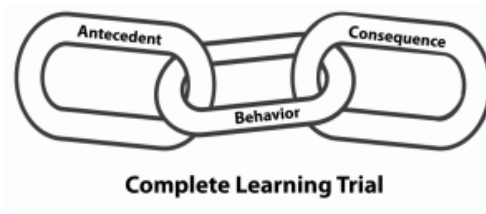
WHAT TO DO ABOUT BEHAVIOR.

1. Child-Parent Relationship
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EVERY BEHAVIOR HAS A PURPOSE. IN ORDER TO ADDRESS BEHAVIORS, WE ALSO NEED TO UNDERSTAND WHAT THEIR FUNCTION IS.



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FUNCTIONS OF A BEHAVIOR: THE BIGGIES IN DS

- Escape/Avoidance
 - E.G., Math is hard, RUN!
 - E.G., I don't want to leave the birthday party, STOP AND FLOP!
- Attention-seeking
 - E.G., These adults aren't paying attention to me, and these toys stink. LIGHTS OUT!
 - E.G., I don't have the language to ask another child to play, WHACK!

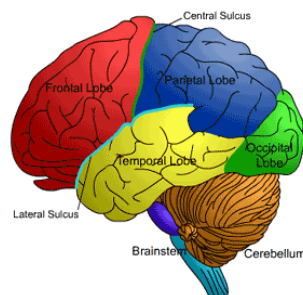
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WHY ARE ESCAPE/AVOIDANCE AND ATTENTION SEEKING SO COMMON IN INDIVIDUALS WITH DS?

- Let's go back to the brain
 - Lower intrinsic motivation → Get me out of here!
 - Hyper-social + reduced impulse control → I'll do anything to get some attention!

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WHAT TO DO ABOUT BEHAVIOR.

1. Child-Parent Relationship
2. Behavioral Principles
3. Functions of a Behavior
4. **POSITIVE Behavior Support Strategies**
5. Focusing on and leveraging strengths
6. Effective Discipline

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WHEN ESCAPE/AVOIDANCE IS DRIVING A BEHAVIOR,
THERE ARE MANY TOOLS WE CAN USE TO HELP BOOST
MOTIVATION, EVEN FOR NON-PREFERRED TASKS



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THERE ARE MANY POSITIVE BEHAVIOR STRATEGIES AND WE CANNOT GO THROUGH THEM ALL. INSTEAD WE WILL FOCUS ON A FEW OF THE MOST POWERFUL **TOOLS** FOR CHILDREN WITH DS.

- Choices
 - “Brush teeth or potty first?”
- Redirection
 - “Please help me set the table”
- Providing the carrot (First-then instructions)
 - “First do homework, then watch Cash Cab.”



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WHEN ATTENTION SEEKING IS DRIVING A BEHAVIOR, WE HAVE A VERY EASY OPTION FOR INTERVENTION.

- An example:
 - *Joshua loves to go into his sister’s room and jump on the bed. When he does this, his sister and father run into the room and become very upset. Joshua laughs and laughs and continues doing this until physically removed by his father.*
- What is the function of this behavior?
- What is reinforcing this behavior?
- What could be done differently?

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PLANNED IGNORING- AN EASY GUIDE

- Based on Ross Greene, PhD, The Explosive Child
- “Baskets” of Ignoring
 - Basket 1- Safety issue, intervene
 - Example: Running into the street
 - Basket 2- Frustrating for all, and one of things we are working on. Let it go or intervene depending on the timing
 - Example- Eating dinner on the couch, not at the table
 - Basket 3- Annoying, but not really causing any harm. IGNORE it.
 - Example- Humming, tongue clicking

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THIS SEEMS VERY SIMPLE, BUT WHEN WE ARE
IN THE MOMENT, IT IS VERY DIFFICULT TO
REMEMBER THESE PRINCIPLES.



D. Stein, Circa 2002?

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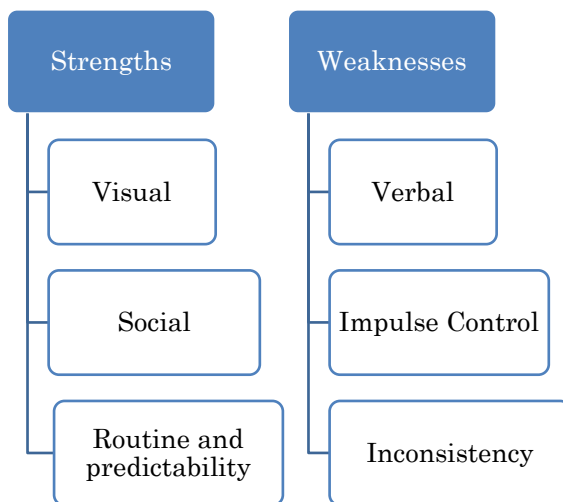
WHAT TO DO ABOUT BEHAVIOR.

1. Child-Parent Relationship
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4. POSITIVE Behavior Strategies
5. Focusing on and leveraging strengths...to adapt the environment.
6. Effective Discipline

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LET'S REVISIT THE BRAIN-BASED STRENGTHS AND WEAKNESSES IN CHILDREN WITH DS...

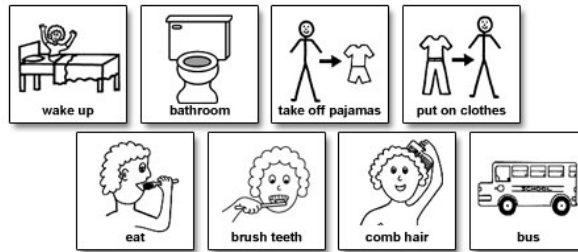


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ON A DAY TO DAY BASIS, WE CAN USE THIS UNDERSTANDING TO STRUCTURE THE ENVIRONMENT AND BRING OUT THE BEST IN CHILDREN WITH DS.

- Keep a routine that provides “sameness”
 - Making the world a more predictable place
- Make that routine visual



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STRUCTURING THE ENVIRONMENT, CONTINUED

- Time is abstract
- Use visual timers



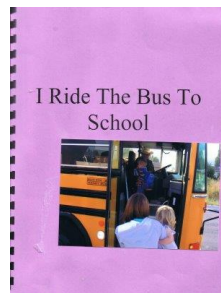
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- Use **social** motivators and rewards
 - Attention!
 - “First clean up, then play with mommy.”

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STRUCTURING THE ENVIRONMENT... FOR DIFFICULT SITUATIONS

- Sometimes, particular situations are hard for children with DS.
- We can use the same ideas and add structure, visuals, and repetition for difficult situations with “Social Stories”
- OR...”Video Modeling”

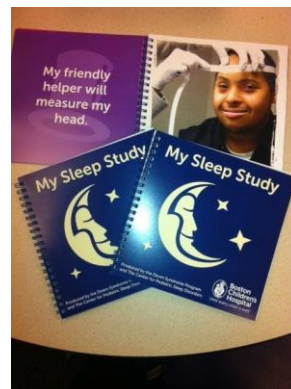


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SOCIAL STORIES- THE BASICS

- Mostly pictures, few words
- Simple, simple, simple
- Shows sequence of events
- Shows DESIRED behaviors
- Lots of repetitions
- Read it as a bedtime story?



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KNOWING THE STRENGTHS AND WEAKNESSES IN DS, WE ALSO KNOW WHAT TO AVOID WHEN STRUCTURING THE ENVIRONMENT

- “Blah, blah, blah...”
 - “Now Jonathan, there is no hitting in this household and if you do you will be in time out!”
 - Or....”No hit.”
- Inconsistency/unpredictability
 - In other words– not keeping a routine
- Social responses for behaviors we don’t want to see
 - Or....Getting upset when your child acts out



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WHAT TO DO ABOUT BEHAVIOR.

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5. Focusing on and leveraging strengths
6. **Effective Discipline**

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NOTICE THAT DISCIPLINE IS LAST AND WE DISCUSSED MANY OTHER WAYS OF MANAGING BEHAVIOR?

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"You'd think if they really wanted to punish me they'd send me to their room!"

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WHY AREN'T WE TALKING MORE ABOUT DISCIPLINE?

- POSITIVE behavior supports > Punishment for all children
- Even more so for DS
 - Remember that, social-emotional radar?
- We often discipline when angry
 - Anger → Strong facial expressions and tone of voice
 - Strong expression/voice → Reinforcing

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DISCIPLINE COMES BACK TO THE BASICS OF BEHAVIOR—REINFORCE WHAT YOU WANT TO SEE MORE OF, AND DO NOT REINFORCE WHAT YOU WANT TO SEE LESS OF.

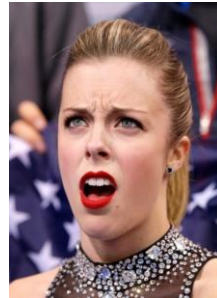
- For reinforcement, we focus on *adding*...
- For discipline, we focus on taking things *away*...

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TO DISCIPLINE EFFECTIVELY, REMEMBER THE BRAIN PROFILE IN DS.

- **Remove Social Reinforcers**
 - DO NOT make eye contact
 - DO NOT use language to reason
 - DO NOT raise your voice
 - DO NOT make strong facial expressions**
- “Social-Emotional Radar”
- Be careful– your face can say a lot...



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WHEN YOU HAVE TO INTERVENE... “RESPOND BUT DO NOT REACT.”

- **Remove** any facial expression or eye contact
- **Remove** a child from the situation
- **Remove** others from the proximity of the child
- **Remove** objects from the environment (e.g., “response cost”)

*Similar to time out, but not the usual time out....

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THE PATTERN OF BEHAVIORAL HEALTH CHALLENGES IN DOWN SYNDROME: CHANGES IN BEHAVIORAL HEALTH IN ADOLESCENCE

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EARLY CHILDHOOD IN DS

- Social
 - Often successful, the “mayor”
 - Often included in school and extra-curricular activities
 - Inclusion has become the norm
 - Structured activities, adult-organized and supported
- Academic
 - Gap between typical peers and those with DS is smaller
 - High degree of structure, consistency
 - Few transitions
 - Inclusion is more successful

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PSYCHOLOGICAL PROFILE OF DS IN EARLY CHILDHOOD

- Mood/Affect: often described as bright, “happy all the time”
- Behavioral:
 - Attention-seeking and avoidance are common
 - Can often be managed successfully
 - High degree of social awareness, wish for acceptance, learning from peer models
 - Strategies such as ignoring and token systems work well
 - Comorbidities emerge (e.g., ASD, ADHD)

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TRANSITION TO MIDDLE/HIGH SCHOOL

- Often a time of new onset behavioral and/or emotional challenges
- For those with previous challenges, often a time of exacerbation

WHY?

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CHALLENGES AT TRANSITION TIMES

- Social
 - Peer interactions become more fluid, less structured, less adult-supported
 - Social opportunities rely on language, problem solving/EF, and shared interests and abilities (e.g., sports teams)
- Academic
 - Ability gap widens
 - Structural changes- transitions, multiple classrooms,
 - Multiple teachers, expectations, demands
- Physical
 - Onset of puberty- hormonal/body changes
 - Changes in physical appearance and emotional lability

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CASE EXAMPLE- SCOTT

- Started in DS clinic at age 3. Medically healthy, very few challenges
- Very much involved in community and included well by peers. Part of the “cool group”
- Academically strong- 3rd grade reading, 2nd grade math, functional writing skills
- Great language, very sociable and endearing
- Talented athlete, played on community teams

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SCOTT’S TRANSITION TO MIDDLE SCHOOL

- At age 12, in grade 6, Scott became very anxious (re: facial hair, friends).
- Parents noted increased self-talk, hyperfocus on videos he watched as a younger child, spending a great deal of time in his room.
- Not invited to play dates anymore. Peers were interested in him, but parents were no longer arranging social events.
- Scott was "included" in birthday parties, etc, but not in every day “hang outs.” He began to feel isolated.
- Academically, Scott began to struggle. He could no longer keep up with the reading and math assignments and spent more time being pulled out.

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SCOTT'S TRANSITION, CONTINUED

- After a few months in grade 6, he ran away from his house and was found by the police 3 miles away near the woods, very upset.
- At school, he began to pull his pants down and even urinated in the classroom.
- Scott talked to himself all day long.
- His parents worried he was becoming psychotic.

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WHAT DID WE DO FOR SCOTT?

- Neuropsychological testing to clarify function and diagnoses (psychosis and regression ruled out)
- Structured activities (e.g., sports, clubs)
- Restructured his school day to optimize his inclusion time and reduce frustration
- Began cognitive behavioral therapy
- Medication consultation

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How did Scott do?

- Scott did not become frankly depressed, and his behavior improved again.
- Scott continued to feel left out, to isolate himself at home, and to be very anxious.
- With supports and structure, he continued to improve but struggled in some ways.

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WHAT DID WE LEARN FROM THIS?

- Prevention, Prepare for the transition
 - Plan for the new school year academically, socially, extra-curriculars?
 - Social stories and visits?
 - Supportive counseling as a prevention tool?
 - Continued need for parental involvement in arranging social engagements?
- Peers in the DD community
- Would medication have made/make a difference?
- We are now intervening more comprehensively before such transitions and seeing better results.

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TAKE HOME POINTS- ADOLESCENCE

- Due to social, academic, and physical changes, transition to middle/high school can be very challenging.
- Both externalizing and internalizing behaviors can arise, and/or worsen.
- Behaviors can be scary for families, and mimic concerning processes such as psychosis.
- Comprehensive supports (behavioral, medical, social, academic) likely provide the greatest odds of smooth transition and/or recovery.
- Increased awareness by families and clinicians should help us to be proactive in providing added structure and supports, to ideally prevent some of these challenges.



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WHEN YOU NEED MORE HELP

- Turn to professionals to clarify what is happening
 - FBA
 - Medical evaluation
 - Developmental/Neuropsychological testing
- Is there another condition that needs treatment?
 - Behavioral or psychiatric disorder?
 - Sleep disorder or celiac disease?
- Is the environment causing problems?
 - Classroom?
 - Losses?

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RESOURCES

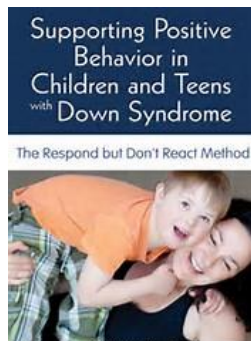
- Professionals- MDs, Psychologists, Behaviorists
 - Diagnostic- Behavior assessment, testing
 - Intervention- Medication, therapies, consultation
- School- Functional Behavior Assessments (FBA), ABA strategies/techniques
- Community- National Down Syndrome Congress, National Down Syndrome Society, Boston Children's Crocker Series

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MORE INFORMATION

- Supporting Positive Behavior in Children and Teens with Down syndrome: The respond but don't react method. Woodbine House, 2016



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SO, WHEN WE ARE DEALING WITH BEHAVIOR FOR ANY CHILD, WE MUST CONSIDER HOW THIS CHILD SEES THE WORLD AND LEARNS FROM IT.

THIS UNDERSTANDING WILL MAKE US MOST EFFECTIVE.

- For children with DS, we have, maybe, a greater understanding of how the brain works and therefore what strategies will work.



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SOME CLOSING POINTS...

- Focusing on your relationship, the positive, and the strengths of a child will help you choose and utilize the best behavior strategies.
- The goal is not perfection, our goal is improvement.
- The “endpoint” is not tomorrow or next month. It is the individual with DS having a fulfilling adulthood and not being limited by behavior problems.

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THANK YOU!

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QUESTIONS?

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