

NEW ENGLAND
NEURODEVELOPMENT, LLC

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

DAVID STEIN, PSY.D.
PEDIATRIC PSYCHOLOGIST
Founder, New England Neurodevelopment, LLC

David Stein, 2019

WHAT MAKES PEOPLE HAPPY?

David Stein, 2019

HARVARD ADULT DEVELOPMENT STUDY

- o <https://www.adultdevelopmentstudy.org/>
 - Tending to health matters
 - Wealth and education matter less
 - Tending to relationships makes people happiest
- In other words, happiness is about relationships.
- That is our guide for behavior management.
- Especially during a quarantine!

David Stein, 2019

BRIEF BACKGROUND

- o The year, 2002
- o My job, "Child Behavior Specialist"
- o My training, a degree in clinical psychology and child development
- o 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, TEACHERS, AND PROVIDERS, WE HAVE TO KEEP OUR EYES ON THE LONG-TERM PRIZE AND REMEMBER TO TAKE CARE OF OURSELVES AND OUR RELATIONSHIPS



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David Stein, 2019



EPIDEMIOLOGY
HOW COMMON ARE BEHAVIOR PROBLEMS IN CHILDREN WITH DS?

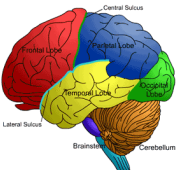
- ~30% of children with DS have diagnosable behavior condition
- 10% of typically developing children have diagnosable behavior condition, meaning children with DS are 3X more likely
- Many more present with common behavior problems that can still get in the way, even without a diagnosis
- Behavior problems in children with DDs 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!

David Stern, 2019

McGuffey, 2008
 Fuchsler & Fidler, 2007

ETIOLOGY
WHY DO CHILDREN WITH DS (AND OTHER DDs) 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

David Stern, 2019

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

David Stern, 2019

THE CONSEQUENCES OF BRAIN DIFFERENCES
IN DS, CONTINUED

- o Information Processing & Memory
 - Stronger visual, less robust verbal processing
 - Challenges with encoding and consolidation, prefer repetition
 - o The world is ever-changing, and scary?
- o Motivation Differences
 - Challenges in intrinsic motivation
 - Greater frustration, over time, can lead to greater avoidance
 - Or... "Gas in the tank" theory
- o 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

David Stern, 2019

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 AND
OTHER DDs TO BE FRUSTRATED IF NOT WELL-SUPPORTED
AND UNDERSTOOD.



David Stern, 2019

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

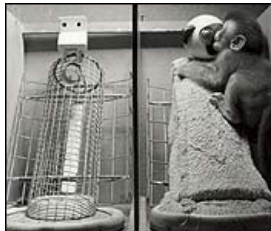
The BIG Picture

1. Adult-Child 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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ATTACHMENT THEORY

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.

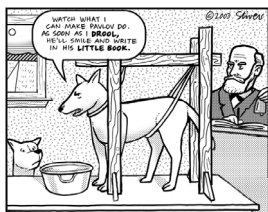
1. Child-Parent Relationship
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David Stein, 2019



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

- o "Reinforce" what you want to see more of.
- o Do NOT reinforce what you want to go away.




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HOW DO WE REINFORCE GOOD BEHAVIOR?

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



"Now will you pay attention to me?"

David Stein, 2019





HOW DO WE REINFORCE GOOD BEHAVIOR? CONTINUED

- o Token Economy...
 - Sounds much fancier than it is
 - o 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

David Stein, 2019

A SAMPLE TOKEN ECONOMY

THE “APPLE” APPROACH— *SIMPLE IS ELEGANT*

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

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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
 - Support the *relationship* by taking the pressure off of interactions around behavior



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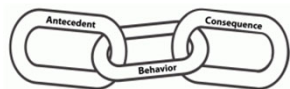
WHAT TO DO ABOUT BEHAVIOR.

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

David Stein, 2019



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



Complete Learning Trial

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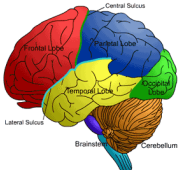
**FUNCTIONS OF A BEHAVIOR:
THE BIGGIES IN DS AND DDS**

- 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!



David Stern, 2019


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

David Stern, 2019

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


DISCLAIMER: YOU KNOW THESE!



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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 DDS.

- 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

- o Based on Ross Greene, PhD, The Explosive Child
- o "Baskets" of Ignoring
 - Basket 1- Safety issue, intervene
 - o 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
 - o Example- Eating dinner on the couch, not at the table
 - Basket 3- Annoying, but not really causing any harm. IGNORE it.
 - o 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?

David Stein, 2019

WHAT TO DO ABOUT BEHAVIOR.

1. Child-Parent Relationship
2. Behavioral Principles
3. Functions of a Behavior
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...

Strengths	Weaknesses
Visual	Verbal
Social	Impulse Control
Routine and predictability	Inconsistency

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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

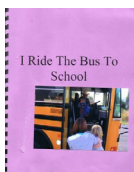


- Use social motivators and rewards
 - Attention!
 - "First clean up, then play with mommy."

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STRUCTURING THE ENVIRONMENT... FOR DIFFICULT SITUATIONS

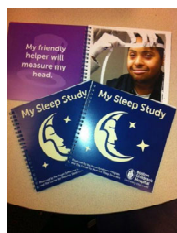
- Sometimes, particular situations are hard for children with DS.
- We can use the same ideas and add structure, visuals, and repetition for difficult situations with "Social Stories"
- OR..."Video Modeling"



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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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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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WHY AREN'T WE TALKING MORE ABOUT DISCIPLINE? HOW DO YOU FEEL WHEN YOU ARE DISCIPLINING?


- o POSITIVE behavior supports > Punishment for all children
- o Even more so for DS
 - Remember that, social-emotional radar?
- o 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.

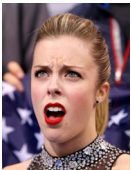
- For reinforcement, we focus on *adding*...
- For discipline, we focus on taking things *away*...

David Stein, 2019




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...



David Stein, 2019




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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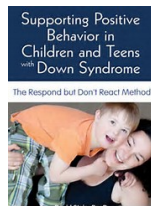
WHEN YOU NEED MORE HELP

- 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?

David Stein, 2019



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



David Stein, 2019



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.




David Stein, 2019



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.

David Stein, 2010



QUESTIONS?

David Stein, 2010

