



BEHAVIOR & DOWN SYNDROME

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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**



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

BEHAVIOR



TIME



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



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HOW COMMON ARE BEHAVIOR PROBLEMS IN CHILDREN WITH DS?

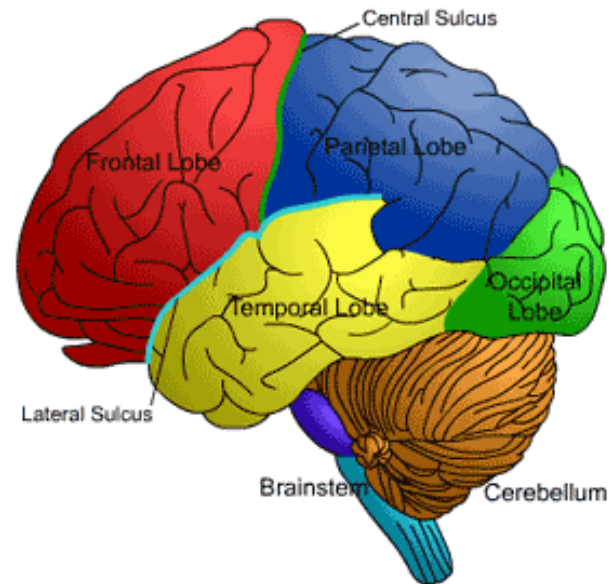
- 30% of children with DS have diagnosable behavior condition
- Many more present with common behavior problems that can still get in the way, even without a diagnosis
- Behavior problems in childhood predict the same in adulthood
- Behavior problems in adults with DS can interfere with living in the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



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 damage to hippocampus



Nadel & Fidler, 2007



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

- Social
 - Often hyper-aware (remember this for later) and hyper-engaged
 - “Aggressive social problem solving”
- Language
 - Stronger receptive vs. expressive, difficulty with formulating ideas
 - Increased likelihood of frustration
- Information Processing
 - Less robust processing/memory for language
 - Very robust processing/memory for visuals
- Motivation Differences
 - Challenges in intrinsic motivation
 - Greater frustration, over time, can lead to greater avoidance
- “Executive Functioning”
 - May not see the stop signs (e.g., impulsivity)
 - May struggle to plan a behavior and/or consider its consequences



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.



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



THE RELATIONSHIP

Harry Harlow, 1959



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



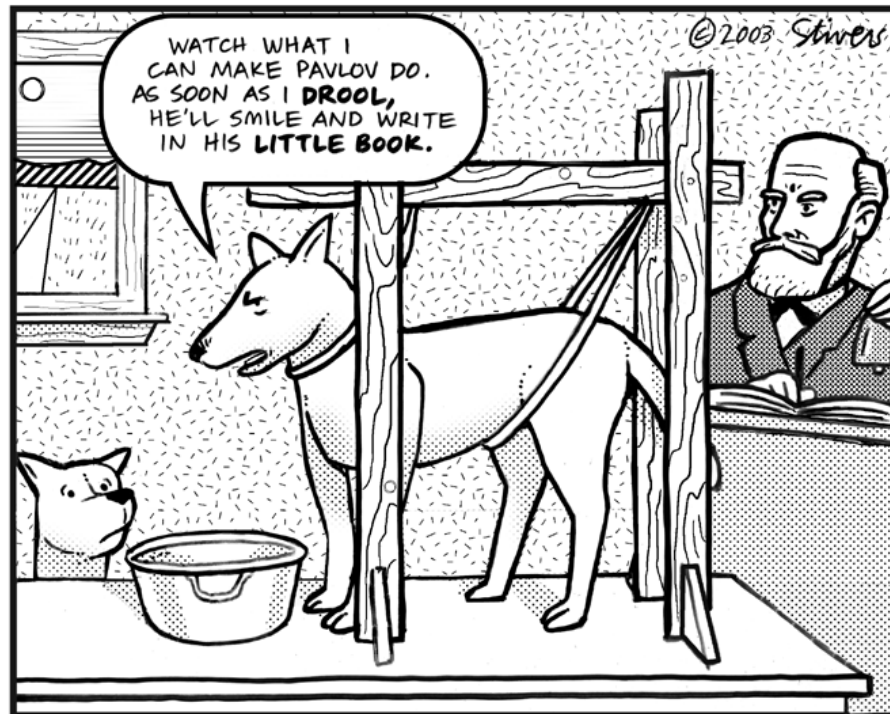
What to do about behavior.

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



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.



HOW DO WE REINFORCE GOOD BEHAVIOR?

- Attention!
 - Notice the behavior and react to it
 - The “MAGIC” of Weight Watchers...
- Praise!
 - Comment on the behavior and have a little party
- Token Economy...
 - Sounds much fancier than it is
 - Pick a few things you'd like to see more of, build a structure around them, and find a motivating reward.
 - It's not only for children, it's also a way to remind us adults to notice the good stuff
 - Complex ≠ effective. **KEEP IT SIMPLE.**



A SAMPLE TOKEN ECONOMY FOR A CHILD WITH DS



	Pants on	Shirt on	Brush teeth	Prize!
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				



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



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

The BIGGIES in DS

- Attention-seeking
 - E.G., These adults aren't paying attention to me, and these toys stink. I'm going to turn the lights off in Dr. Stein's office!
 - E.G., I don't have the language to ask another child to play, so I am going to pinch him to get his attention.
- Escape/Avoidance
 - E.G., Math is hard, so I am going to run out of the classroom to avoid it.
 - E.G., I don't want to leave the birthday party, so I will flop to the floor and refuse to move.



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?



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



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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



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”
- Replacement behaviors
 - Holding hands while walking down the stairs to avoid pushing
- Providing the carrot (First-then instructions)
 - “First do homework, then watch Cash Cab.”



David Stein, 2012

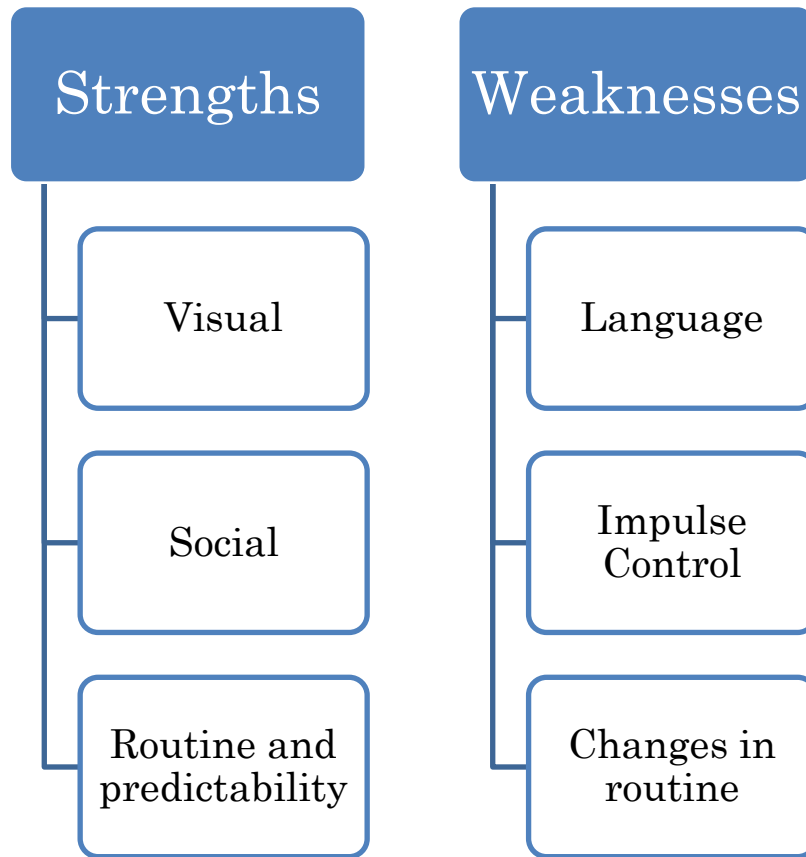


WHAT TO DO ABOUT BEHAVIOR.

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

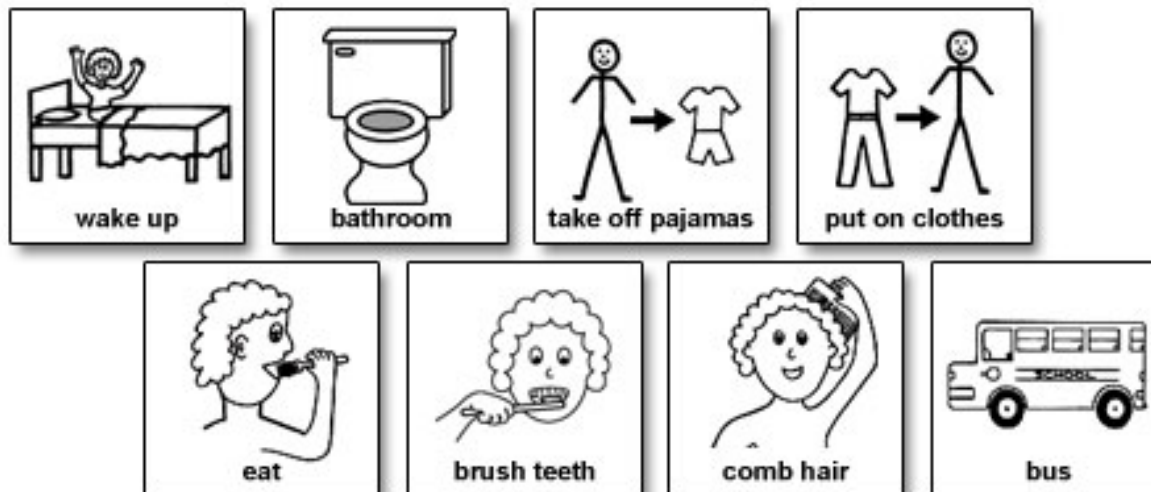


LET'S REVISIT THE BRAIN-BASED STRENGTHS AND WEAKNESSES IN CHILDREN WITH DS...



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”
- Make that routine visual



STRUCTURING THE ENVIRONMENT, CONTINUED

- Use visual timers

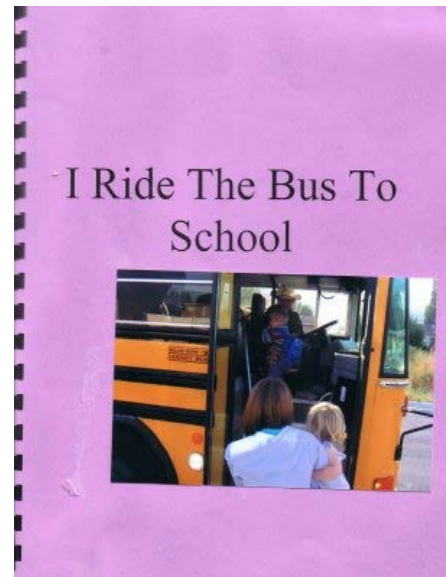


- Use **social** motivators and rewards
 - Attention!
 - “First clean up, then play with mommy.”



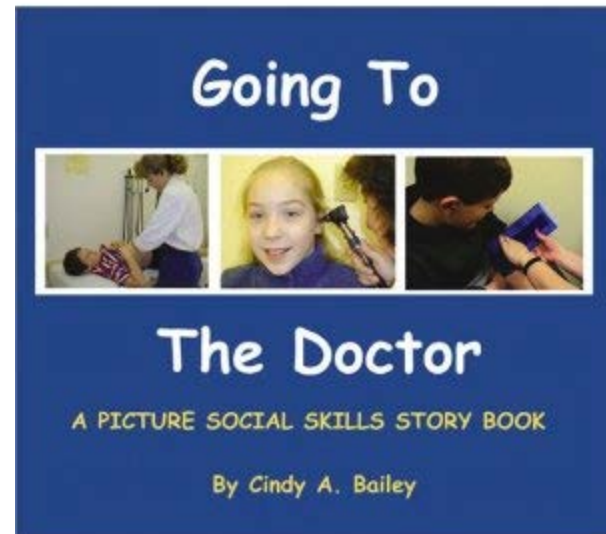
STRUCTURING THE ENVIRONMENT, CONTINUED...WHEN THINGS GET TOUGH...

- 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”



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?



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
- Social responses for behaviors we don't want to see



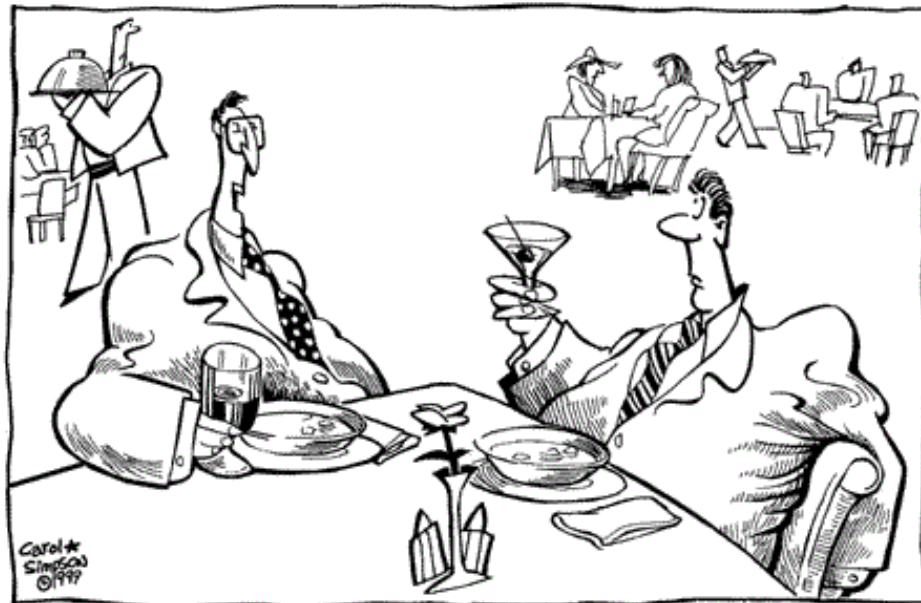
WHAT TO DO ABOUT BEHAVIOR.

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**



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

- This is because children with DS respond far better to POSITIVE behavior supports than to discipline AND there are many ways to deal with behavior without disciplining.



*"Positive reinforcement may be more productive, but, dammit...
it's just not as much fun."*

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.



WHEN WE DO HAVE TO DISCIPLINE, WE NEED TO CONSIDER HOW A CHILD WITH DS THINKS AND LEARNS, AND ADJUST ACCORDINGLY.

○ What NOT to do....

- DO NOT make eye contact
- DO NOT make strong facial expressions
- DO NOT yell
- DO NOT use language to reason

○ REMEMBER...

- Each of these reactions can actually reinforce a behavior by making it FUN or INTERESTING!



SO WHAT CAN YOU DO? REMEMBER, IF WE WANT TO MAKE A BEHAVIOR GO AWAY, WE HAVE TO MAKE IT LESS FUN AND INTERESTING. RATHER THAN ADDING A RESPONSE, WE ARE TAKING IT AWAY.

- Step 1: **Ignore** it...if you can...
 - Basket 1- Safety issue, cannot ignore
 - Basket 2- Not a safety issue, but potentially problematic, MAY ignore or respond
 - Basket 3- Not a safety issue, and not that big of a deal, consider letting it go.
 - From The Explosive Child, By Ross Greene, PhD

- Step 2: “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”)



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

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



SOME CLOSING POINTS...

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



THANK YOU!

- My team at Children's Hospital Boston
- All the wonderful children and families who have taught me so much and made my work life so fun and meaningful.



QUESTIONS?

