

Behavior & Down syndrome

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Paraphrasing....

Every child, parent, and teacher does the best they can with the tools they have.

-Ross Green, Ph.D.

Have you ever seen this in action?

- "Familiar" examples:
 1. Not understanding directions in the classroom? Throw something!
 2. Don't know how to ask another child to play? Pinch him!
 3. Can't get Dr. Stein's attention while he blabs away with your parents, turn the lights off!

Goals

1. The lay of the land—behavior problems in children with DS
2. Causes of behavior problems in children with DS
3. Practical interventions and guiding principles for parents
4. Resources

The Lay of the Land

- Roughly 30 % of children with DS have clinically significant behavior problems
- Many more subclinical?
- 10% of controls
- 30% of ADULTS with DS have behavior problems
- Behavior problems in childhood are predictive of those in adulthood
- The bottom line—behavior problems need to be addressed early and effectively.

McCarthy, 2008
Cuskelly & Dadds, 1992


Causes of Behavior Problems in DS

- Communication
- Motivation
- Self-regulation
- Delayed gratification

Cuskelly, et al., 2003
Jahromi, et al., 2008

What can we do about it?

- Stay positive
- Be proactive




Not only are these ways of intervening more fun, they're also more effective in children with DS!

As a guiding principle, children with DS respond best to “positive behavior supports,” rather than punishment.

Today, we will discuss all of the powerful ways we can intervene as adults to help this AWESOME group of children do their best.

Even better news!

- We have become SO GOOD at positive behavior support, that even the law (IDEA, 2004) suggests that positive behavior interventions should be exhausted before we move on to “punishment” strategies!

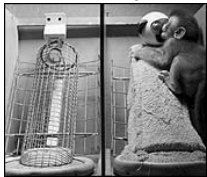


What can parents do?

1. Maintain a positive relationship
 - Attachment
2. Adjust language to child's needs
3. Focus on the positive and celebrate victories
4. Provide structure
5. Pick your battles
6. Coach (Social stories, code words)
7. Use effective discipline

The Power of Relationships

- Harry Harlow, 1959
- Rhesus Monkeys
- Wire vs. Terry Cloth Surrogates
- Attachment not simply based on biological needs



So kids like it, but does it *really* matter?

- YES!
 - Solid parent-child bond →
 - Enhanced ability to self-regulate

A “sciencey” example:

- High-licked Rats
 - Healthy H-P-A Axis
 - Enhanced stress-buffering
- Low-licked Rats
 - Dysregulated H-P-A Axis
 - Decreased stress-buffering

-Meaney, 2007

Attachment Trumps All

- A supportive parent-child relationship provides the best chance for optimal development.
- Attachment is interactive—parents benefit too!
-Beebe, 2007
- Meeting your child where he/she is at provides the most chances for SUCCESS for both you and your child.

The Bottom Lines:

You are really important people!
Whenever you're unsure, think about the relationship!

What can parents do?

1. Maintain a positive relationship
2. Adjust language to child's needs and abilities
Communication as a cause of misbehavior and a means for intervention
3. Focus on the positive and celebrate victories
4. Provide structure
5. Pick your battles
6. Coach (Social stories, code words)
7. Use effective discipline

Adjusting Language

- "Prolonged exertion of energy in the form of repeated trials put forth toward a consistent end, increases the likelihood of meeting that end to the optimal degree."

Multiply X 1000,
add in frustration of people who think you aren't
"following directions..."

How would YOU behave???

- Or just say, "Practice makes perfect!"

Language Development

- What does your child understand?
- How does your child communicate?
- Tools:
 1. Observation
 2. Testing/work with professionals
 3. *Resource:
<http://www.down-syndrome.org/information/language/overview/>

Meet your child where he or she is at...

- What type of communication are you using?
Pictures, sign, verbal language?
- How complex is your communication?
How many steps per command?
Can these steps be broken down?
Are commands immediate, sequential, or delayed?

What can parents do?

1. Maintain a positive relationship
2. Adjust language to child's needs and abilities
3. Focus on the positive and celebrate victories
Paying attention to good behavior as a way of increasing it
4. Provide structure
5. Pick your battles
6. Coach (Social stories, code words)
7. Use effective discipline

Focus on the Positive

- Increasing awareness
- Setting aside time each day to watch or play with your child
- Looking for times when your child is doing something positive
- Point it out and celebrate!

Barkley, 2005

The Formal Version: Token Economies

- A plan which:
 1. Increases your awareness of good behaviors
 2. Provides a structure for rewarding them

For example...

Case example

- “Alex”
- 5 years old
- Many “acting out” behaviors
- Lots of Time Out, yelling, and disciplining by parent
No improvements in behavior....

A New Approach: Alex’s Token Economy


- Sticker chart in the bedroom (****VISUAL)
- Sticker received for every time Alex...
 1. Brushed his teeth
 2. Used the toilet in the morning
 3. Ate breakfast

Mom and Dad were reminded by the sticker chart to notice good behaviors!
- A full sticker chart got Alex a prize!

How did Alex do?

- His parents started paying attention to positive behaviors and provided reinforcement...
- They noticed...
 - Increase in positive behaviors
 - Decrease in problem behaviors
 - Decrease in PARENT STRESS!
 - Increase in self-esteem, “I’m a good boy!”

Token Economies



Steps:

1. Understand your child’s thinking skills
 - a. Does my child understand cause and effect?
 - b. Does my child connect past and present? (immediate or delayed)
2. Find a motivator
 - a. Try to avoid food...
 - b. Affection?
 - c. Stickers?
 - d. Poker Chips?
 - e. Time with parent?

Developing a System, Staying Consistent

- When/how often will you reward?
-Be *generous* with positive reinforcement
- How are rewards tracked and/or displayed?
 1. Sticker chart prominently displayed?
 2. Water jug showing all the poker chips?
 3. Bigger prize when you fill the water jug?

The Hardest Part...

- One week, every other day, or any other inconsistency is not going to get the job done...
- Children often do worse in the beginning...
- The hardest part is sticking with it....

What can parents do?

1. Maintain a positive relationship
2. Adjust language to child's needs and abilities
3. Focus on the positive and celebrate victories
4. Provide structure and environmental supports
Support your child's understanding of the world and its expectations
5. Pick your battles
6. Coach (Social stories, code words)
7. Use effective discipline

Why is routine so important?

- Any guesses?
- What if your morning routine, your work day, and your night time routine were different every day?
- Children and adults, with and without Down syndrome, do best with ROUTINE!
 - Makes the world more predictable
 - One day's success helps with the next day

Supporting your child's routine: Visual Supports

- Support areas of relative weakness with areas of relative strength...

*Resource: Picture schedule examples available at
<http://www.bellaonline.com/articles/art45166.asp>

Picture Schedule



What can parents do?

1. Maintain a positive relationship
2. Adjust language to child's needs and abilities
3. Focus on the positive and celebrate victories
4. Provide structure
5. Pick your battles
 - **Be flexible when you can and save your energy for what really matters**
6. Coach (Social stories, code words)
7. Use effective discipline

Is your rule a good one?

- What is the reasoning or goal behind your rule or routine?
- Has your child "outgrown" the rule or routine?
- Are there other ways to achieve the same goals?

How can I stick to a routine *and* be flexible???

- Case vignette
"Michael won't drink his milk."

Options:

1. Time out (ineffective)
2. Scream and yell (REALLY ineffective)
3. Reconsider the rule (*VERY EFFECTIVE!*)

Picking Battles

- Offering choices
"You can drink your milk or have a yogurt"

Benefits

1. Achieve primary goal (nutrition)
2. Avoid fight (think attachment)
3. Empower your child (think self-esteem and attachment)

Picking Battles

Basket 1= Non-negotiable
(ex. Running into a busy street)


Basket 2= Not life or death, situation-dependent
(ex. Eating ice cream for dinner)

Basket 3= Really not worth a fight
(ex. Drinking a little less milk!)

*Resource: The Explosive Child, by Ross Green, Ph.D.

Empowering Your Child with CHOICES

- Why will a child throw rocks into a pond over and over...and over?



(Adapted from 1-2-3 Magic, by Thomas Phelan, PhD)

We all want to have an
IMPACT!

Offering choices can be a great way to diffuse power struggles and allow your child to be successful, independent, and empowered.



What can parents do?

1. Maintain a positive relationship
2. Focus on the positive and celebrate victories
3. Adjust language to child's needs and abilities
4. Provide structure
5. Pick your battles
6. Coach
 - Be creative and prepare your child for difficult situations
7. Use effective discipline

Preparing your child for difficult situations

- Anticipate—

You know your child best, what events, transitions, times of year have been hard in the past?

Preparing Your Child for Difficult Situations

- Respond—don't be afraid to be creative

- Social stories:

Write or draw a story with your child about an upcoming, potentially stressful event

*Resource: www.theGRAYcenter.org

Preparing Your Child for Difficult Situations

- Practice runs:

Go for a visit to a potentially problematic place (e.g., new classroom), or practice in the home.

Preparing Your Child for Difficult Situations

- Code words:

A word, sign, or symbol that can be used as a signal for your child to say, "I've had enough."

Be Proactive: Make Difficult Times Easier

- Disarm and Distract

- Your child is starting to escalate or misbehave →
 - Sing a favorite song
 - Ask him to do a "job" for you



Be Proactive: Make Difficult Times Easier

- Pair difficult tasks or behaviors with those that are more fun!

- Your child HATES going to bath-time → Now her favorite toy goes with her and is part of bath time!



Collaborate

- When you ask your child to do something challenging, offer to do the task with him.
- Jordan HATES doing his alphabet homework → Have Jordan do half of his letters and you do the rest.



Offer Alternatives: "Replacement Behaviors"

- Throwing the cat...
- Pushing down the stairs...
- Pinching peers...



What can parents do?

1. Maintain a positive relationship
2. Focus on the positive and celebrate victories
3. Adjust language to child's needs and abilities
4. Provide structure
5. Pick your battles
6. Coach
7. Use effective discipline
 - What works in general and what works for your family?

The "D" Word: *Discipline*

- Notice how the "D" word is LAST?

There is so much more to behavior management than discipline!

Remember, children with Down syndrome do better with POSITIVE BEHAVIOR SUPPORTS than with discipline!

That said...

- Discipline is important and powerful
- What do you use?
- How is it going?
- If it ain't broke, don't fix it...

What tends not to work...

- Physical punishment: Stops behavior, but no decrease over time. Increase in violent behavior.
- Yelling: Stops behavior sometimes, no decrease over time. Can be harmful for parent-child relationship.



What to watch out for...

- Negative attention seeking
- Yelling, screaming, being "firm" can all reinforce
- A firm "Time Out!" can backfire in children who seek negative attention

Step 1: Stay CALM

- Emotional reactions to negative behaviors have a negative impact:
 - Can reinforce a behavior
 - Make parents/teachers/providers more upset
 - Make children more upset
 - Make the rest of the day more difficult

Staying calm provides less reinforcement...

Step 2: Consider how your child responds to different forms of punishment.

- Can you ignore? Remove eye contact? (Which basket are we in?)
- "Response cost": IF you do that, THEN you will have to do an extra chore. IF you do that, THEN you lose TV time.
- Does a formal time-out decrease or increase the likelihood that the behavior will recur?
- What about an informal "time-out"?

Understanding "Time Out"

- The term "Time Out" DOES NOT MATTER
- Time-out= **Remove all reinforcers** for a behavior.
- Wording is not important, it's the technique
 - "Take a break"
 - "Have a rest"
 - "Go to the quiet spot"
 - "Go to your room until you calm down"

“We tried time-out, but it doesn’t work”

- It’s trickier than it seems...
- Guidelines for time-out:
 1. Immediate
 2. Appropriate length (think developmental age)
 3. Not fun (no toys, no attention, no *reinforcers*)
 4. Consistent (one time-out for every ten bad behaviors will not improve overall behavior)

Other Options

- Removing privileges...
 1. Make sure your child understands relationship between action and consequence
 2. Make sure the punishment fits the crime
 3. Try it out and see if it works

Where can I get more help?

- School
 - Functional Behavioral Analysis
 - Behavioral Intervention Plan
- Child Psychologists
- Parent groups
- CHB- give us a call!

What can parents do?

A LOT!

BUT...

Parenting is difficult so...

Use professional resources!
Be creative!

Don't forget to take care of yourselves!

THANK YOU!

Questions?