Using an Evidence-Based Approach to Understand & Treat Behavioral Issues in Fragile X Syndrome

Lauren Moskowitz, PhD
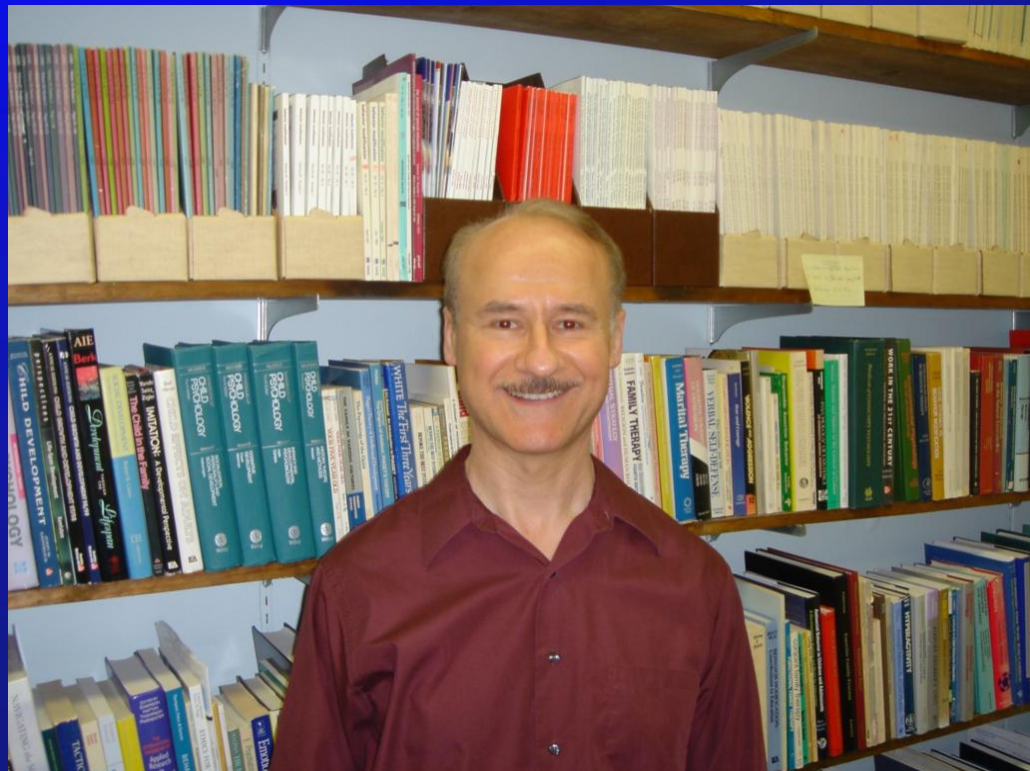
Lauren Moskowitz, PhD
Assistant Professor
Department of Psychology
St. John's University
MoskowiL@stjohns.edu

This presentation is dedicated to my mentor
Edward (Ted) Carr
1947-2009

What Is "Problem Behavior"?

- **Aggression**

- **Self-injury**

- **Property destruction**

- **Tantrum behavior**

- **Disruptive Behavior**

- **Noncompliance**

- **Repetitive behavior/stereotypy**

- **Avoidance**

What is Evidence-Based Treatment for Problem Behavior in Developmental Disabilities (DDs)?

- **Behavioral interventions effective in reducing PBs displayed by individuals with DDs (Horner, Carr, Strain, Todd, & Reed, 2002)**
  - **Reductions of $\geq$ 80% in 1/2 to 2/3 of individuals**
  - **Reductions were reported for all classes of problem behavior, and with individuals with <u>all diagnostic labels</u>**

- **Type of disability was <u>not</u> found to predict level of intervention success (Carr, Horner, et al., 1999; Didden et al., 1997; Horner et al., 2002)**
  - **Emphasis on diagnostic labels appears less relevant for developing effective interventions than information gleaned from functional assessment (Horner et al., 2002; Koegel et al., 1996)**

- **Treatments based on <u>functional assessment </u>are about *twice* as likely to succeed as those that are not (Carr et al., 1999)**

What is Behavioral Intervention? ABA/PBS

- **Applied Behavior Analysis (ABA)**
  - ➤ **The application of principles of operant conditioning**

- **Positive Behavior Support (PBS)**
  - ➤ **Extension of ABA focused on real-world settings**
  - ➤ **Assessment-based (intervention plan is based on results of a comprehensive functional behavior assessment [FBA])**
  - ➤ **Customized/individualized**
  - ➤ **Systems change**
  - ➤ **Preventative & educational**
  - ➤ **Comprehensive & long-term focused**

Assumptions of Behavioral Intervention

1) **Behavior is <u>functional</u>**

> Behavior serves a purpose

2) **Behavior is <u>learned</u>**

3) **Behavior depends on <u>context</u>… it doesn't occur in a vacuum!**

Problem Behavior is Functional

❑ **Children engage in challenging behavior because it pays off – it serves a <u>FUNCTION</u> or PURPOSE**

❑ **Problem behavior persists because it meets an immediate need**

> e.g., waiting quietly in line can be boring or overwhelming; "acting up" can provide attention and/or escape from boredom or overstimulation

❑ **Behaviors persist because children want/need to…**

➢ **Gain parent/peer/staff attention**

➢ **Obtain preferred items or activities**

➢ **Escape or avoid demands/situations/anxiety**

➢ **Gain sensory stimulation**

➢ **Feel sense of control/mastery**

off the mark.com by Mark Parisi

DUMBO! I WANT DUMBO!!

THE ORIGINAL "MOVIES ON DEMAND"

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Problem Behavior = Communication

- **Functions of Communication**

  - **Request object, activity, person** (e.g., "I want the book")
  - **Request help or assistance** (e.g., "I need help")
  - **Obtain attention** (e.g., "Look at this!" or "Talk to me!")
  - **Request social interaction** (e.g., "Can I play with you?")
  - **Request information** (e.g., "How much longer do we have?")
  - **Request sensory stimulation** (e.g., "This motion makes me feel calm")
  - **Escape demands** (e.g., "I don't want to do this work")
  - **Escape activity** (e.g., "I don't like this; I need a break")
  - **Escape a person** (e.g., "I don't want you to talk to me")
  - **Escape anxiety** (e.g., "This makes me anxious; I need to get out of here!")
  - **Escape sensory stimulation** (e.g., "This noise is too loud")
  - **Comment** (e.g., "I like you" or "Look at that airplane")
  - **Protest** (e.g., "No, I don't want to do that")
  - **Reassurance/predictability** (e.g., "I'm afraid, I need consistency")
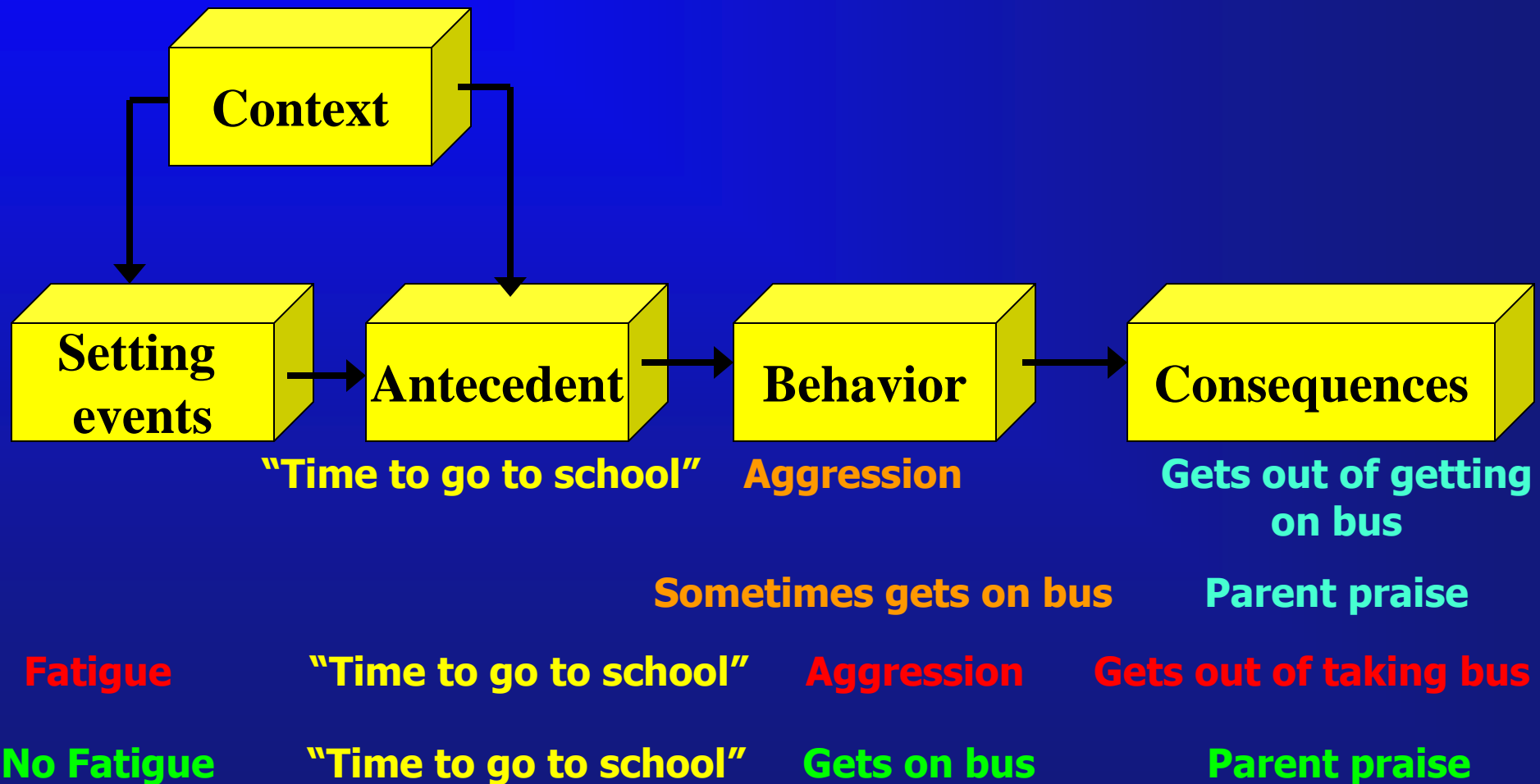
I hate this!
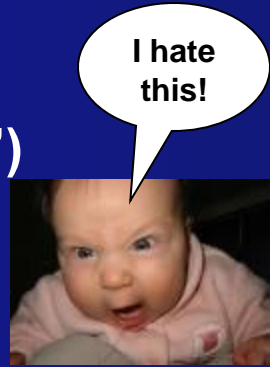
The Problem with Nonfunctional Interventions

"If we select an intervention based on the child's behavior only, and ignore the environmental reasons, we can - at best - stop the behavior temporarily

We cannot stop it for good because the reasons for it continue to exist"

- Ted Carr

Problem Behaviors Depend on <u>Context</u>

Setting events	Antecedent	Behavior	Consequences
	"Time to go to school"	Aggression	Gets out of getting on bus
		Sometimes gets on bus	Parent praise
Fatigue	"Time to go to school"	Aggression	Gets out of taking bus
No Fatigue	"Time to go to school"	Gets on bus	Parent praise

FBA: Example Excerpt from Interview

After identifying the problematic context, identify the specific situations that set off problem behavior

Example Problematic Context : *Having to wait*

- **What <u>specific activity</u> is most/least likely to cause PB?**
  - **Example: Having to wait in line at the store**.
- **With <u>whom</u> is the PB most/least likely to occur?**
  - **Example: Having to wait in line at the store with father**.
- **In what <u>setting</u> is the PB most/least likely to occur?**
  - **Example: Having to wait in line at Target**.
- **During what <u>time of day</u> is the PB most/least likely to occur?**
  - **Example: Having to wait in line at the store after school**.
- **How do you <u>respond</u> to the PB?**
  - **Example: Leave the store**.
- **What is your <u>child's reaction</u> to your response?**
  - **Example: He calms down after leaving the store.**
  - <u>**Hypothesis?**</u>

FBA: Example of ABC Chart

Antecedent	Behavior	Consequence	Most likely function?
Mother is on the phone (not talking to Eddie)	Eddie yells	Mother says, "Eddie, I'm on the phone."	
Mother asks Eddie to do math homework.	Eddie yells	Mother stops interacting with Eddie and leaves him alone.	
As dinner time nears, Ben's mother goes into kitchen	Ben walks into the kitchen and begins to cry and then scream	Ben's mother quickly gives him one of favorite foods	
Going to library. Mother says, "Let's go inside."	Jen screams, kicks, drops to floor, becomes wet noodle	Mother picks her up to carry her into library	

How Do We Treat Problem Behavior with PBS?

- **Key idea: <u>assessment is linked to treatment</u>. Functional Assessment information is used to design treatment**

- **Prevention Strategies**
  - **Antecedent Strategies** (e.g., cues & prompts)
  - **Setting Event Strategies** (e.g., redesign environment, curricular modification, increase predictability)

- **Replacement Strategies**
  - **Communication Skills (i.e., FCT), Coping Skills, Academic Skills, Daily Living skills, Problem-Solving, etc.**

- **Consequence/Response Strategies**
  - **Positive Reinforcement**
  - **Extinction**
  - **Differential Reinforcement (DRA, DRI, DRO, DRL)**

- **Typically, these are combined to increase effectiveness**
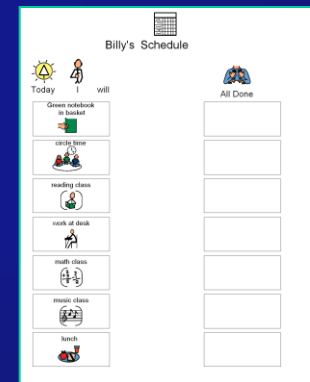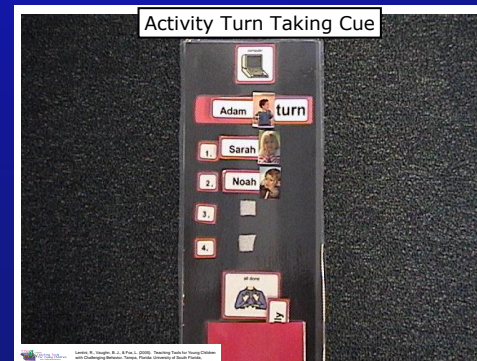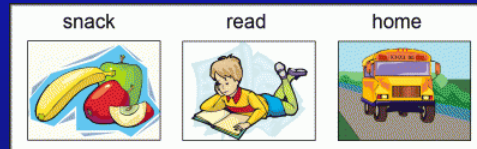
Intervention based on functional assessment (example)

Setting Event	Antecedent (Trigger)	Behavior	Consequence
Amount of time since toy was last played with (i.e., child has not had access to his toys for a while)	Toys are currently out of reach	Self-injury (bangs his head)	Mother gives child his toys
Alter setting event: Immediately schedule play time with preferred toys	**Remove trigger:** Place toys within child's reach	**Teach replacement for behavior:** Teach child to request his toys	**Alter consequences:** If child appropriately requests toys, give toys to him. If he head-bangs, do NOT give toys

Example Prevention Strategies

Prevention Strategies:
Increase Predictability - Visual Schedules

- **Helps make the environment, activities & tasks more predictable, less overwhelming**
- **Enhances sense of control over environment; promotes independence**
- **Reduces stress, uncertainty, anxiety**
- **Helps child prepare for transitions, preview what is coming next**
- **Builds on child's strengths**

First | Then
Potty | Play

snack read home

Activity Turn Taking Cue

Billy's Schedule

Hall, McClannahan & Krantz (1995); Mesibov, Browder, & Kirkland (2002)

Prevention Strategies:
Increase Predictability – Advanced Warnings

- **Visual representations of time (e.g., timers) and/or verbal warnings (e.g., countdowns)**
- **Used to alert child of end of activity**
- **Provides child with time to prepare**
- **Makes transition a gradual process, instead of abrupt ending**
- **Increases predictability, provides greater sense of control**

Dettmer, Simpson, Myles, & Ganz (2000); Mace, Shapiro, & Mace (1998)

Prevention Strategies:
Increase Predictability - Priming

- **<u>Previewing</u> future events, materials, or learning activities on a 1:1 basis, under relaxed conditions, so they become more predictable**
- **Effective for children for whom group instruction may be overwhelming**
  - e.g., parents read story at home the night before
  - e.g., **Video priming**
    - e.g., Carried camera to show the environment as the child would see it when progressing through the transition (e.g., moving through a store and entering another store)

Priming: Wilde, Koegel, & Koegel (1992)
Video priming: Schreibman, Whalen, & Stahmer (2000)

Prevention Strategies:
Social Stories

- **Written stories, sometimes illustrated, that give child information on social topics**
- **Written from the child's perspective, describes situation/skill/concept, gives child relevant cues, perspectives of others, and common responses**
- **Read on multiple occasions immediately prior to situation**
- **Should be informed by FBA**
- **May be more effective when used to target behavior reduction than teach appropriate social skills (Kokina & Kern, 2010)**
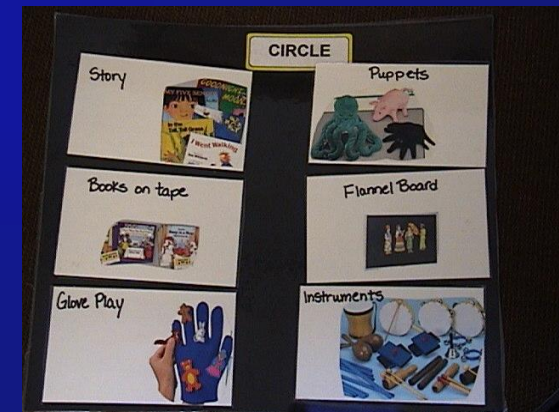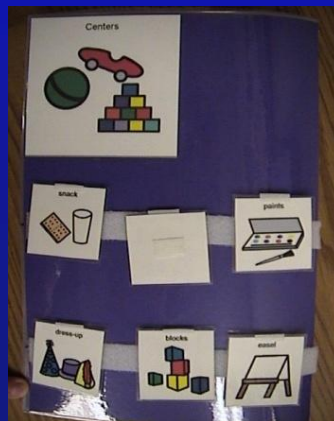
Kuttler, Smith Myles, & Carlson (1999); Ozdemir (2008)
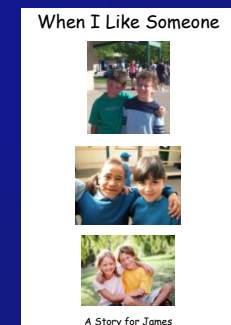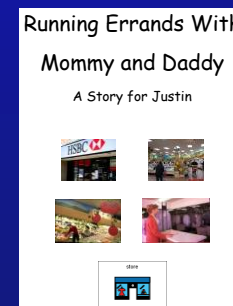
Prevention Strategies: Provide Choices

- **Provide frequent opportunities to make choices**
  - **Enhances sense of control**
  - **Child learns to become an active participant, rather than a passive, helpless bystander**
  - **Increases motivation to participate & behave well**

Shogren, Faggella-Luby, Bae, & Wehmeyer, (2004)

Prevention Strategies: Embedding

❑ **Intersperse highly preferred, easy tasks among more difficult & disliked ones**

❑ **Benefits:**

> Increases opportunities to experience success

> Enhances motivation

Example:

"Judy, what kind of shoes will you buy at the mall? Will you be getting a birthday card for your mother too? OK, <u>finish making your bed</u>, and then I'll tell you about the party this weekend"

Blair, Umbreit, & Bos, (1999); Carr, Newsom, & Binkoff, (1976)

Prevention Strategies: Incorporating Perseverative Interests

❑ **Incorporating a child's preferences or interests into a disliked or unpleasant activity can increase motivation and reduce the likelihood of problem behavior**

❑ e.g., handwriting book exercises replaced with copying instructions from a preferred video games' bonus point booklets

❑ **Perseverative:**

❑ An object, activity, or topic with which the child is intensely interested or even preoccupied (highly salient, highly preferred)

Baker, Koegel, & Koegel (1998); Vismara & Lyons (2007)
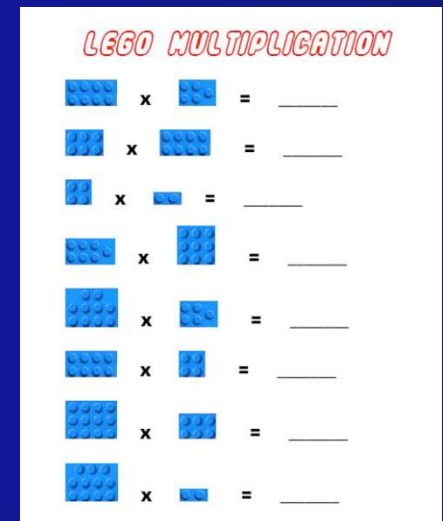
Example Replacement Strategies

Reducing Problem Behaviors Requires Increasing Alternatives
(Building replacement skills)

❑ **If problem behavior is functional, it meets some need for the child**

    ❑ **We can't simply *remove* something that is serving a purpose without *replacing* it with a more appropriate alternative**

❑ **First step is understanding the <u>function</u> it serves (what need it meets)**

❑ **Next step is to offer the child a <u>better way</u> to meet that need**

❑ <u>**Types of skills that serve as Alternative Behavior:**</u>
   - ➤ **Self-regulation**
   - ➤ **Communication skills**
   - ➤ **Social skills**
   - ➤ **Academic skills**

Replacement Strategies: Communication Skills

- **Functional communication training: Teaching children to ask for what they want through language instead of problem behavior.**
- **Examples of appropriate communication:**
  - **Function: Attention**
    - Ask for social interaction, attention, or praise
  - **Function: Escape**
    - Ask for break, ask for help, ask for change in activity
  - **Function: Tangible**
    - Ask for preferred items, activities, or people; ask for a turn
  - **Function: Sensory**
    - Ask for item that provides sensory stimulation or privacy
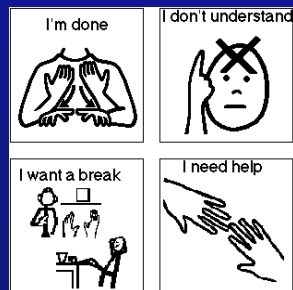
Carr & Durand (1985); Schieltz, Wacker, et al. (2011)

Replacement Strategies:
## Teaching to Request a Break

take break

- **Designate a quiet, neutral area in the home or classroom where child can go to "chill out" & use coping skills**
    - **Set up area to be calming (e.g., bean bag chair, soft music with headphones, stress-squeeze balls)**
    - **Post a list of coping strategies on wall in "Break Area" as visual reminders of ways to calm down**
    - **Set timer (5 minutes), alert them that when it beeps, they will return & continue task**
    - **Child should be able to go to this area when needing to chill out, calm down**

Replacement Strategies: Coping Skills
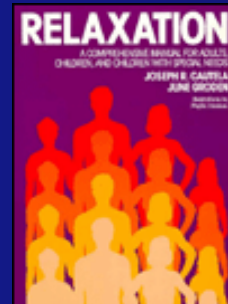
🌼**Relaxation Exercises**
  ➤**Deep Breathing**
  ➤**Progressive Muscle Relaxation**
🌼**Coping Self-Statements**
  ➤**e.g. ,"I can do it!"**
  ➤**Thinking of funny statement, line from cartoon, etc.**

Relaxation: Mullins & Christian (2001)
Coping Self-talk: Kendall (1994); Reaven et al. (2012)
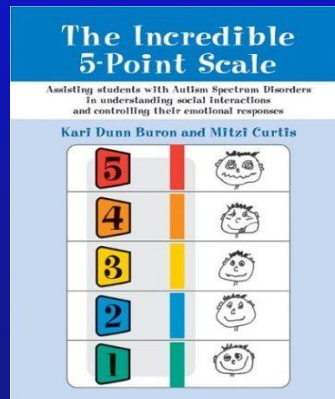
Example Response/Consequence Strategies

(also known as "Management strategies")

Response/Consequence Strategies

- **How can we respond differently to problem behaviors and replacement skills?**

- **What consequences can we use to <u>decrease problem behavior</u> and <u>increase replacement behaviors</u>?**

- **Responding to Problem Behavior – Goals:**
  - Reduce outcomes for problem behavior
  - **Only alternative skills work** to bring about desired outcomes (problem behaviors do NOT work)

Response Strategies:
Positive Reinforcement

- **An individual is reinforced contingent upon performing a <u>specific behavior</u>**

- **Types of reinforcers:**
  - ➤ **Social**: praise, cheering, hugs, high-5, attention
  - ➤ **Tangible:** toys, favorite objects, dessert, money
  - ➤ **Activity:** TV, video games, singing song, baseball

- **Reinforcers should be <u>individualized</u> depending on child's interests**

- **Reinforcers most effective when based on <u>function</u>**

Response Strategies: Positive Reinforcement
Linking Positive Reinforcers to FUNCTION of Behavior

	Function: Attention	Function: Escape	Function: Tangible
Examples of Daily Rewards:	•Sit in teacher's chair •Line leader •First in lunch line •Play freeze tag with class for 5 minutes •Get to tell 1 joke to class at end of the day (or end of each period)	•Choosing which homework or classwork problem the teacher will give the answer to for a "freebie" •Get to go to Lunch or Recess 5 min early	•10 min of Computer time •Get to play Angry Birds on class Ipad for 5 min •10 min of reading preferred book •Pick a book from school library at end of day
Examples of Weekly Rewards	•Invite 1 or 2 friends to eat lunch in classroom •Read morning announcements over loudspeaker •Choose book for teacher to read aloud to class •Breakfast with favorite person (e.g., custodian)	•Get out of homework pass •Get out of classwork pass •"Buy back" a bad grade •Get to leave school a half-hour early on Friday	•Trip to vending machine at school •Get to buy lunch instead of bring lunch for a day •Get to pick a prize (toy or treat) from a prize box •Get to print out 10 pictures from computer

Response Strategies: Extinction

- **Withdrawing reinforcement from a previously reinforced behavior; its rate of occurrence decreases**

  e.g., A child cries at night after being put to bed.

  Positive Reinforcement: Her parents come to her room to comfort her and calm her down.

  Outcome: The child now cries more often at bedtime.

  Extinction: Parents stop coming to the room.

  Outcome: If the parents stop coming to the child's room when she cries at night, the child is <u>less likely</u> to cry during bedtime in the future

Effects of Extinction

- **Initial** effects of extinction are different from **long-term** effects!
  - Initially, the behavior actually **INCREASES**
  - **Extinction burst**: increase in frequency, duration, intensity, or variability of the un-reinforced behavior during the extinction process
    - This is why people doing intervention often give up

- **Long-term** effect of extinction is that the behavior gradually **decreases**
  - Person learns behavior is no longer effective, so it stops!
  - (Although there may be spontaneous recovery)

Putting it All Together

Example Interventions if Function is to Gain Attention

- **Prevention Strategies**
  - Schedule adult attention: give undivided attention for periods of time
  - When adult is occupied, assign highly preferred or easier task or a preferred solitary activity
  - Schedule peer attention

- **Teach Replacement/Coping Skills**
  - Teach child communication skills to ask for your attention.
    - e.g., "Watch what I'm doing!" "Look what I did!"
    - e.g., "Can I play with you?", "Do you want to play Uno?"
    - e.g., "Hi, what's up?", tap on arm
    - e.g., "Can you read to me?"

- **Response (Consequence) Strategies**
  - When child engages in inappropriate attention-getting behaviors, ignore these completely!
  - When child engages in appropriate attention-getting behaviors, respond immediately with praise or attention!

Example Interventions if Function is to Gain a Preferred Item/Activity

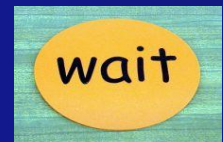- **Prevention Strategies**
  - Provide advanced warning (that activity will end soon)
    - Use Timer
    - Use Countdown
  - Provide access to preferred item/activity on a schedule
  - Schedule Transition Activity (e.g., transition song)

- **Teach Replacement/Coping Skills**
  - Teach child communication skills to ask for object/activity
    - e.g., I want book please." ("want book.")
    - e.g., "Can I play with that?"
    - e.g., "Can I take a turn with that?"
    - e.g., "My turn please."

  My turn

  wait

- **Response (Consequence) Strategies**
  - When child requests item/activity appropriately, give it to him
  - Over time, have the child wait for longer periods of time to obtain the item/activity

Example Interventions if Function is to Escape Demand

- **Prevention Strategies**
  - Modify mode of task completion (e.g., typed vs. handwritten)
  - Use embedding or behavioral momentum
  - Provide more frequent breaks
  - Include child's preferences & interests in the activity
  - Offer choices between tasks or how to complete tasks

- **Teach Replacement/Coping Skills**
  - Teach child communication skills to….
    - Escape by requesting assistance
    - Escape by requesting a break
    - Escape by ending activity
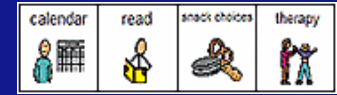   - Escape by rejecting

How much longer?

- **Response/Consequence Strategies**
  - As soon as child asks appropriately, provide assistance, simplify the activity, or give him a short break
  - Provide child with labeled praise, reward, and/or stickers/tickets/tokens to count towards reward for doing task/activity

Example Interventions if Function is to Escape Anxiety

- **Prevention Strategies**
  - Increase predictability
  - Offer choices ahead of time to give child a sense of control
  - Pair anxiety-provoking situation with highly positive stimuli

- **Teach Replacement/Coping Skills**
  - Teach to ask for a break from stressful or anxiety-inducing activities. Encourage child to use this communication skill when anxious (e.g., teach him to say, "I want a break," use **Break Card**, or ask, "What is happening next?")
  - Teach Relaxation training
  - Teach child to request a calming object or calming activity
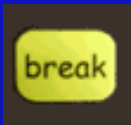
- **Response/Consequence Strategies**
  - Acknowledge anxiety & provide positive reinforcement (e.g., labeled praise, reward) for "brave behavior" (e.g., for completing anxiety-inducing activity)

Moskowitz et al. (in preparation)

Example Interventions if Function is to obtain Sensory Reinforcement

- **Prevention Strategies**
  - Provide alternative sensory reinforcement
    - e.g., offer radio to a child seeking auditory reinforcement
- **Replacement Strategies**
  - Teach replacement behavior that is incompatible with self-stim
    - e.g., if child bites his finger, teach to chew gum or licorice
    - e.g., if child pinches himself, teach to squeeze ball or play with play-doh
    - e.g., if child finger-flicking, teach to fiddle with jewelry or draw picture
- **Response Strategies**
  - Provide non-problem-behavior alternatives for accessing preferred sensory stimuli; use sensory activity as a positive reinforcer (reward)
  - Differential reinforcement of incompatible behavior (DRI)
    - Provide reinforcement for an alternative behavior that is physically incompatible with the problem behavior; gradually increase DRI interval
  - Allow the sensory activity during a specific time/place/situation
  - *Example: thumb-sucking in FXS – DRA with praise, DRL/DRO with chewing gum (Saloviita & Pennanen, 2003)*

Assessing & Treating Problem Behavior in Fragile X (FXS)

Problem Behavior in FXS

- **Parents & professionals report problem behavior is their <u>greatest concern</u> re: their children w/FXS (Hatton et al., 2000; 2002)**

- **However, lack of research on behavioral assessment & intervention in FXS**

  - ➢ **In fact, dearth of research on factors *other than genetic variables* that may contribute to problem behavior in FXS (e.g., Hall, 2009; Hills-Epstein et al., 2002)**

Absence of FXS in PsycInfo Search in Behavioral Intervention Journals

Journal	Autism	FXS
Journal of Applied Behavior Analysis	**502**	1
Behavior Therapy	**188**	0
Behavioral Interventions	**160**	1
Journal of Positive Behavior Interventions	**120**	0
Behavior Modification	**100**	0
School Psychology Review	**53**	0
Behavior Analysis in Practice	**45**	0
Journal of Behavior Therapy & Experimental Psychiatry	**44**	0
Journal of Behavioral Education	**44**	0
The Behavior Analyst	**42**	0
Analysis & Intervention in Developmental Disabilities	**25**	0
Journal of the Experimental Analysis of Behavior	**19**	0

Why Lack of Behavioral Research in FXS?

- **Researchers have predisposition for choosing biological/medical interventions over behavioral interventions because FXS is a "medical" condition** (as opposed to behaviorally defined disorder like autism) (Hall, 2009)

- **Parents often believe problem behavior is "uncontrollable" because of fMRP deficiency** (e.g., Woodcock, Oliver, & Humphreys, 2009)

Merging Biomedical & Behavioral Fields

- **It's possible that biological variables associated with FXS – such as elevated stress hormone levels – can be <u>setting events</u> that make children w/FXS *more likely* to display problem behavior in certain situations**

  - ➢ e.g., FMR1 mutation may alter relative reinforcing property of escape from social stimulation (Hall et al., 2009)

- **However, this does not rule out an important role for environmental interventions**

- **Research on behavioral phenotype in FXS *and* behavioral principles can both inform assessment and intervention**

Functional Assessment with FXS

- **Assess setting events associated with <u>phenotype</u> such as:**
  - **Increased anxiety/hyperarousal**
  - **Hyperactivity, inattention, and/or impulsivity**
  - **Perseveration**
  - **Tactile defensiveness**
- **Consider role of social escape/avoidance behaviors in FXS**
  - **Boys w/FXS showed EC aversion 80% of time during 5-min social interaction w/unfamiliar person (Hall et al., 2006)**
    - **Increase in cortisol predicted decreased EC & decreased fidgeting**
    - **Interaction between biological & environmental factors**
- **BUT, important to <u>individualize</u>; e.g., out of 8 children w/FXS, only 1 child w/high levels of PB in social avoidance condition (Langthorne et al., 2011)**
  - Suggests social contact not as aversive for other 7 children (also low PB in attention condition)
  - 0 children attention-maintained PB & 5 children escape-maintained PB (removal of demands or social attention)

Behavioral Intervention with FXS: Moskowitz, Carr, & Durand (2011) - Method

- **Participants: 3 boys with FXS**
- **Procedure:**
  - **Assessment:** CAI to identify multiple problem contexts. Baseline observations conducted to identify function(s) of PB in high-priority context.

  - **Intervention:** multi-component behavioral intervention; treatment strategies addressed a function of the child's problem behavior by:
    - **Focusing on an antecedent to child's problem behavior**
    - **Altering a relevant setting event**
    - **Providing a response alternative to problem behavior**
    - **Changing a consequence**
- **Design: Multiple baseline design** (a single-subject experimental design)

Context #1: Bedtime

- **Problem: BR (age 10) will not go to bed.**

  - ➢ **Yells, screams, utters obscenity**

  - ➢ **Runs out of bedroom repeatedly after mom puts him to bed**

  - ➢ **Mom chases BR around house**

- **The Function(s) of BR's problem behavior:**

  - ➢ **Gain Attention from Mom (i.e., cat-and-mouse chase)**

  - ➢ **Escape going to bed**

Context #1 Bedtime: Intervention

✓ **Manipulate Setting Events**
  - ❖ <u>**Increasing Predictability**</u> **– establish consistent bedtime routine to help BR know what to expect & what is expected of him**
  - ❖ <u>**Providing Choices**</u> **– choice of calming mother-son bedtime activity; choice of 2-3 rewards he can earn next day for staying in bed night before**

✓ **Address Antecedent/Trigger (S^D)**
  - ❖ <u>**Prevention Checklist**</u>**– prevent problem behavior from occurring by minimizing the triggers that typically set it off**

✓ **Address Consequence**
  - ❖ <u>**DRA**</u> **– Positive reinforcement for alternative behavior of "staying in bed"; no reinforcement for problem behavior of "coming out of bedroom"**
  - ❖ <u>**Extinction**</u> **– Ignore all attention-seeking behavior once mom exits room**
  - ❖ <u>**Immediate redirection**</u> **– Stand outside bedroom door to immediately redirect BR back to bed if he emerges from his bedroom**

✓ **Skills training/teach alternative to problem behavior**
  - ❖ <u>**Social Story**</u> **– teach BR what behavior is expected of him and what reinforcers he will receive for appropriate behavior**
  - ❖ <u>**Calming bedtime activity**</u> **– provide BR with alternative way to receive one-on-one attention from his mother before bedtime**

Context #2 - Running Errands

- **Problem: RE (age 7) engages in problem behavior (e.g., yelling, tantrums, self-injury, aggression) when running multiple errands**

- **Function(s):**

  ➢ **Escape situation that causes anxiety & frustration**

  ➢ **Gain preferred activity (e.g., going home)**

- **Detriment to Quality of Life:**

  ➢ **Mom feels trapped by her child; he dictates where she can go and what she can do**

Running Errands: Intervention

✓ **Manipulate Setting Events**

❖ <u>**Visual Schedule & Social Story**</u> **– provide info proactively to increase predictability, thereby reducing anxiety re: transitions**

❖ <u>**Providing Choice**</u> **– increase task engagement by providing increased control over environment**

✓ **Address Antecedent/Trigger (S^D)**

❖ <u>**Presenting S^D for appropriate behavior**</u> **– introduce S^Ds associated w/appropriate behavior or redirect attention to S^Ds**

✓ **Address Consequence**

❖ <u>**Positive reinforcement**</u> **– increase motivation to complete errands**

❖ <u>**Extinction**</u> **– reduce escape motivation by removing reinforcement**

❖ <u>**Exposure**</u> **– expose to the feared situation so that he habituates**

❖ <u>**Counterconditioning**</u> **– pair anxiety-provoking activity (errands) w/positive stimuli, thereby reducing motivation to escape**

✓ **Skills training/teach alternative to problem behavior**

❖ <u>**Social Story**</u> **– teach replacement behavior of helping Mom**

Running Errands
Visual Schedule

Context #3: Toileting

bathroom

- **Problem: TL (age 9) does not understand that the toilet is the place he is supposed to urinate or defecate.**

- **He eliminates in diapers, on sofa, on bed, on floor, etc.**

- **If mom attempts to make him sit on the toilet and try again, he yells or pushes her and runs away.**

Context #3 Toileting: Intervention

✓ **Manipulate Setting Events**

❖ <u>**Prevention**</u> **– Track TL's accidents; adjust schedule and increase monitoring during times when accidents more likely to occur**

✓ **Address Antecedent/Trigger (S^D)**

❖ <u>**Transfer stimulus control over viewing DVDs**</u> **– bring DVD requesting under narrow SC so that sitting on toilet no longer S^D for DVDs**

❖ <u>**Transfer stimulus control over elimination**</u> **– transfer SC over elimination from high-probability stimulus (e.g., tub, floor) to low-prob stimulus (toilet); change toilet from neutral stimulus to S^D for elimination**

✓ **Address Consequence**

❖ <u>**Positive reinforcement of on-toilet elimination**</u> **– use most highly preferred & perseverative reinforcer as toileting-specific reinforcer**

❖ <u>**Natural consequences**</u> **– clothe TL in underwear; if TL has accident while watching TV, turn TV off immediately & prompt to clean**

✓ **Skills training/teach alternative to problem behavior**

❖ <u>**Continuous Prompting**</u> **– prompt TL to use toilet immediately after he signs "potty," if nonverbal body signals indicate need to eliminate, or if 30 min pass without elimination**

❖ <u>**Practice trials**</u> **– during first few days, provided with extra fluid**

Context #3 – Toileting Intervention Visual Supports

FIRST	THEN
bathroom	Skittles

Context #3 – Toileting Intervention
Visual Supports – Take 2

FIRST	THEN

Results of Intervention

**86% reduction
in frequency of pb**

**97% reduction
in frequency of pb**

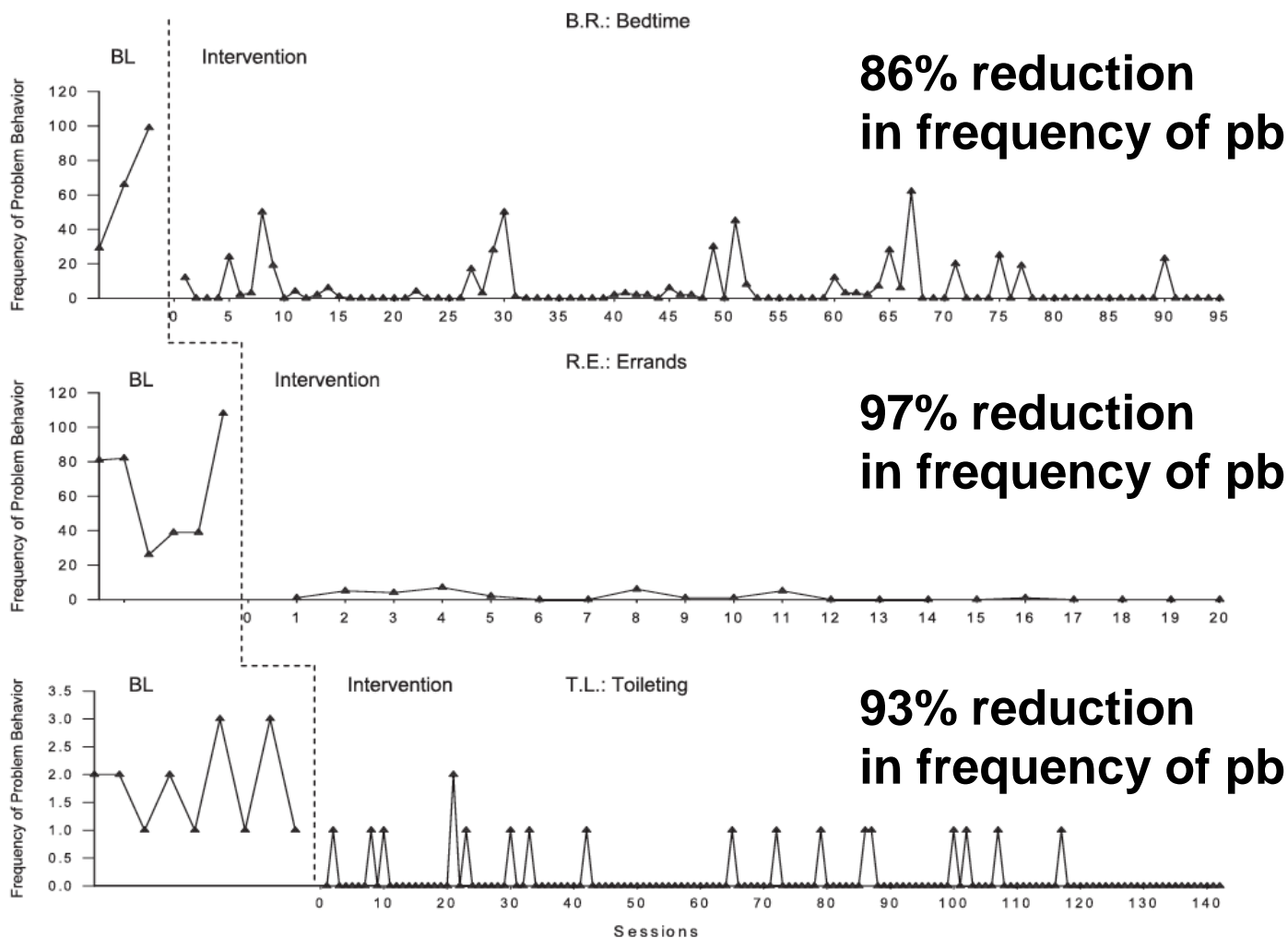**93% reduction
in frequency of pb**

Figure 1. Frequency of problem behavior for the 3 participants (B.R., R.E., and T.L.) and in the priority routines during the baseline (BL) and intervention (INT) phases.

Moskowitz, Durand, & Carr (2011), *AJIDD*

Take-Home Message ✅

- **It is possible to treat a purely <u>biological</u> syndrome with <u>behavioral</u> intervention so that you can reduce problem behavior and improve quality of life**

- **Fragile X syndrome may make problem behavior *more likely* to occur, but problem behavior is *not uncontrollable or inevitable* because a child has FXS**

- **Problem behavior serves a <u>function</u> in children with FXS, *just as in any other child or adult!***
  - e.g., A child may engage in PB because he is **anxious** and doesn't know how to escape or calm himself**, frustrated** and **can't communicate** it, **wants attention** and doesn't know how else to get it, etc.

- **In order to know how to handle the PB, you need to know WHY the child is exhibiting PB**
  - Then modify the <u>antecedents</u> or <u>setting events</u> that lead to PB, teach skills to <u>replace</u> the PB, and <u>respond</u> to PB in a way that does not reinforce it (and reinforces positive behavior instead)

Good News... a Hand Search of Journals Yielded Behavioral Intervention Studies that Included 1 or More Participants with FXS!

- **18 studies on skill acquisition, including training skills such as:**
  - ➢ **Fraction-decimal relations**
  - ➢ **Laundry & wash dishes**
  - ➢ **Conversation skills**
  - ➢ **Signing for "please"**
  - ➢ **Work tasks**
  - ➢ **Social skills**
  - ➢ **Toileting**
  - ➢ **Engagement (e.g., visually attending to person or materials)**
- **13 studies on reducing problem behavior using strategies such as:**
  - ➢ **FCT with extinction**
  - ➢ **DRA and guided compliance**
  - ➢ **Social stories**
  - ➢ **Noncontingent attention on a fixed time schedule**

Conclusion

- **Small # of behavioral intervention studies including participants with FXS indicates that there is more than we thought, but additional applied intervention research with individuals with FXS will be necessary before conclusions can be made re: most effective intervention strategies**

- **But behavioral intervention (operant strategies based on functional behavior assessment) is the most promising evidence-based environmental intervention that we have to date**
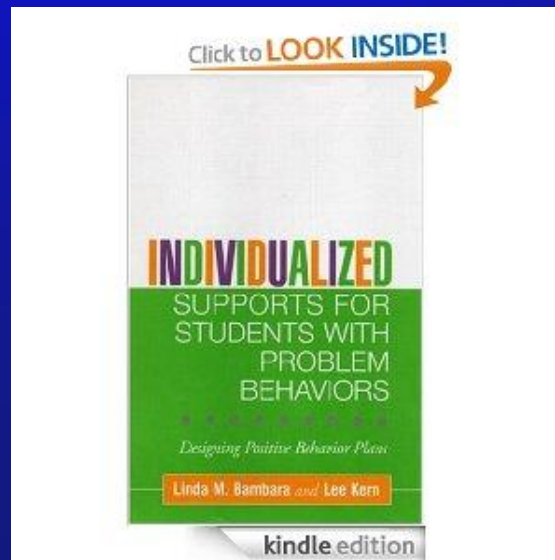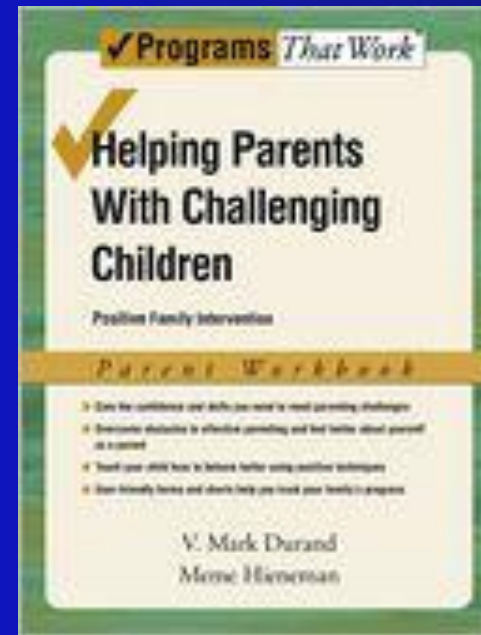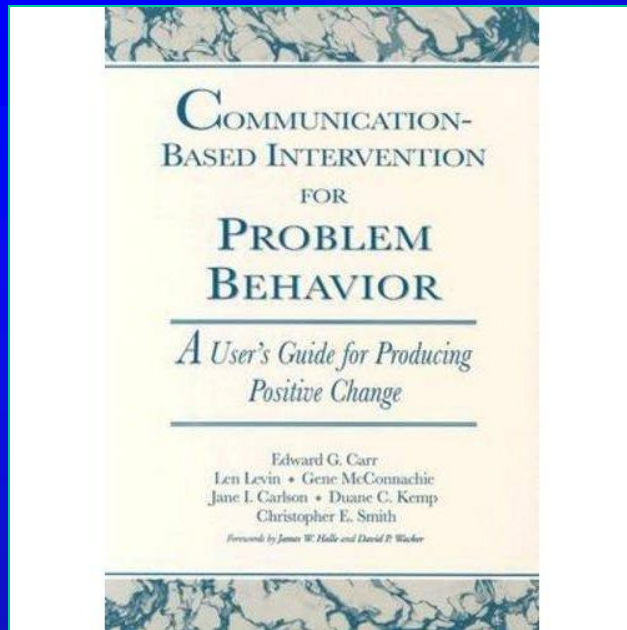
Future Research Directions…

- **Explore utility of behavioral intervention strategies designed to target common characteristics associated with the behavioral phenotype of FXS, such as high anxiety/hyperarousal, perseveration, etc.**
  - *Note: surprisingly, only 1 of 3 children in study by Moskowitz et al. (2011) exhibited significant anxiety/hyperarousal, which is thought to be a hallmark of FXS*
  - Need more intervention research focusing on anxiety/hyperarousal as a setting event for problem behavior
- **Tap into rich literature on intervention techniques that have been successfully used with children with ASD, anxiety disorders, ADHD, and other populations, extrapolating treatments from other relevant disorders to the treatment of FXS**

Resources: Websites on Positive Behavior Support (PBS)

➤ **The Association for Positive Behavior Support (APBS)**
www.apbs.org

➤ **The Behavior Doctor – Positive Interventions & Effective Strategies**
www.behaviordoctor.org

➤ **Positive Behavior Support – Beach Center on Disability**
http://www.beachcenter.org/pbs/default.aspx

➤ **Technical Assistance Center on Social Emotional Intervention for Young Children**
www.challengingbehavior.org

➤ **Center on the Social & Emotional Foundations for Early Learning**
www.vanderbilt.edu/csefel

➤ **OSEP Center on Positive Behavioral Interventions & Supports**
www.pbis.org

➤ **Kansas Institute for Positive Behavior Support**
www.kipbs.org

➤ **Florida's Positive Behavior Support Project**
http://flpbs.fmhi.usf.edu

Book Recommendations

Communication-Based Intervention for Problem Behavior
A User's Guide for Producing Positive Change
Edward G. Carr
Len Levin • Gene McConnachie
Jane I. Carlson • Duane C. Kemp
Christopher E. Smith
Forewords by James W. Halle and David P. Wacker

✓ Programs That Work
Helping Parents With Challenging Children
Positive Family Intervention
Parent Workbook
V. Mark Durand
Meme Hieneman

Click to LOOK INSIDE!
INDIVIDUALIZED SUPPORTS FOR STUDENTS WITH PROBLEM BEHAVIORS
Designing Positive Behavior Plans
Linda M. Bambara and Lee Kern
kindle edition

Interested in Participating in Intervention Research?

If you live in the New York City area and have a child with fragile X syndrome, please contact me if you are interested in participating in research on behavioral intervention, or if you have any questions about behavioral intervention:

Lauren Moskowitz, Ph.D.

Assistant Professor

Department of Psychology

St. John's University

8000 Utopia Parkway

Queens, NY 11439

MoskowiL@stjohns.edu