Behavioral Intervention for Problem Behavior in Children with Fragile X Syndrome

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What Is “Problem Behavior”?

- Aggression
- Self-injury
- Property destruction
- Tantrum behavior
- Disruptive Behavior
- Noncompliance
- Repetitive behavior/ste y
- Avoidance

Problem Behavior in FXS

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

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

- Lack of research on factors *other than genetic variables* that may contribute to problem behavior in FXS

How to Treat Problem Behavior in FXS

- Deficiency in FMRP → characteristic behavioral phenotype (e.g., hyperarousal, social anxiety, hyperactivity, autistic-like behaviors, pragmatic deficits)
- Parents of children with FXS often express the belief that their children's problem behavior is "uncontrollable" b/c the underlying fMRP deficiency makes such behavior inevitable
  - **Over 30% of parents reported that their children with FXS did not have control over their temper outbursts or overt displays of anxiety (Woodcock, Oliver, & Humphreys, 2009).**
- Present study sought to demonstrate that behavioral interventions can be effective in treating the behavioral symptoms of FXS
  - **Because problem behavior serves a function, and these same functions can be seen in all individuals (with & w/out FXS)**

Assumptions of Behavior Theory

1) Behavior is functional
   - **Behavior serves a purpose**

2) Behavior is learned
   - **So if you learn an inappropriate behavior, you can learn a replacement or new behavior**

3) Behavior depends on context… it doesn't occur in a vacuum!

Problem Behavior is Functional

- Children engage in challenging behavior because it pays off – it serves a FUNCTION 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 the boredom or escape from the overstimulation of waiting in line**
- 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**

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"

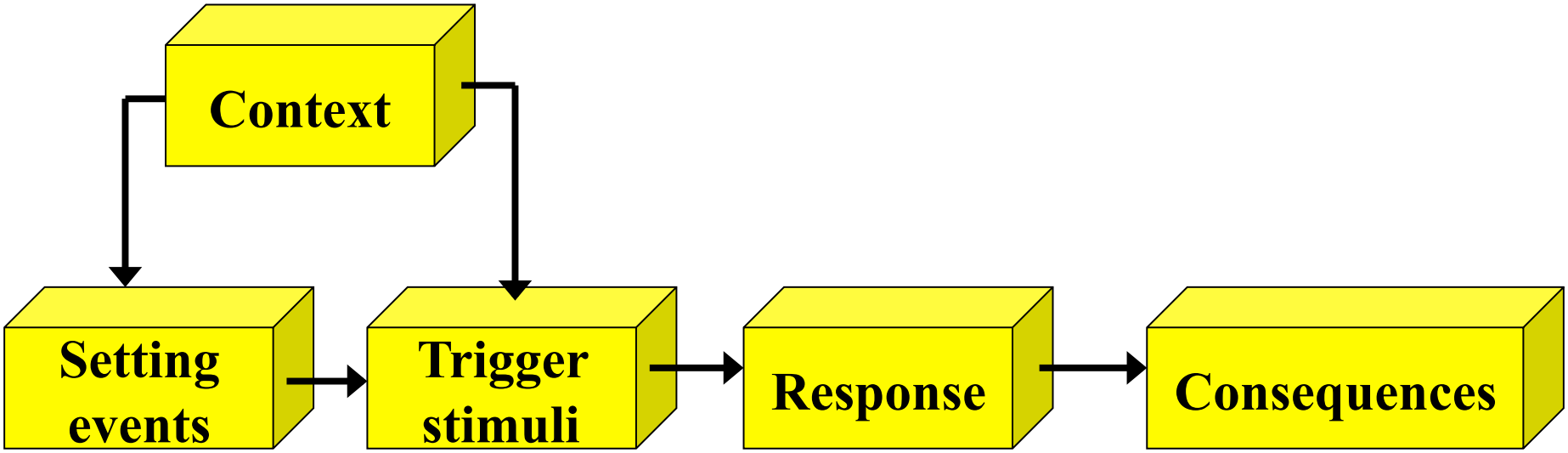
- Ted Carr

Problem Behaviors = Communication

Sample Communications:

- 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 I have?”)
- Request sensory stimulation (e.g., “This makes me 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., “I need to get out of here!”)
- Escape sensory stimulation (e.g., “This noise is too loud”)

Problem Behaviors Depend on Context



Anxiety	"Time to go to school"	Aggression	Gets out of taking bus
No Anxiety	"Time to go to school"	Gets on bus	Parent praise

Critical Concept

Problem Contexts → Problem Behavior

If you want to do something about the problem behavior you need to do something about the problem contexts.

Intervention:
Positive Behavior Support

- Prevention Strategies
  - **Antecedent Strategies (e.g., cues & prompts)**
  - **Setting Event Strategies (e.g., environment redesign, curricular modification, ↑ predictability)**
- Replacement Strategies
  - **e.g., Communication Skills, Coping Skills, Life Skills, Problem Solving Skills, Academic Skills, Daily Living skills**
- Response Strategies
  - **Consequence-based strategies**
    - **e.g., Positive Reinforcement**
    - **e.g., Extinction**

How Well Has PBS Succeeded (Outcome)?

- *Wide variety* of problem behaviors treated successfully using PBS
- Depending on the studies reviewed, between *one-half to two-thirds* of the individuals treated show at least 80-90% reduction in problem behavior from baseline
- Treatments based on functional assessment information are about *twice* as likely to succeed as those that are not

See meta-analyses by Carr et al. (1999) & Horner et al. (2000)

Intervention if the Function is to
Gain Attention

- Prevention Strategies
  - **Scheduled attention: give undivided attention for periods of time**
  - **When adult occupied, assign highly preferred or easier work (e.g., computer game) or a preferred solitary activity (e.g., drawing)**
- Teach Replacement/Coping Skills
  - **Teach child communication skills to ask for your attention**
    - **e.g., "Watch what I'm doing!" "Look at that!" "Look what I did!"**
    - **e.g., "Can I play with you?", "Do you want to play Uno?"**
    - **e.g., "Hi, what's up?"**
    - **e.g., "Can you read to me?"**
    - **e.g., tap on arm**

- 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 attention!**

Intervention if the Function is to

Gain a Preferred Item/Activity

- Prevention Strategies
  - **Provide advanced warning that activity will end soon (e.g., use timer or countdown)**
  - **Provide access to preferred item/activity on a schedule**
  - **Use Transition activity (e.g., clean-up song)**

- Teach Replacement/Coping Skills
  - **Teach child communication skills to ask for item/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?"**

- Response (Consequence) Strategies
  - **When child requests object/activity appropriately, give it to him (when he screams/grabs, do *NOT* give it to him)**
  - **Over time, teach child to wait for increasingly longer periods of time to obtain item/activity after he asks for it**

Intervention if the Function is to Escape Demand

- Prevention Strategies
  - **Offer choices between tasks or how to complete tasks**
  - **Adjust task difficulty (e.g., easier/shorter task, more frequent breaks)**
  - **Modify mode of task completion (e.g., typed vs. handwritten)**
  - **Embedding, activity interspersal, or behavioral momentum**
  - **Incorporate child's interests in activity**
- Teach Replacement/Coping Skills

  - **Teach child communication skills to….**
    - **Escape by requesting assistance (e.g., "I need help.")**
    - **Escape by requesting a break (e.g., "I need a break")**
    - **Escape by terminating an activity (e.g., "I'm finished")**
    - **Escape by rejecting (e.g., "No, thank you")**

- Response Strategies
  - **As soon as child asks appropriately, provide assistance, simplify activity, or give a short break**

  - **Provide child with praise, reward, or stickers/tickets/tokens to count towards reward for completing the task/activity**

Intervention if the Function is to

Escape Anxiety/Hyperarousal

- Prevention Strategies
  - **Increase predictability (e.g., Visual Supports, Social Story, video modeling)**
  - **Offer choices ahead of time to give child a sense of control**
  - **Pair anxiety-provoking situation with anti-anxiety stimuli**
- Teach Replacement/Coping Skills

  - **Teach to ask for a break from stressful activities**
  - **Teach Relaxation training (e.g., deep breathing, progressive muscle relaxation) and coping self-talk**
  - **Teach to request a calming object or calming activity**

- Response Strategies
  - **Acknowledge anxiety & provide positive reinforcement (e.g., praise, reward) for facing anxiety-producing situation**
    - ❖**Reward "brave behavior" (confronting fears)**
  - **Do not avoid or end task when child engages in problem behavior even if he is anxious; the more you face fears, the easier they become**

Purpose of Study

- Problem behavior is a major issue for families of children with FXS
- Lack of applied intervention research to reduce problem behavior in children with FXS
- Research question: Do behaviorally-based interventions targeting problematic contexts reduce problem behavior for children with FXS?

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

Method of Study

- **Participants**: 3 boys with fragile X syndrome
- **Procedure**:
  - **Assessment: CAI administered to parents to identify multiple problem contexts. Baseline observations conducted to assess problem behavior pre-intervention**
  - **Intervention: multi-component; techniques developed collaboratively w/parents to teach child and/or parent to cope with high-priority contexts; treatment strategies addressed a function of the child's problem behavior by:**
    - **Focusing on an S^D for child's problem behavior**
    - **Altering a relevant setting event**
    - **Providing a response alternative to problem behavior**
    - **Changing a consequence**
- **Design**: Multiple baseline design used to demonstrate effects

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

Context #1: Bedtime

- Problem: BR (age 10) did not go to bed.
  - **Yelled, screamed, uttered obscenity**
  - **Ran out of bedroom repeatedly after mom put him to bed**
  - **Mom chased 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

- **Increase Predictability – establish consistent bedtime routine to help BR know what to expect & what is expected of him**
- **Provide Choices – choice of calming mother-son bedtime activity; choice of 2-3 rewards he can earn next day for staying in bed night before**

✓Address S^D

- **Prevention Checklist– prevent problem behavior from occurring by minimizing the triggers that typically set it off (e.g., noise)**

✓Address consequence

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

✓Skills training/teach alternative to problem behavior

- **Social Story – teach BR what behavior is expected of him and what reinforcers he will receive for appropriate behavior**
- **Calming bedtime activity – provide BR with alternative way to receive one-on-one attention from his mother before bedtime**

Context #1– Bedtime Intervention:
Barriers to Implementation

- Hard to be consistent/predictable (e.g., guests, events)
- "Slipping" when things have been going well for a few nights
- Providing intermittent reinforcement for attention-getting behavior
  - BR kept coming up with new ways of getting mom's attention (covers, lightswitch, door-slamming) - keep pulling weeds!

  - Just like taking antibiotics, bedtime intervention has to be used consistently - the same every day - or else it just won't work!
- Seems cruel to parents not to respond to child
  - Not responding is teaching the child to cope on his own ("self-soothe")

Context 2:
Running Errands

- Problem: Child 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

Context 2 – Running Errands:
Excerpt from Sample Baseline Session

- 4:46:53 – Child yells, “I wanna go home!”
- 4:47:21 – Child yells, “Turn around!”
- 4:47:50 – Child yells, “Turn around!”
- 4:48:27 – Child yells “Home!” Slaps his leg. Mom yells, “That’s unacceptable! You can tell me that you’re frustrated, but you cannot hit yourself.”
- 4:48:54 – Child yells “I wanna go home!” 5 times.
- 4:49:06 – Child hits his head 3 times. Mom says, “Please do not hit your head!”
- 4:49:15 – Child screams, “Turn around!” Mom says, “When the clock says 5:00, we will be going home.”
- 4:49:21 – Child screams, “Turn around!” Mom does not respond.
- 4:49:32 – Child screams, “Turn around!” Mom does not respond.
- 4:49:42 – Child screams, “Turn around!” Mom does not respond.
- 4:49:49 – Child screams, “Turn around!” Mom says, “When you speak to me properly and stop hitting yourself, that’s when I will start talking to you.”
- 4:50:03 – Child screams, “Home! Home! I wanna turn around!”
- 4:50:14 – Child screams, “I wanna go home!”
- 4:50:23 – Child screams, “Home!”
- 4:50:34 – Child screams, “Home!”
- 4:50:55 – Child slaps his leg.
- 4:51:24 – We pull into a parking spot at the butcher’s.

Running Errands: Intervention

- ✓Manipulate Setting Events
  - **Visual Schedule & Social Story – provide info proactively to increase predictability, thereby reducing anxiety re: transitions**
  - **Providing Choice – increase task engagement by providing increased control over environment**
- ✓Address S^D
  - **Presenting S^D for appropriate behavior – introduce S^Ds associated w/appropriate behavior or redirect attention to S^Ds**
- ✓Address consequence
  - **Positive reinforcement – increase motivation to complete errands**
  - **Extinction – reduce escape motivation by removing reinforcement**
  - **Exposure – expose to the feared situation so that he habituates**
  - **Counterconditioning – pair anxiety-provoking activity (errands) w/positive stimuli, thereby reducing motivation to escape**
- ✓Skills training/teach alternative to problem behavior
  - **Social Story – teach replacement behavior of helping Mom**

Running Errands
Visual Schedule

home 	clothing store 	grocery store 	home 

Context 2 – Running Errands:
Excerpt from Sample Intervention Session

- 4:37 – We are driving to the post office (2nd errand). Child says, “I want to go home.” Mom says, “First we’re going to the post office, then home.”
- 4:37 – Child stomps his feet and yells, “Home!” Mom repeats, “First we are going to the post office, and then we will go home.” Child is quiet for almost a minute.
- 4:38 – Child asks quietly, “Can we go home?” Mom says, “I’m going to the close post office, and then we’re going home. I have a job for you to do at the post office. Will you swipe my credit card for me at the post office?” Child smiles.
- 4:39 – Child resumes looking through his Cars sticker book and talking about the Cars with Mom and Lauren.
- 4:43 – Child arrive at the post office and go inside. (Child gets out of car and walks in without a problem, carrying his Cars sticker book.)
- 4:44 – Mom waits in line at the post office and child sits on the floor playing with his Cars sticker book. He is ripping the stickers off and sticking them on pages. This continues the entire time Mom is in the post office.
- 4:51 – Child swipes credit card when it is time to leave.
- 4:53 – We get back in the car. Child says, “And now home?” Mom says, “Yes, now we get to go home!” Lauren prompts child to remove the post office picture from his visual schedule as she says, “We are finished with the dry cleaner, finished with the post office, and now we get to go home!” Mom and Lauren praise child for what a great job he did at the post office.
- 4:58 – We get home.

Context #3: Toileting

- 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.

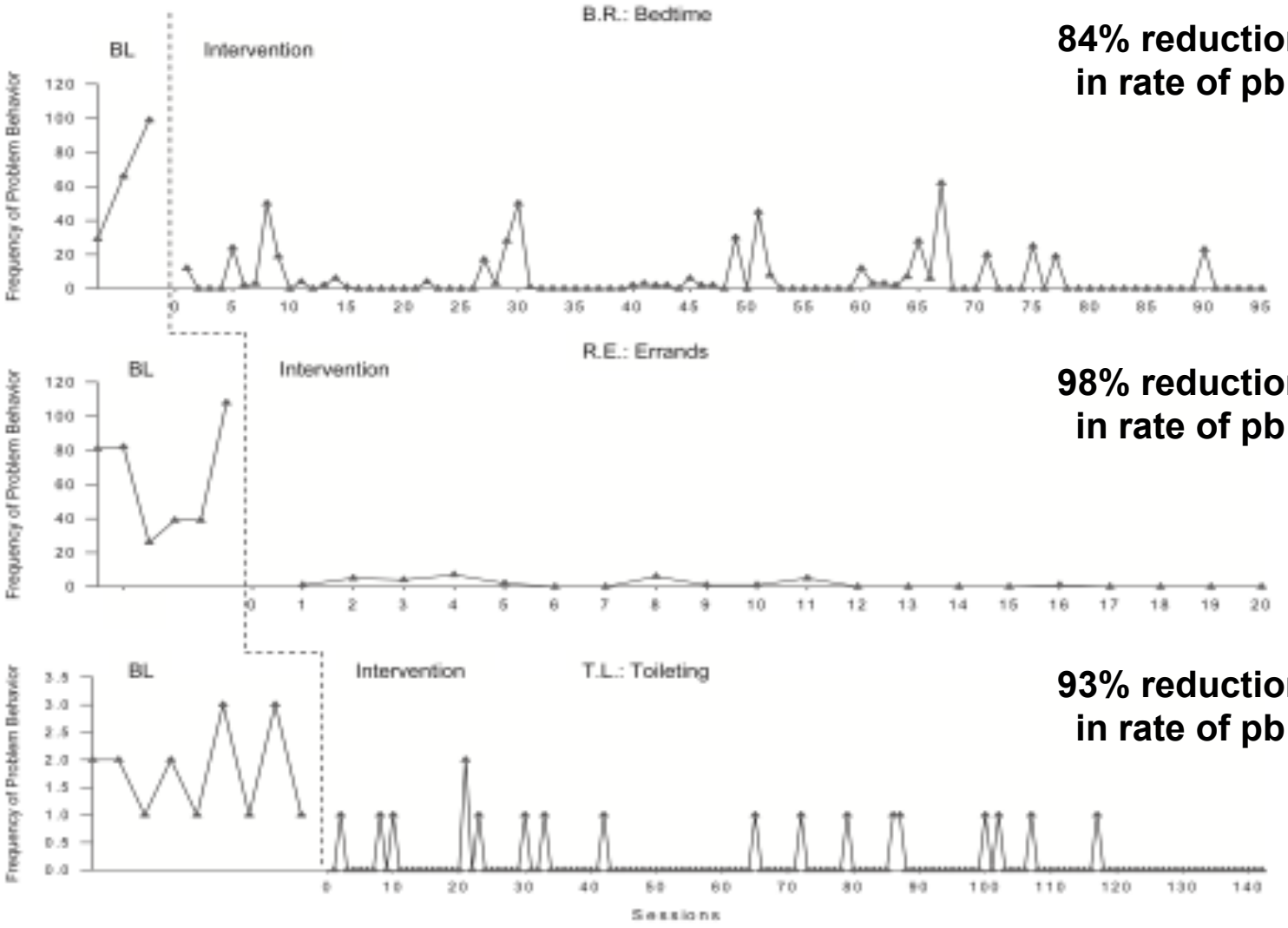
Context #3 Toileting: Intervention

- ✓Manipulate Setting Events
  - **Prevention – Track TL's accidents; adjust schedule and increase monitoring during times when accidents more likely to occur**
- ✓Address S^D
  - **Transfer stimulus control over viewing DVDs – bring DVD requesting under narrow SC so that sitting on toilet no longer S^D for DVDs**
  - **Transfer stimulus control over elimination – 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
  - **Positive reinforcement of on-toilet elimination – use most highly preferred & perseverative reinforcer as toileting-specific reinforcer**
  - **Natural consequences – 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
  - **Continuous Prompting – 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**
  - **Practice trials – during first few days, provided with extra fluid**

Context #3 – Toileting Intervention
Visual Supports

FIRST	THEN
	

Results



84% reduction in rate of pb

98% reduction in rate of pb

93% reduction in rate of pb

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

What We Have Learned About Treatment of Fragile X Syndrome

- It is possible to treat a purely biological syndrome behaviorally so that you can reduce problem behavior and improve quality of life, even though you do not “cure” the syndrome
- Fragile X may make problem behavior *more likely* to occur, but problem behavior is NOT because a child has fragile X.

Take-Home Message

- Be aware of behavior patterns persons w/FXS may be predisposed to (e.g., anxiety, social escape behavior)
  - **Can inform functional assessment, types of antecedent & consequence-based interventions chosen, & types of replacement behaviors taught**
- However, important to remember that FXS phenotype is only a guide – individualized assessment & treatment must always be conducted!
- Problem behavior serves a function in FXS, just as in ASD and neurotypical individuals!
  - **Child may engage in problem behavior because he is anxious and doesn't know how to calm himself, frustrated and can't communicate it, or wants attention and doesn't know how else to get it, etc.**
  - **In order to know how to handle it, you need to know WHY child is exhibiting problem behavior**

Future Research Directions

- Further explore utility of behaviorally-based interventions in more children with FXS in wider variety of contexts
- Continue to tap into rich literature on intervention techniques that have been successfully used with children with ASD, children with anxiety disorders, and other populations
- Examine predictors of intervention success and barriers to success

Assessing and Treating Anxiety in Developmental Disabilities

Purpose of Dissertation

- Not always possible to identify a function of PB
- Possible that internal variables such as anxiety may be controlling PB in these instances
- However, potential role of anxiety in contributing to PB not investigated
- Primary aims of study are to
  a) Use a multimethod strategy to assess anxiety in children with ASD & ID
  b) Use assessment info to develop multicomponent intervention to treat anxiety & associated PB

Method

- 3 children with ASD and ID
- Operationally defined “anxiety” for based on parent interview, subjective rating scales, & direct observation
- Functional Analysis Probes: examined effect of High-Anxiety vs Low-Anxiety conditions on PB (randomized ABAB design)
- ECG was recorded using Alive monitor
- Anxious behavior & PB recorded using LifeCam
- ≈ 50% sessions coded for IOA

Participants' Contexts & Behaviors

1) **Jon (6yo)**
   - **HA Context: participating in group activity (Happy Birthday)**

2) **Ben (9yo)**
   - **HA context: fear of being left alone**

3) **Sam (8yo)**
   - **HA context: Left/right turns while riding in car**

Results of Study 1 (Assessment Study)

Anxious behavior and problem behavior were both significantly higher in the "High-Anxiety" conditions than in the "Low-Anxiety" conditions for all 3 children

Heart rate was significantly higher in the "High-Anxiety" conditions than in the "Low-Anxiety" conditions for 2 of the 3 children

Treating Anxiety in ASD and DDs

a) CBT procedures reducing anxiety in TD children

- i.e., exposure, cognitive restructuring, psychoeducation (see Albano & Kendall, 2002 for review)

b) BT procedures shown to reduce avoidant responding in children with autism

- e.g., systematic desensitization, reinforcement, modeling (Ellis et al., 2006; Koegel et al., 2004; Love et al., 1990; Luscre & Centre, 1996; Rapp et al., 2005; Ricciardi et al., 2005)

c) ABA/PBS antecedent-based & replacement strategies used w/ASD & DD (Carr et al., 2002; Lucyshyn et al., 2007)

- e.g., choice, visual supports, social stories, noncontingent reinforcement, FCT

Multicomponent Intervention

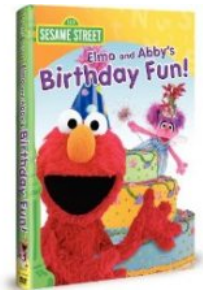
- ✓ Psychoeducation
- ✓ Increasing predictability
- ✓ Providing choice
- ✓ Incorporating perseverative interest
- ✓ Graduated exposure
- ✓ Counter-conditioning
- ✓ Noncontingent presentation of SR+
- ✓ Contingent presentation of SR+
- ✓ Escape extinction
- ✓ DRA
- ✓ Introducing S^D's for nonproblem behavior
- ✓ Coping self-talk

Case #1: Jon – Baseline of Happy Birthday

- Watch Video

Case #1: Happy Birthday Intervention

- ✓ Increasing Predictability
- ✓ Graduated Exposure
- ✓ Counter-conditioning
- ✓ Positive reinforcement
- ✓ Incorporating perseverative interest
- ✓ Escape extinction

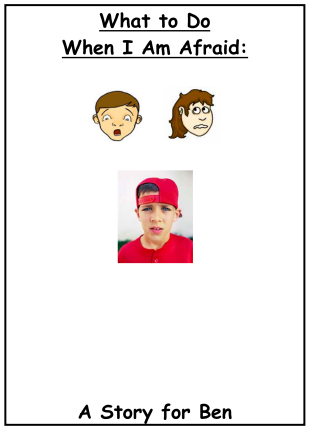


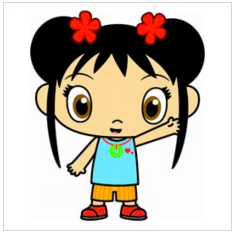
Intervention for Happy Birthday:
Exposures

- Video clip #1
- Video clip #2
- Video clip #3
- Video clip #4

Case #2: Separation Anxiety Intervention

- ✓ Psychoeducation
- ✓ Increasing Predictability
- ✓ Providing Choice
- ✓ Graduated Exposure
- ✓ Counter-conditioning
- ✓ Incorporating perseverative interest/activity
- ✓ Coping self-talk
- ✓ Extinction





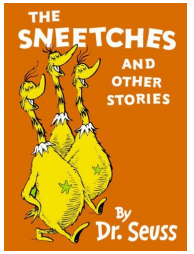
Case #3: Driving Intervention

- ✓ Increasing Predictability

- ✓ Providing Choice
- ✓ Graduated Exposure

- ✓ Counter-conditioning

Left/Right Turns =



- ✓ Incorporating perseverative interest
- ✓ Extinction

Results of Study 2 (Intervention Study)

Significant decreases in both anxious behavior and problem behavior for all 3 children with ASD and ID

Summary

- PB exhibited by children with DDs may be functionally related to feelings of anxiety
- Before we can systematically study anxiety in children with DDs, we need valid measures to assess anxiety in this population
- Identifying anxiety in children with DDs can help to inform treatment
  - Change conceptualization
  - Change intervention approach

Acknowledgements

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1947-2009

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Positive Behavior Support (PBS) Resource List

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PBS Websites

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

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

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