



Fragiles-X Kongress German FXS Conference 2016

October 1, 2016

9:30-10:10 Auslöser von Verhaltensausbrüchen und die Vermeidung weiterer Eskalationen (Dr. M. Braden)



Effective Behavior Intervention: Understanding Triggers and How to Avoid Meltdowns.

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Neuro-behavioral Theory

Neurobiology

- Protein depletion

Behavioral Phenotype

- Sensory defensiveness/hyper-arousal
- Anxiety
- ADHD
- Aggression
- Self abuse

Function

Escape

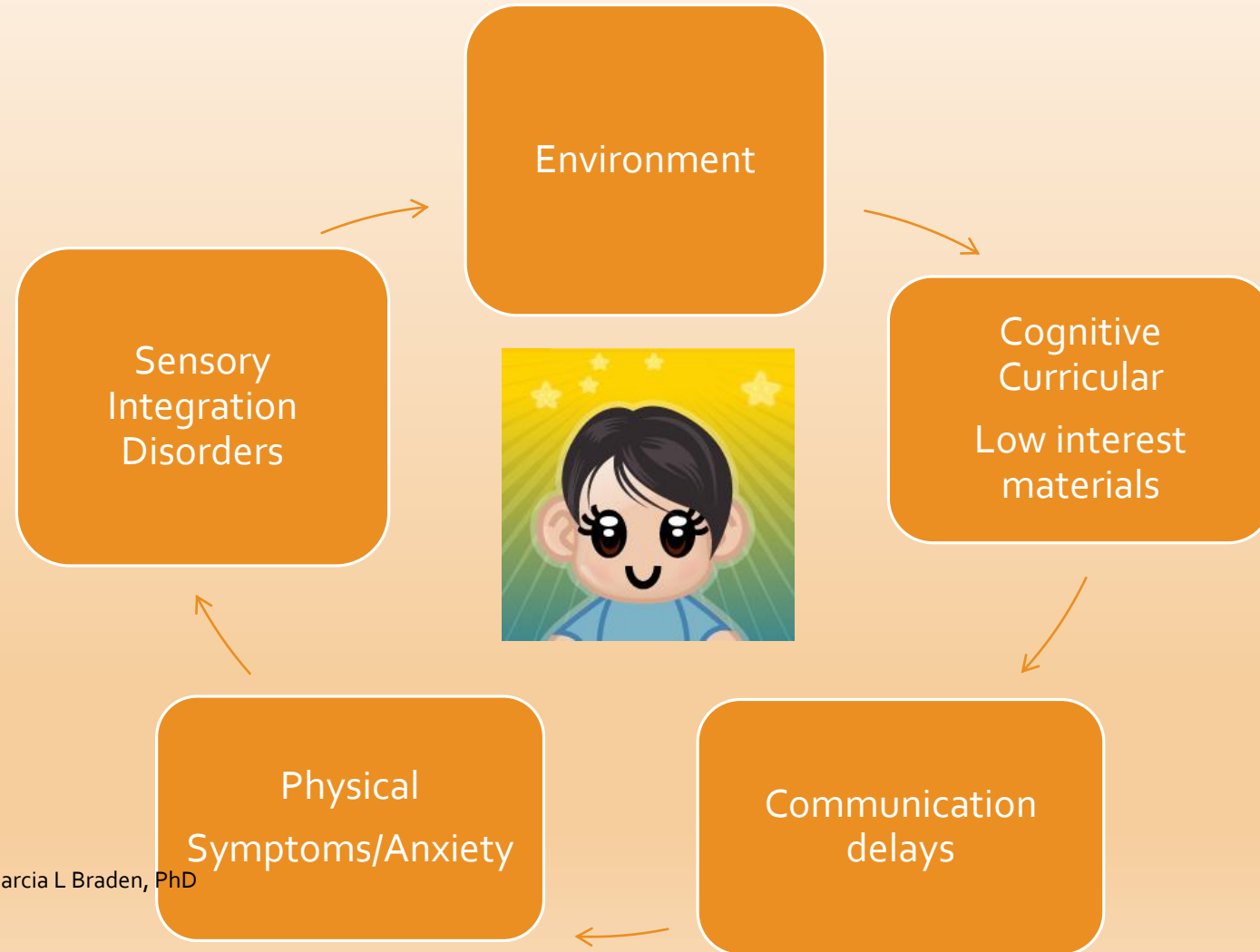
Avoidance

Gain Access to preferred activity

Attention seeking

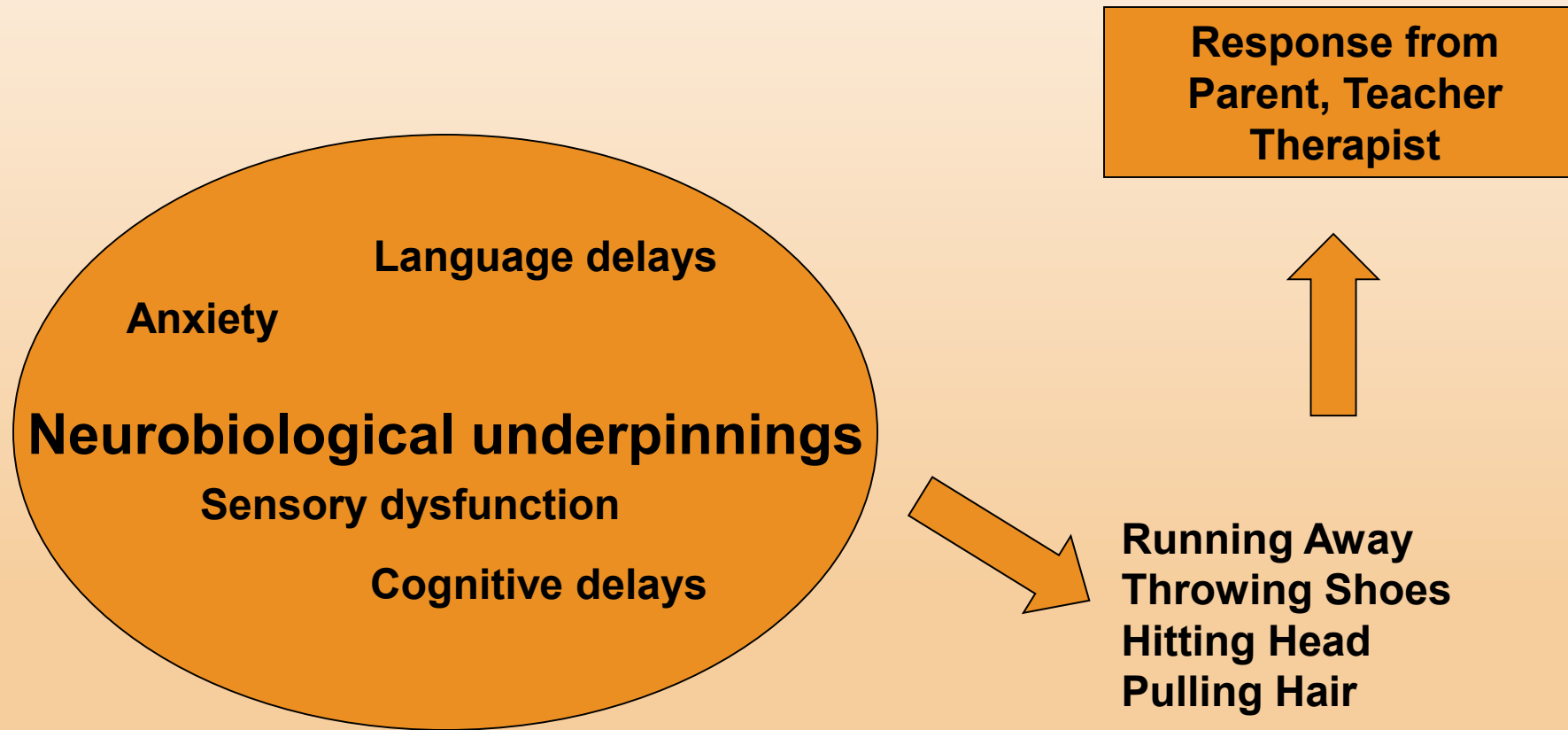
Reduce anxiety

Factors that Impact Behavior



Marcia L Braden, PhD

The behavioral cycle



Foundations of Behavior

- In order to change behavior we must first understand the foundational aspects of behavior.
- All behavior serves a purpose.
- Behaviors do not continue unless they are reinforced in some way.
- Sometimes the reinforcing aspect of the behavior is internal.
- If you do not address the cause of the behavior it will not change.

Common Antecedents

- Removing access to preferred item or activity
- Requiring compliance
- Requesting completion of non preferred tasks
- Participation in a group

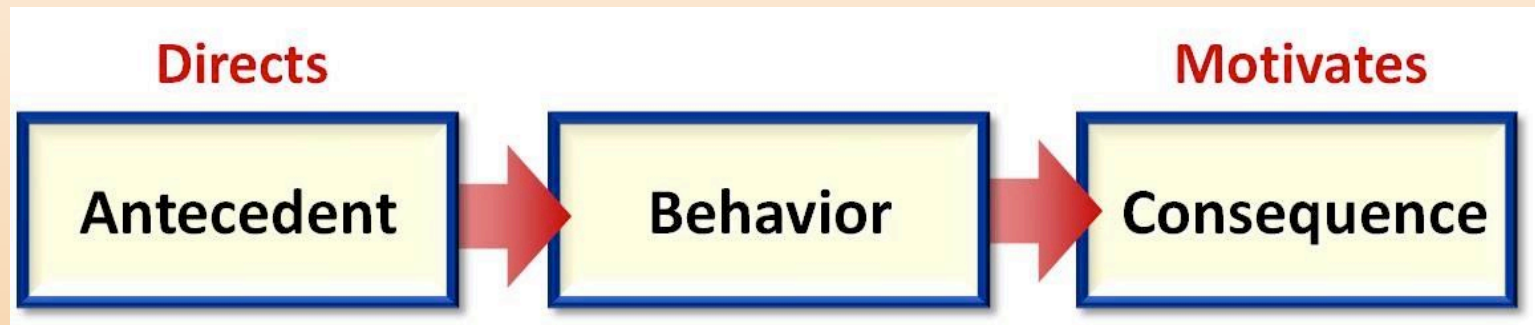
Hidden Antecedents

- Social
 - Greetings, phone calls, introductions, novel social settings
- Physical
 - Ill
 - Anxious, panicked, headaches, gastro intestinal issues
- Curricular
 - Tasks that are too difficult
 - Alternative curricula is not provided
- Environmental
 - Transitions
 - Crowds
 - Loud and unpredictable sounds
 - Change in routine

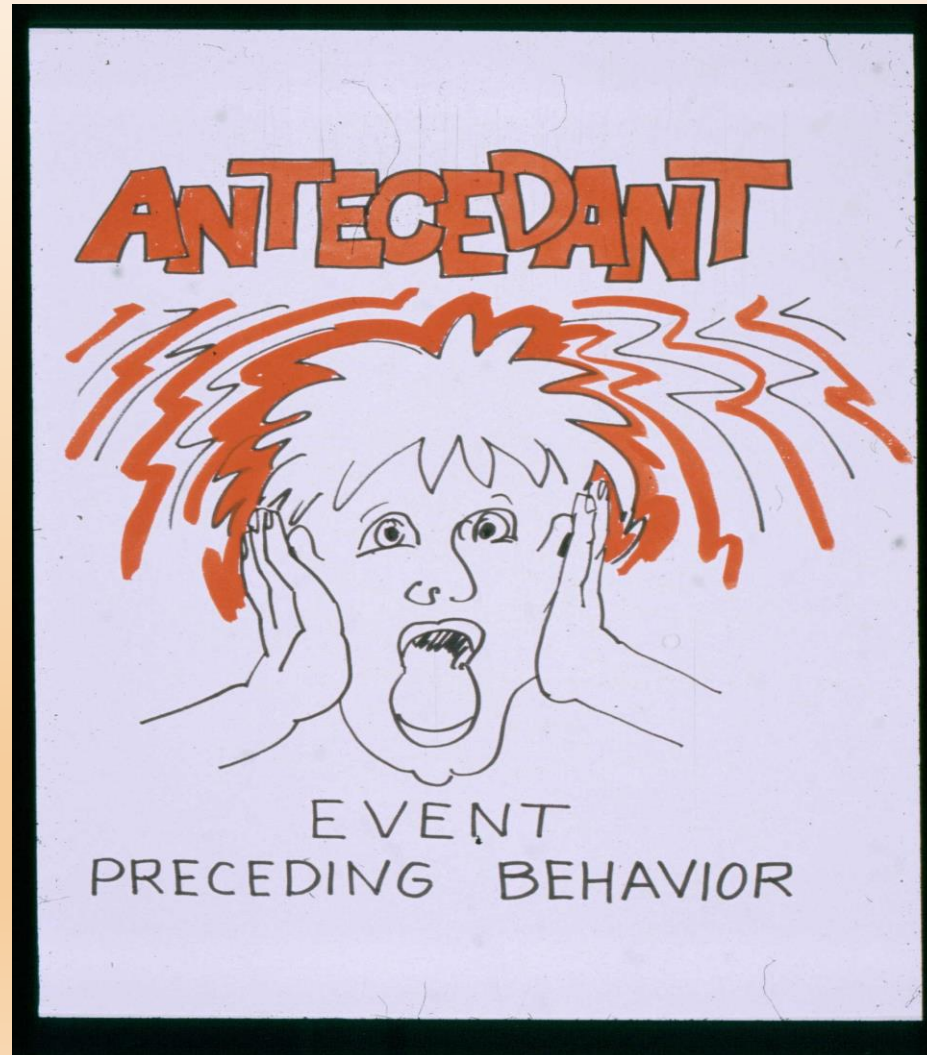
Functional Assessment

- The ABC's of Behavior
 - Antecedent (the action that occurs directly before the behavior)
 - Behavior (the specific act or behavior)
 - Consequence(what happens directly after the behavior)

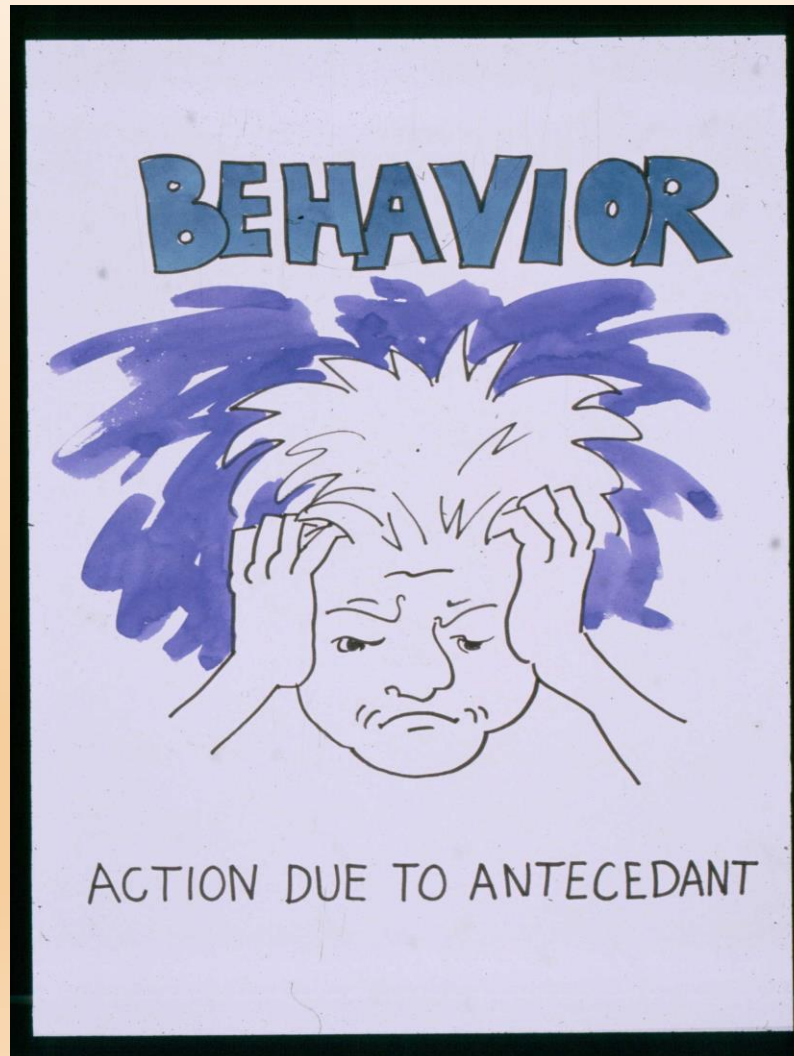
ABC's of Behavior



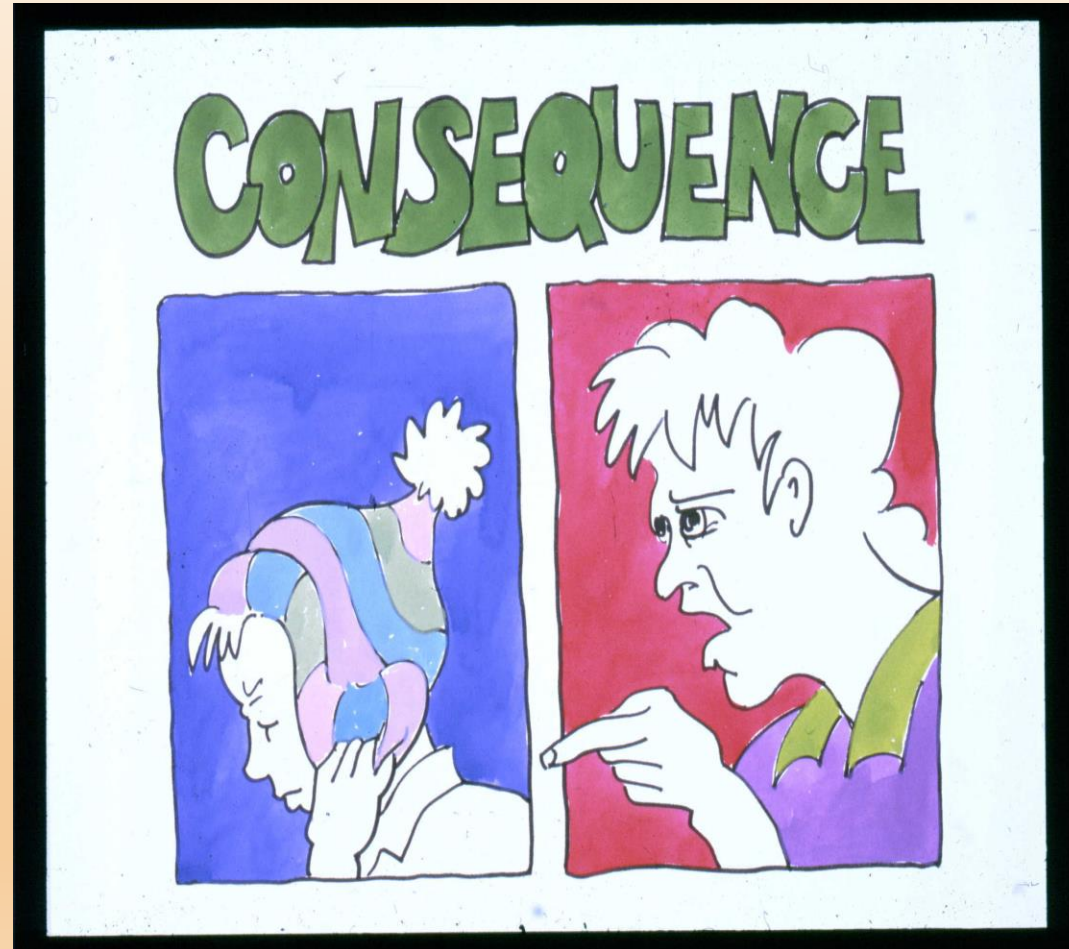
Behavioral Factors



Behavioral Factors



Behavioral Factors



ABC's of Understanding **Why** students engage in problem behavior: Finding out the Pay-off or Function of Behavior

A = Antecedent(s). Find out the events that occur right before the behavior.

- Allows you to predict: **Where** (During routine)? & **When** (Trigger event)?

ABC's of Understanding **Why** students engage in problem behavior:

Finding out the Pay-off or Function of Behavior

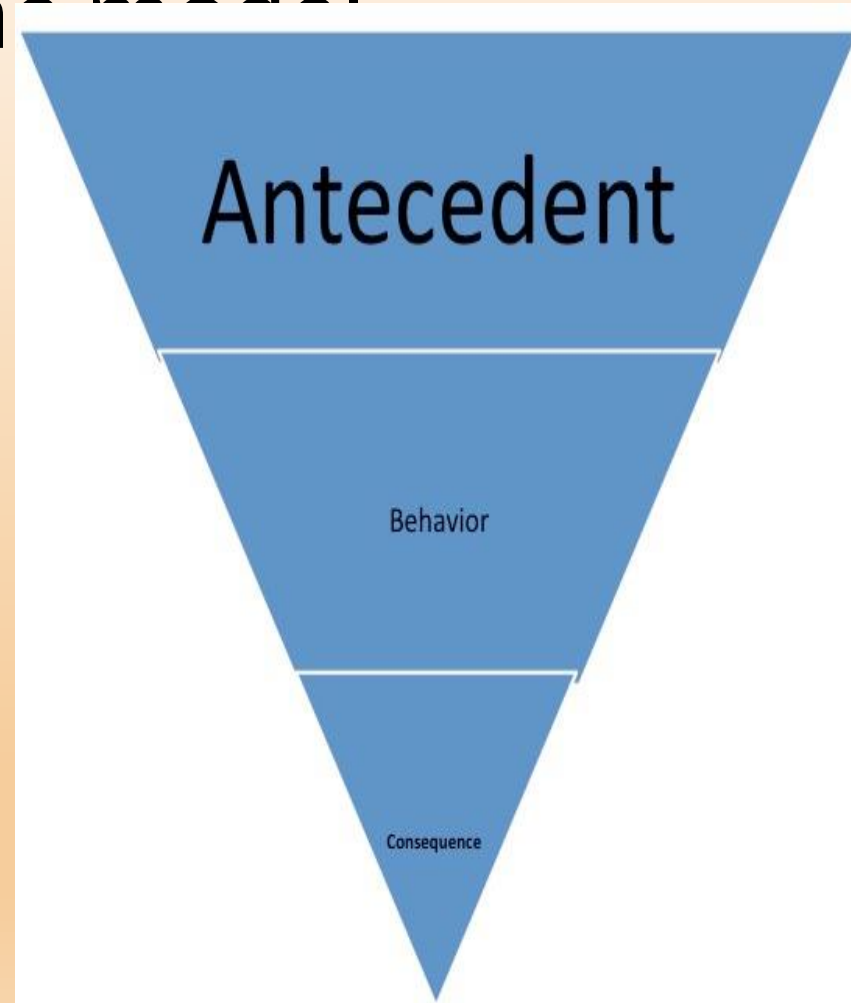
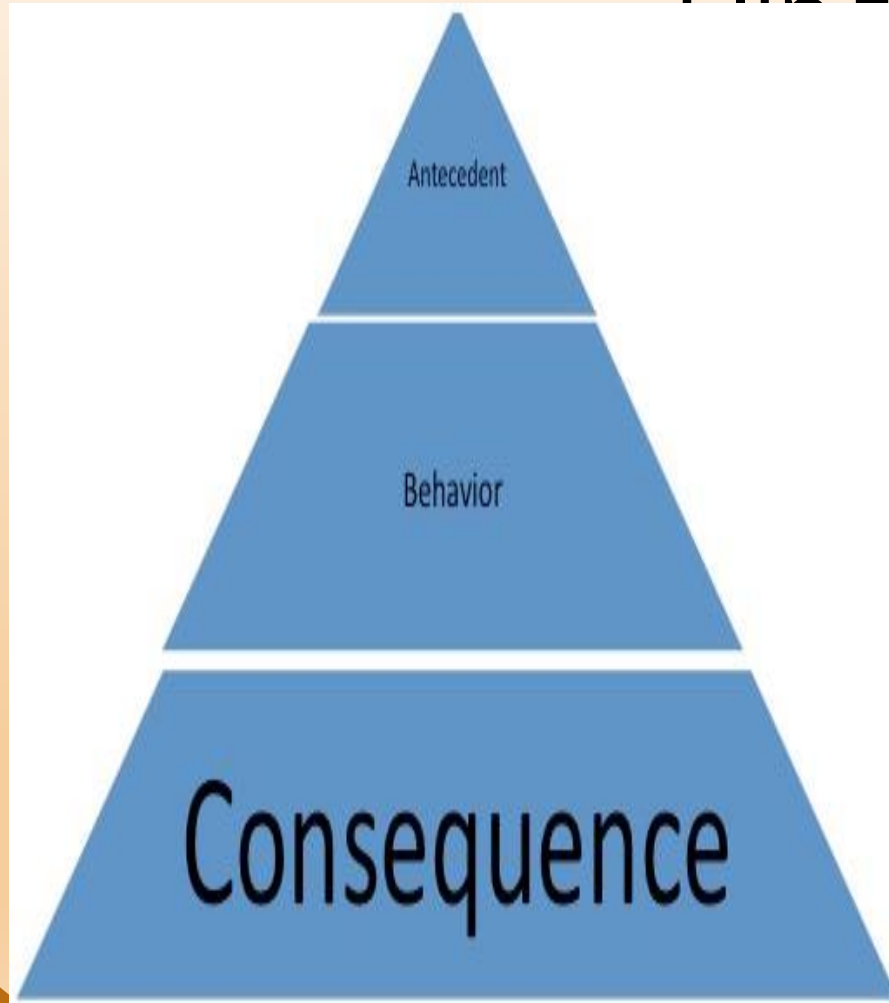
B=Behavior. Find out **what** is the observable problem behavior?

C=Outcome/ Consequence. Find out what happens after the behavior occurs? **WHY?**

A → B → C



Flip the model



Behavior Intervention Plan

Setting Event Strategies (Reduce impact of setting events)	Antecedent Strategies (Decrease likelihood that behavior will occur)	Behavior Teaching Strategies (Alternative Behaviors) (Increase the likelihood that the appropriate replacement behavior will occur through instruction)	Reinforcement Strategies (Consequence) (When student demonstrates the desired behavior, the need behind the behavior is met – e.g. obtain or avoid)
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The ABC Sequence

Antecedents or Triggers	Behavior	Consequence What is maintaining the behavior?
Patrick is in a training session and hits the trainer when she tells him to sit down		

The ABC Sequence

Antecedents or Triggers	Behavior	Consequence What is maintaining the behavior?
Patrick is in a DT session and hits the trainer when she tells him to sit down	Patrick hits the trainer	

The ABC Sequence

Antecedents or Triggers	Behavior	Consequence What is maintaining the behavior?
Patrick is in a DT session and hits the trainer when she tells him to sit down	Patrick hits the trainer	The trainer takes him to a new activity

ABC Pattern Examples

Scenario 1

Jane is doing the restroom routine

She finished rinsing her hands but continues to splash the water. Her trainer says, "turn off the water."

Jane continues to splash in the water

The trainer repeats the direction to turn off the water several times

Scenario 2

John's dad takes him to the grocery store

John walks to the checkout stand and reaches for the gum

John's dad says, "no gum today"

John screams and starts pacing back and forth

His dad is embarrassed and buys the gum and John is now quiet



Hyperarousal

“Hyperarousal” refers to a state of excessive nervous system activation that interferes with the production of effective organized behavior.



Hyperarousal

People with Fragile X syndrome:

- are unable to normally regulate their arousal
 - are hypersensitive to stimulation
- remain highly aroused after stimulation ends



Hyperarousal

Poor self-regulation of arousal, and the resulting hyperarousal, are important characteristics of Fragile X syndrome, and underlie many of the behavioral problems associated with it.

with permission from Vicki Sudhalter, PhD

Make Regulation Tools Accessible

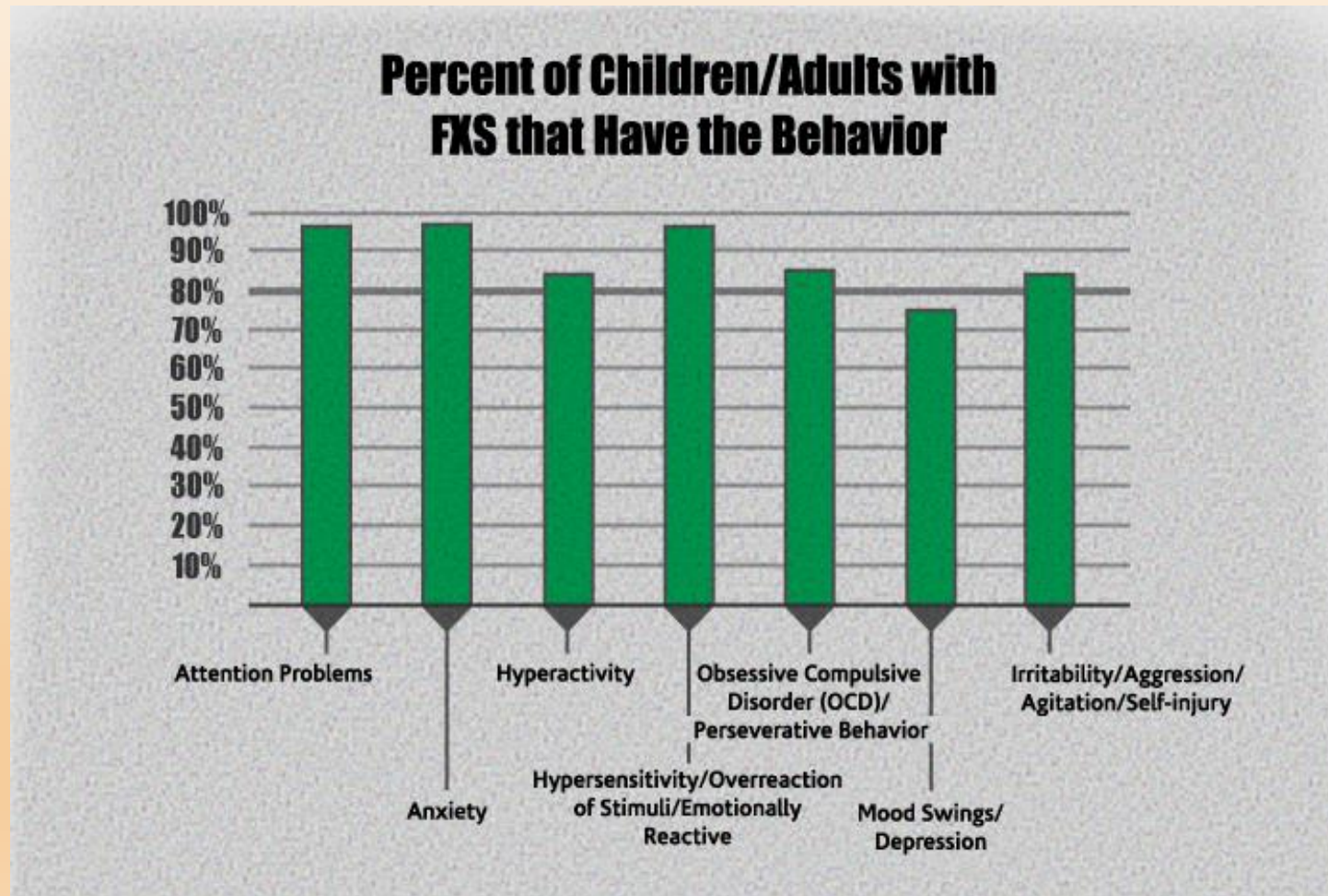


Integrate therapies

- This is the stage in thinking to integrate therapies into the daily routine in a meaningful way.
 - How to we work on speech at dinner?
 - When should we be including heavy work?
 - Can we work on counting in the car or should we be doing it at bath time?
 - How can I create opportunities for successful social interactions?

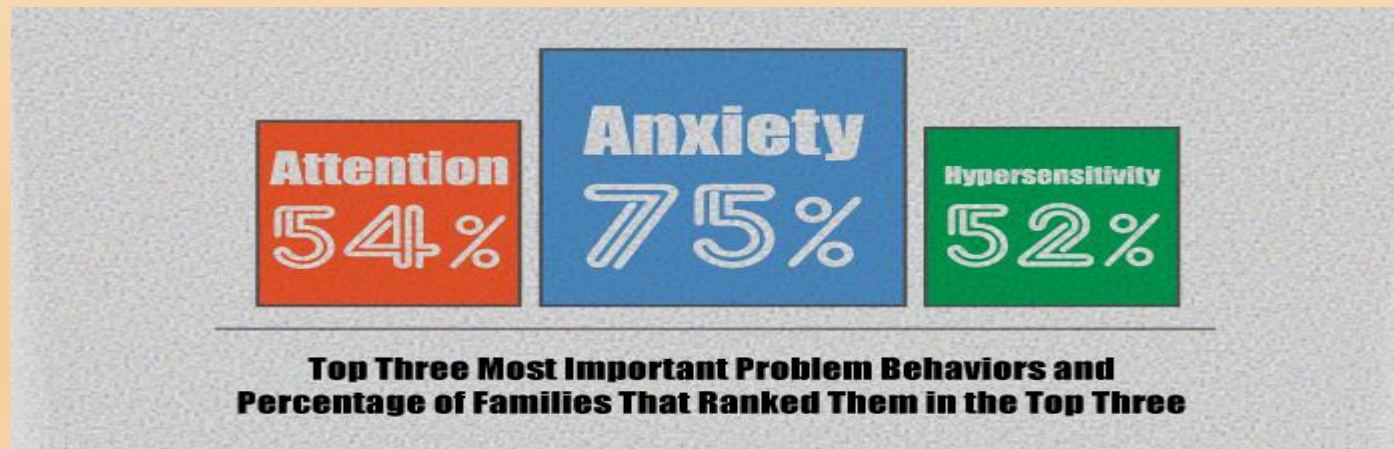
NFXF Behavioral Survey 2014

Craig Erickson, MD Liz Berry-Kravis, MD

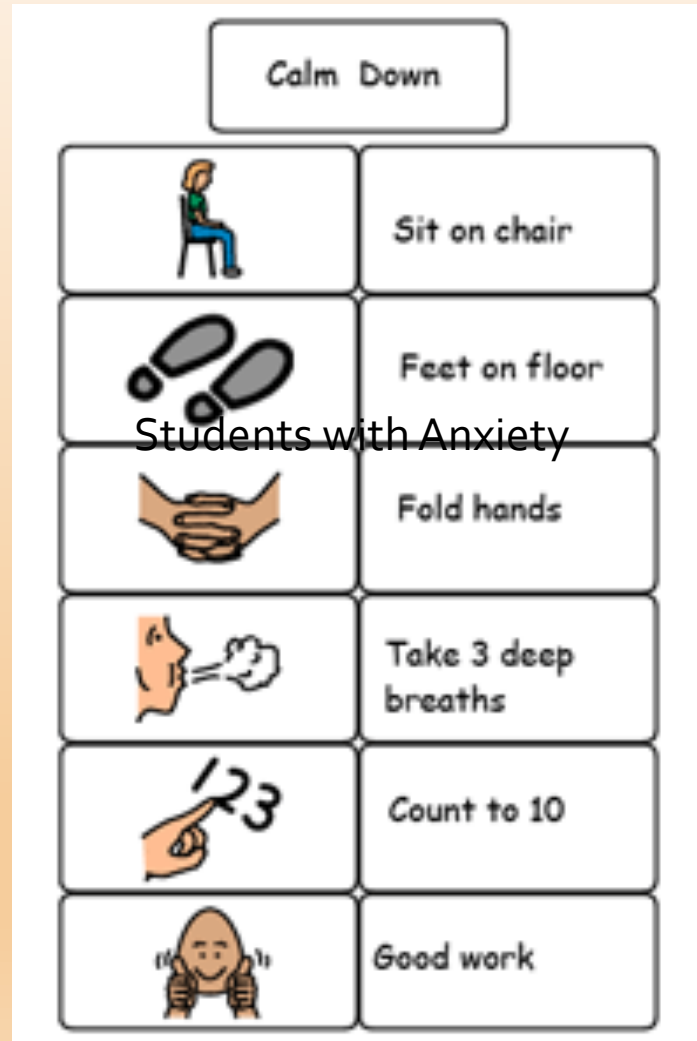


NFXF Behavioral Survey 2014

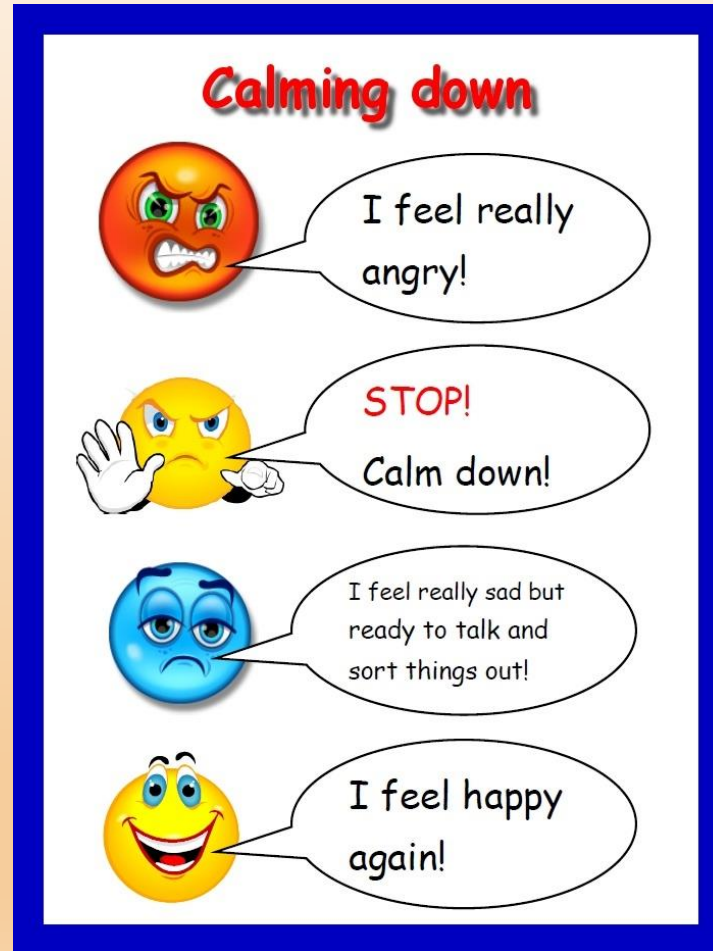
- 704 responses
- The average age of the children and adults with FXS surveyed was 15 years of age, with 86 percent males and 14 percent females.

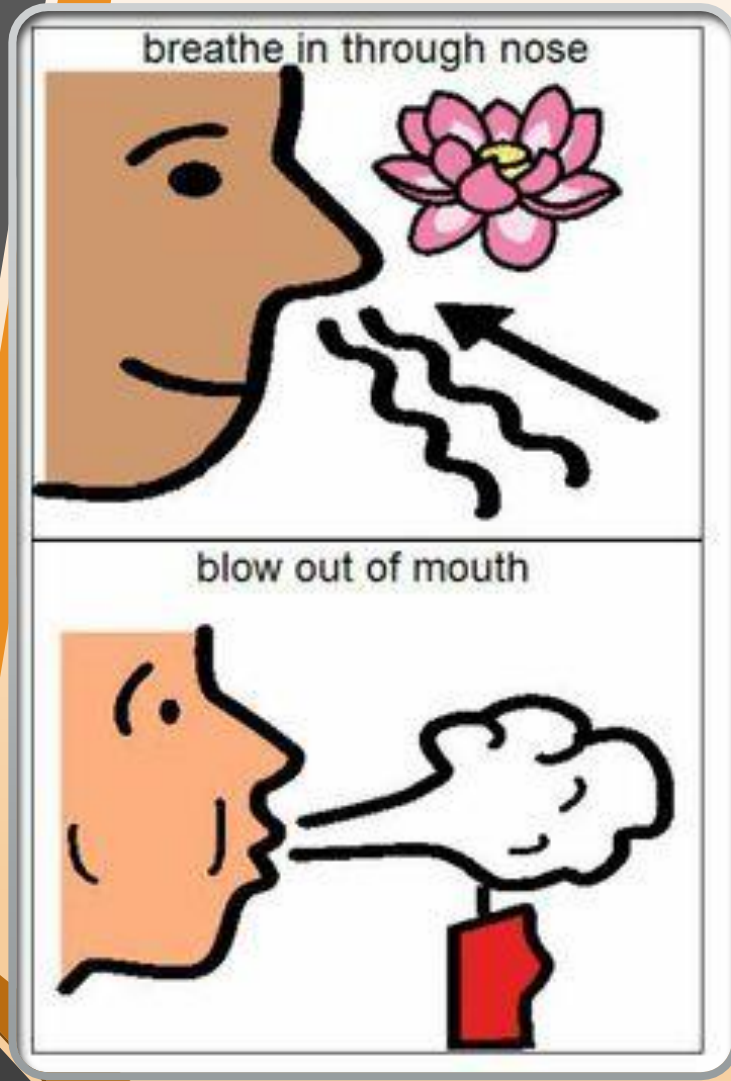


Students with Anxiety



Students with Anxiety





Three Key Strategies

- 1. Know your triggers for anxiety and worry
- 2. Know how to identify your feelings and know how big they are
- 3. Know how to calm your mind and body using coping tools
- Practice, practice, practice!

Breathing Routines



I can take 5 deep breaths

1

2

3

4

5

What about parents and teachers?

- Examine the impact that parents, teachers, therapists, and siblings etc. have on the behavior of the individual with FXS.
- Examine the impact that the individual and his/her behavioral issues has on parents, teachers, therapists, siblings.
- SIP theorizes that the ways in which individuals understand, interpret and process social cues within situations influences their behavior (Crick & Dodge, 1994; Dodge, 1986; Lemerise & Arsenio, 2000)
- Examine the role that anxiety plays when individual with FXS are involved.

Understanding your own scale



- Changing behavior is not easy
- The behavior will get worse before it gets better
- Understand the trade-offs
- You do not need to change everything now



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11:00 Creating Supportive Environments to Promote Positive Behavior at School, Home and Work.

Günstige Umgebungen für Menschen mit Fragilem-X Syndrom in Schule, Arbeit und Wohnbereichen (Dr. M. Braden)

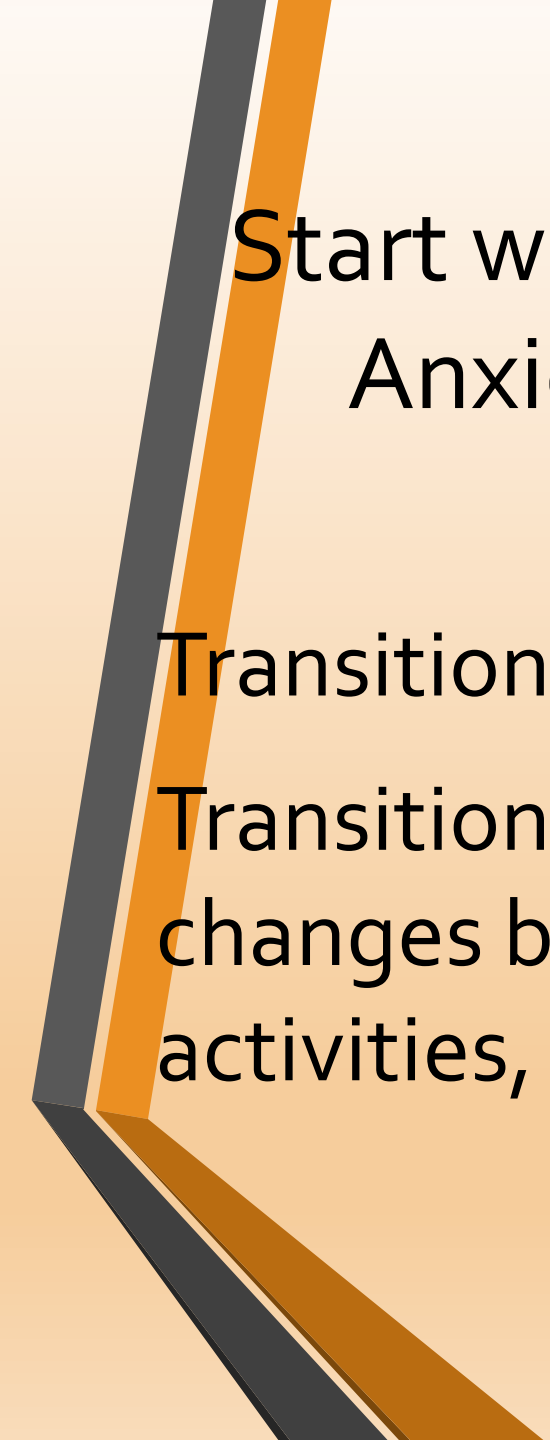
How Does the Right Environment Promote Positive Behavior?

- When a person with FXS feels supported (we understand what they need) they do not have to express discomfort through their behavior.
- Understanding the behavioral phenotype enables us to structure the environment in a way that is supportive
- Providing supports to mediate the behavioral deficits such as reduced noise, less verbiage, secure and predictable direction, opportunities for breaks, less demands when dysregulated and positive reinforcement will promote engagement and positive outcomes



Behavioral/Emotional Profile

- Anxiety Disorders, Panic Attacks and Social Anxiety
- Sensory Integration Disorder
- Attention problems, Hyperactivity
- Mood Lability, Mood Swings
- Aggression



Start with the Environment


Anxiety/Panic Attacks

Transitions

Transitions are movements or changes between environments, activities, people, stages or states

Transitions

- All children endure transitions throughout the day.
- Transitions occur at home, in school, during play, etc.
- Though all individuals experience some form of arousal when in transition, individuals with FXS experience greater degrees of arousal at those times than those without FXS.



Examples of transitions that occur within the home include:

- Bed to bathroom
- Bathroom to kitchen
- Undressed to dressed
- Playing to eating
- Waking to sleeping
- Parents to babysitter

with permission from Vicki Sudhalter, PhD



Examples of transitions that occur at school include:

- Home to bus to school
- Classroom to class or therapy room
- Classroom to cafeteria or gymnasium
- Teacher to teacher, therapist or para
- Class lesson to lesson or activity
- School to bus to home



Examples of transitions that occur at work include:

- Home to work/ work to home
- Work station and setting
- Work to break
- Transitions from one supervisor to another
- Transition from one job to another

Examples of transitions that occur anywhere include:

- Morning to afternoon
- Day to night
- Weekday to weekend
- Inside to outside activities



Start with the Environment

What can the environment provide to reduce anxiety caused by transitions?

- Prepare for transitions by providing a predictable schedule- use visual icons. Embed sensory activities prior to the transition
- Provide a transitional object or job to be incorporated into the transition
- Established routines such as morning breakfast, getting ready for school or work, dressing for work and getting there, bedtime.
- Organize the environment to promote consistency

Transitions

- Why are transitions so difficult? The obvious reason relates to the anxiety provoked by the unknown- what is the expectation when I enter the new environment? What is the environment like? Will it be noisy, and chaotic? Who will I see there?






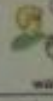


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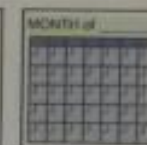


Modify the schedule to assist in transitioning

- It is much easier to modify the schedule than to modify the individual to fit the schedule.
- What are the challenging times? And what are challenging activities? Don't mix the two.
- What is the purpose of the current schedule and what can be shifted?
- Use physical props to help with the schedule/transitions.

My visit to the doctor

	Go to doctor	✓
	Wait in room	✓
	Listen to music	
	Take height & weight	
	Take blood pressure	
	Wait to see doctor	
	Exam	
	Say "Goodbye!!"	



I will visit the doctor this week.

I will wait patiently in the waiting room.



While I am waiting, I can listen to music or read my Simpson's book.



The nurse will call my name. She will take my height and weight and take my blood pressure.



I will wait to see the doctor.

The doctor will come in and do an exam.



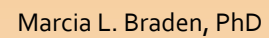
Once the exam is over, I will say 'bye' and get a special treat!



Start with the Environment at School

- Consider lighting, visual clutter and extraneous noises
- Pair verbal with visuals
- Reduce verbiage
- Organize spaces with desk placement and work table charts
- Make clear the expectation; what work, how much work, when finished
- Provide opportunities to interact with typical peers

Overcome this



Or this..with this



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Start with the Environment at School

- Visual timetables and supports
- Consistent routines that build predictability
- Boundaries
- Movement breaks (www.yourtherapysource.com)
- Heavy work activities
- Fidgets
- Seating options
- Fast paced presentation
- High interest materials to enhance engagement
- Opportunities to interact socially with adults and peers

We Would Use Visuals to Sequence a Behavioral Intervention



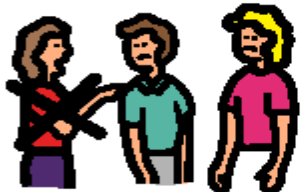
Hair Pull Protocol



Move students



Don't talk to us



ONLY come if asked

Use Visuals to Teach Behavioral Regulation

Don't hurt people

When I'm upset
I may hurt people.



Pulling hair
hurts.



Scratching
hurts.

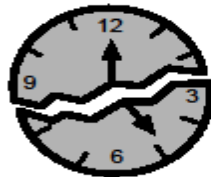


Kicking
hurts.



I will try to be in control of my body.

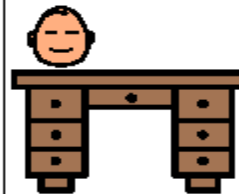
Ask for a
break.



Squeeze
hands



Head on
desk



Go to
sensory
room



Take deep
breath



Use physical props to help control the aspects of the environment that you can't control.



with permission from Karen Riley, PhD

Start with the Environment at School

- Incorporate high interest material into instruction
- High interest links familiarity with novelty
- Novel skills are not taught in isolation, but embedded into the high interest materials
- Interests may neutralize the full impact of learning something new and unfamiliar, hopefully reducing anxiety
- Utilize peers as teaching models. This facilitates indirect learning and reduces the intensity of the learning experience.
- Use side dialoging to introduce a schedule change, subtle shift in activity or other communication need.



Start with the Environment at Home

- Set a schedule
- Establish a routine
- Set up a responsibility chart, chore checklist, and jobs
- Honor requests to stop an activity, access support or leave
- Provide a safe place to regroup or time out socially
- Limit transitions especially when dysregulated



Start with the Environment at Home

- Allow for a quiet place away from noises and people in the house
- Honor requests to remove themselves from a family activity or gathering
- Avoid conflict, loud arguments or incessant verbalization
- Avoid embarrassment and attention



The End