



Parker Lentini, Vice President/Young Adult with Chronic Illness

Purple Playas Foundation

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Participants will learn...

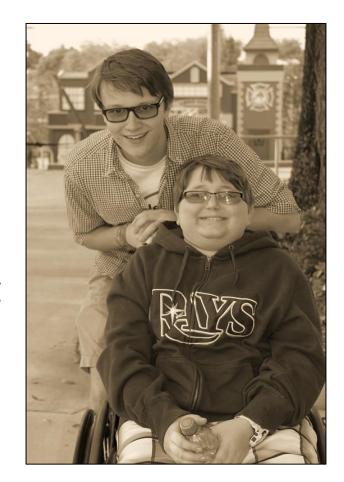


- The 3 stages of learning to guide social emotional development
- All behavior has a communicative message, interventions that are based on understanding the purpose of the challenging behavior are most effective
- Intervention activities for guiding and teaching socialemotional skills to assist in coping with medical trauma

View From the Family's Perspective



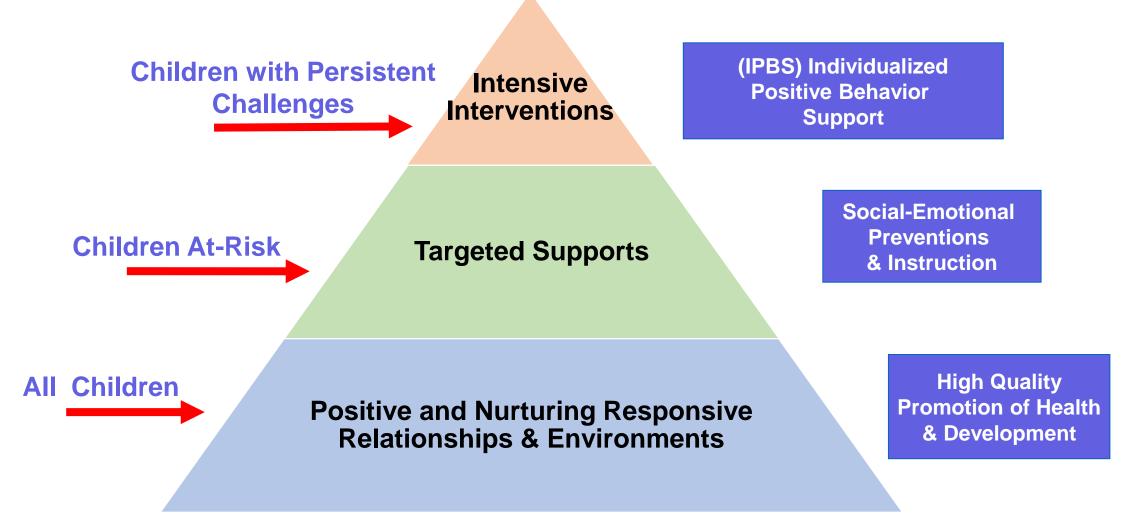
- ✓ Chronic illness impacts the entire family
- ✓ Parents have multiple roles and competing demands
- ✓ Effective resources can help minimize consequences of raising a child with chronic illness
- ✓ It is normal to experience a wide variety of emotions
- √ How a situation is viewed can impact coping/adjusting
- ✓ We model what we know
- ✓ Coping begins early...families are empowering toddlers/preschoolers, school age children, and teens with tools for adulthood



The Pyramid Model:



Promoting Social-Emotional Competence within Family Homes & Care Environments



Medical needs
Social services
Education
Sibling needs
Finances
Partner's needs
Emotional needs
Therapies

Seeking/accepting help
Adapting priorities
Health/exercise
Maintaining/building relationships
Work
Advocacy
Vacations/down-time
Family time

Teeter Totter Effect: Creating a Sense of Balance in a State of Hyper-Vigilance

Intensive Interventions

Targeted Supports

Positive and Nurturing Responsive Relationships & Environments



Importance of Addressing Behavior and Social-Emotional Development

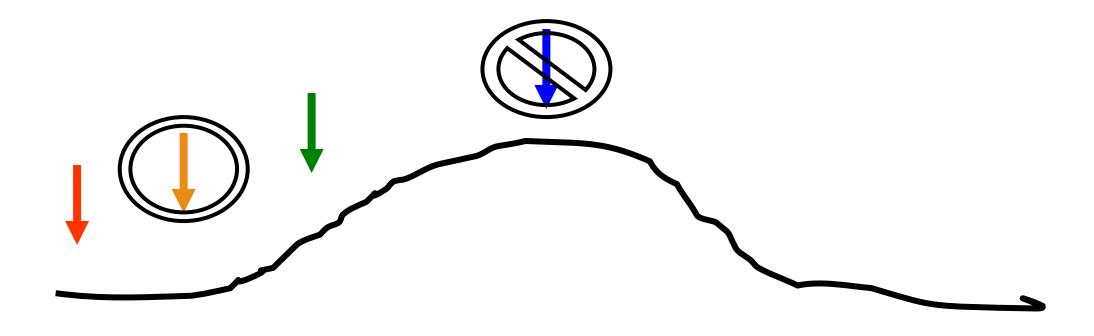


- Challenging behavior can impact interventions and treatments
- Delayed development can lead to more severe problem behavior
- Social emotional growth can affect ability to engage in a socially acceptable manner
- Children with severe challenging behavior are deeply at risk for social exclusion and academic failure





Identifying Teachable Moments



If You Want It, TEACH IT!



"If a child doesn't know how to read, we teach."

"If a child doesn't know how to swim, we teach."

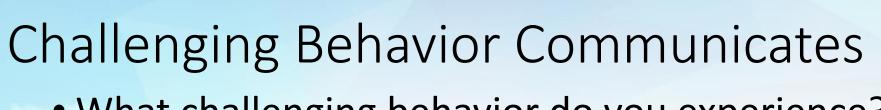
"If a child doesn't know how to multiply, we teach."

"If a child doesn't know how to drive, we teach."

"If a child doesn't know how to behave, we...

.....teach?punish?"

"Why can't we finish the last sentence as automatically as we do the others?"



- What challenging behavior do you experience?
- Why do you think kids have challenging behavior?
- What have you tried when children use challenging behavior?
- Does it always work/help?











Antecedent + Behavior + Consequence = Function

- 2 Functions of Behavior
 - → To Obtain/To Get Something
 - To gain access
 - To get attention
 - To obtain something
 - To get a toy, favorite food, prize, place, activity, person, item, fun, more time, etc.

- → To Escape/To Get Get Out of Something
 - To escape a demand
 - To get out of a task
 - To get away from something scary
 - To avoid doing an activity
 - To get out of doing an routine, taking a med, homework, seeing a person, etc.





- Setting Events
 - Illness, lack of sleep, change in routine, divorce, marriage, birth of a sibling, medication side effect, disability, etc.
- When possible, honor the function of the behavior
- When you can't honor the function ...prevention strategies and responses are more critical
 - For example, we can't honor wanting to escape from: car seat, medication, wearing clothes out of the house, procedures/treatments, blood work, hospital stay, going to bed, etc.
- Warning! Extinction bursts are a real result of NOT using the "old consequence" that was previously reinforcing a challenging behavior



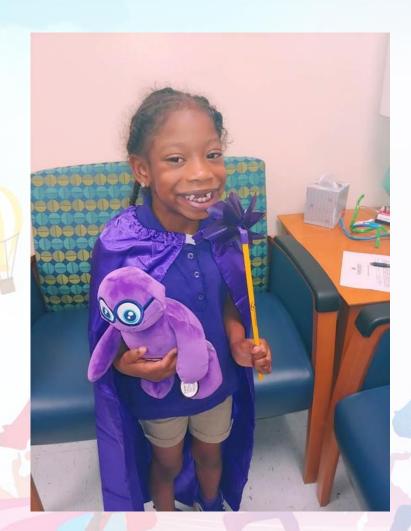




- Emotional Expression, Perception, and Understanding
- Problem Solving
- Coping Strategies due to:
 - Pain
 - Loss
 - Emotions of disappointment, fear, anxiety, frustrations, anger, etc.
- Self-advocacy

Stages of Learning





1. Show and Tell

Acquisition – new skill or concept

2. Practice Makes Perfect/Permanent

 Fluency – the ability to immediately use the skill or concept without a prompt

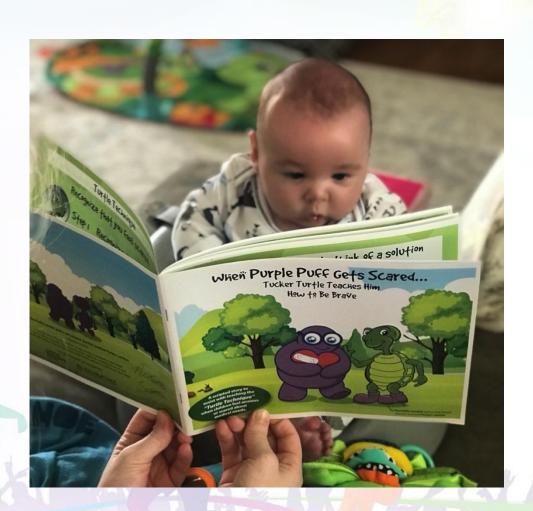
You Got It!

- Maintenance continuing to use the skill or concept over time
- Generalization applying the skill or concept to new situations, people, activities, ideas, and settings

Acquisition Stage: Show and Tell



- Explain concretely
- Demonstrate
- Link to other ideas or concepts
- Examples and non-examples
- Encourage child when learning
- Warning! The new skill or concept can be easily lost at this stage...encourage, encourage



Fluency: Practice Makes Perfect/Permanent



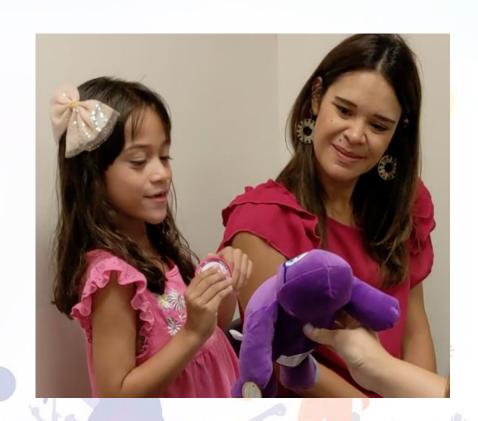
- Offer multiple opportunities to practice
- Help child link concept or skill to others
- Prompt the child to use the skill or concept in new situations
- Elaborate on the skill or concept

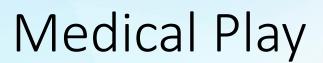


Maintenance and Generalization: You Got it!

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- Provide opportunities to use the skill or concept in new situations or with new people
- Provide opportunities within a variety of activities and in new applications
- Comment on the child's ability to maintain the skill and generalize it's use





- Instruction is embedded within medical play and routine activities
 - When possible, includes home play
- Major focus is to facilitate social-emotional understanding, coping skills, appropriate interactions and concept development
- Instructional activities should be brief and concrete





Play-Based Strategies

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- Adult Modeling
- Modeling with Characters (puppets, stuffed animals)
- Activities with Family
- Prompts/Cues
- Priming of what's to come
- Encouragement
- Incidental Teaching
- Distraction Techniques

- Role Playing
- Games
- Songs
- Fingerplays
- Sensory/Fidget Toys
- Flannel Board Activities
- Children's Literature
- Scripted Stories
- Etc.

Coping and Self-Regulation

- Emotions/Feelings
- Calming Techniques
- Problem Solving/Solutions
- Developmental Communication
 - First, Then
 - Choices
 - Clear Expectations
 - Visuals/Hands-on Tools
- AND 3 Stages of learning...
 - Prepare for skill needed and help child understand/handle situation (being brave, possible disappointment and/or change, etc.)
 - Practice steps/skills frequently
 - Recognize and comment when the child stays calm





Emotional literacy

is the ability to identify, understand, and express in a healthy way.



Building Children's Ability to Express Emotions

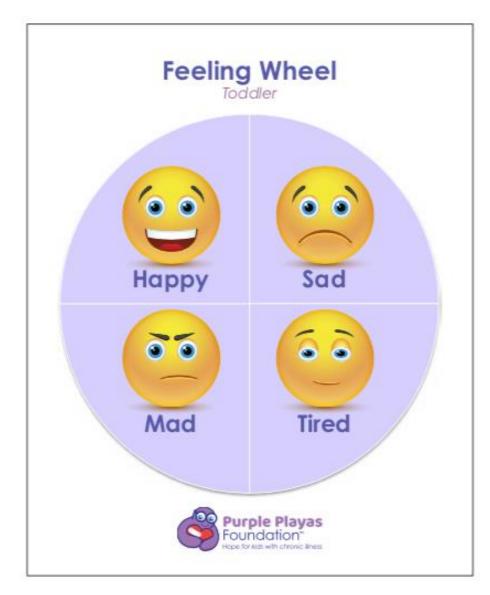


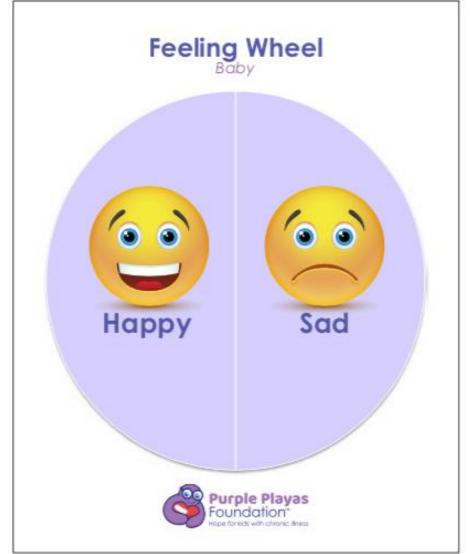
(including siblings)

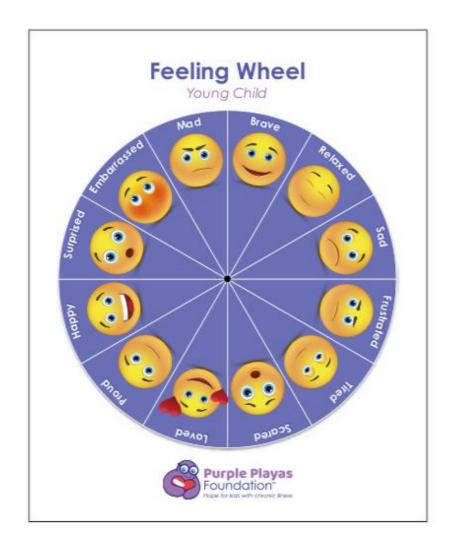
- Teach new emotions words:
 - frustrated, disappointed, anxious, confused, hurt, worried, scared, etc.
 - calm, peaceful, joy, loved, proud, brave, etc.
- Talk about, describe and reflect on:
 - own feelings
 - feelings of others
 - feelings of characters in books, videos, TV show, movies
- Pretend play using "feeling words" with toys, stuffed animals, puppets, dolls, or action figures
- Draw pictures about feelings
- Cue child, "Tell me how you feel."
- Support, accept, and <u>validate</u> child's expression of feelings
- Model how to cope and stay calm



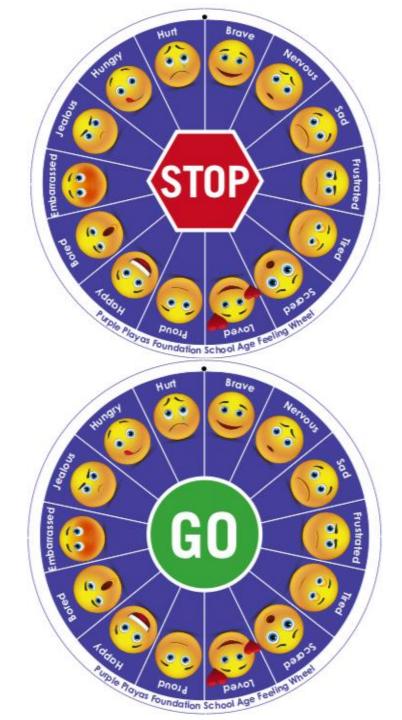














Turfle Technique

Recognize that you feel scared.



Step 1 Recognize your feeling (scared, angry, etc.)

Step 2 Stop.



Step 3 go inside shell; take 3 deep breaths to calm

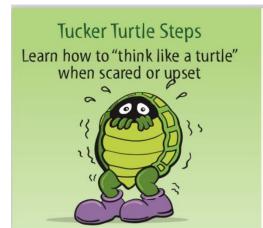
Step 4 come out of shell when calm and think of a solution.

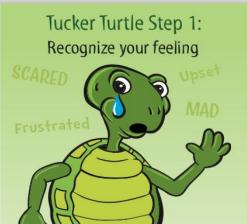


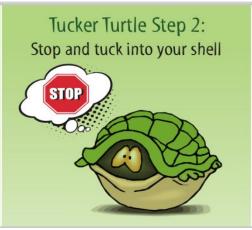


Wallet Cue Cards



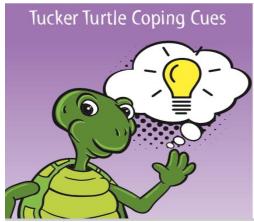
















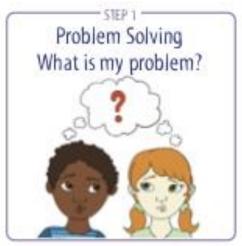


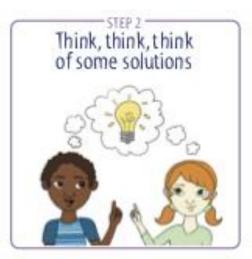


Wallet Cue Cards





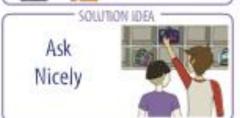




























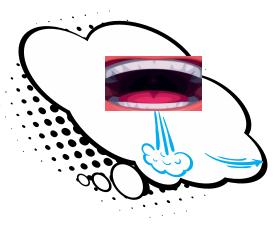


Deep Breathing Takes Practice

- Practice when child is calm
- Breathe in through your nose, out through your mouth
- At least 3-5 breaths per practice session
- Can utilize props
- Consider modeling, visually cueing

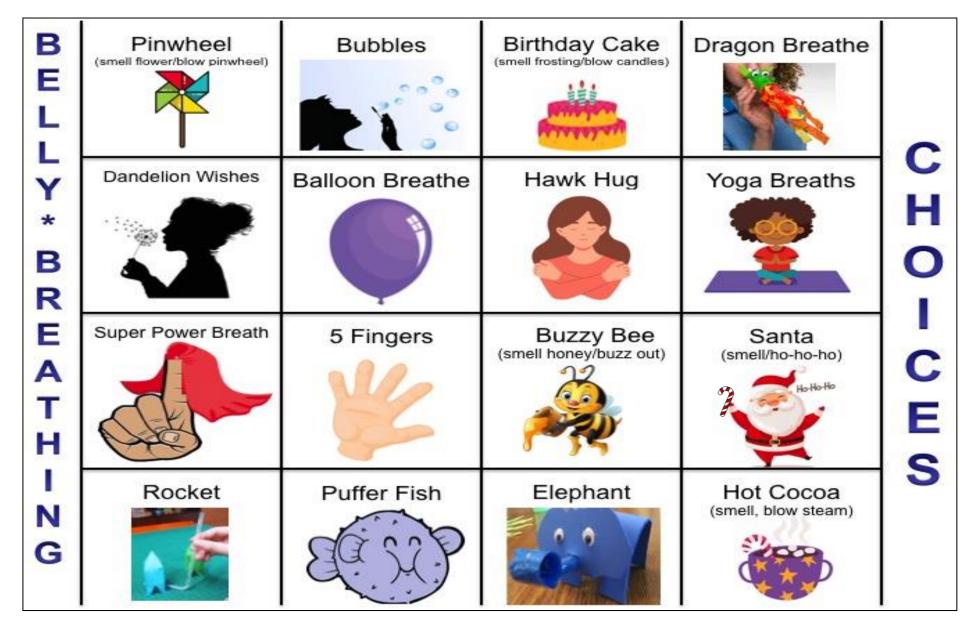






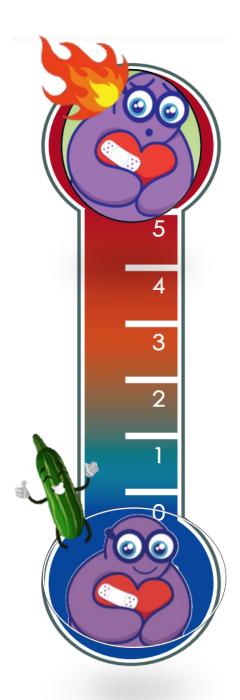
If you want it, teach it...





Think about when you are tense, scared, stressed, angry.







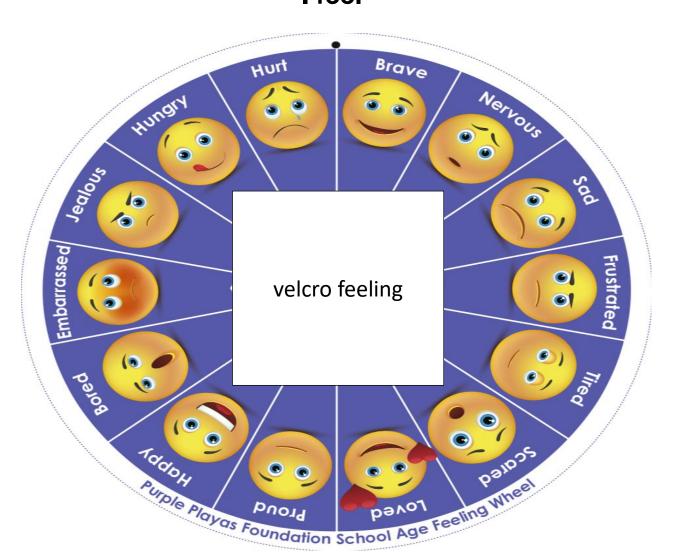
What is happening inside your body?

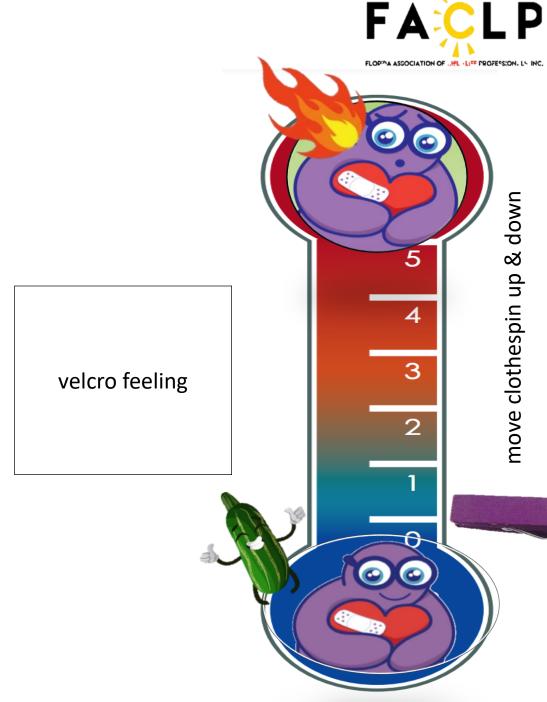


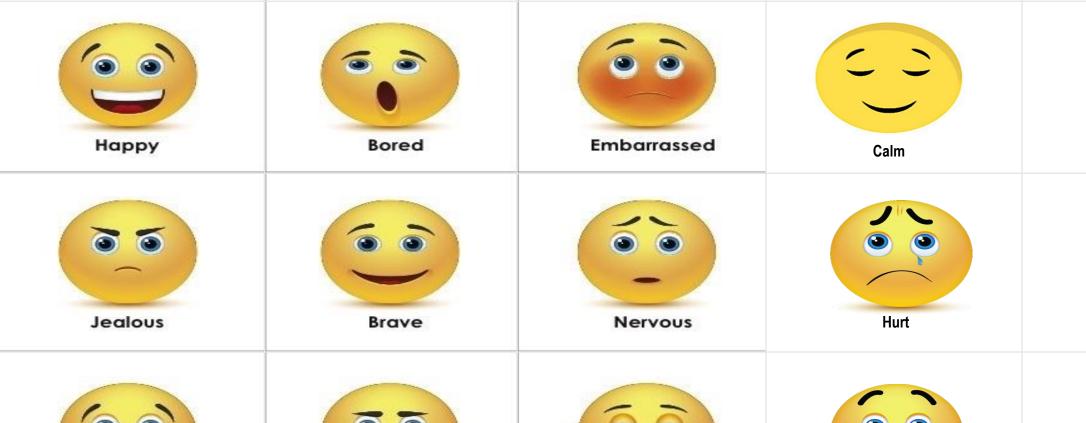
Internal Thermometer

Am I calm and cool as a cucumber?

I feel



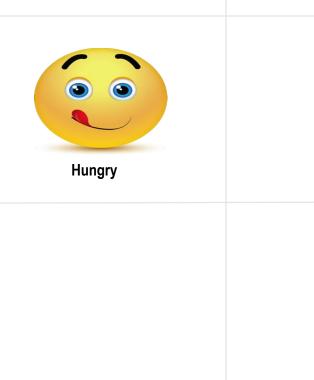


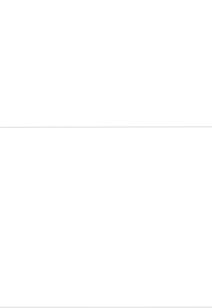












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FIRST

I make a plan of how to numb my shot spot, belly breathe, and what activity I want to do.



THEN



Then an adult helps me do my activity and shot. I either sit in a "comfort position" on a lap or bymyself.



Buzzy Bee Magic Cream Freezie Spray N FLOPINA ASSOCIATION OF THE LITE PROFESSION, L' INC. Ice Shot shield Ladybug Flutter M N G Purple Playas Foundation

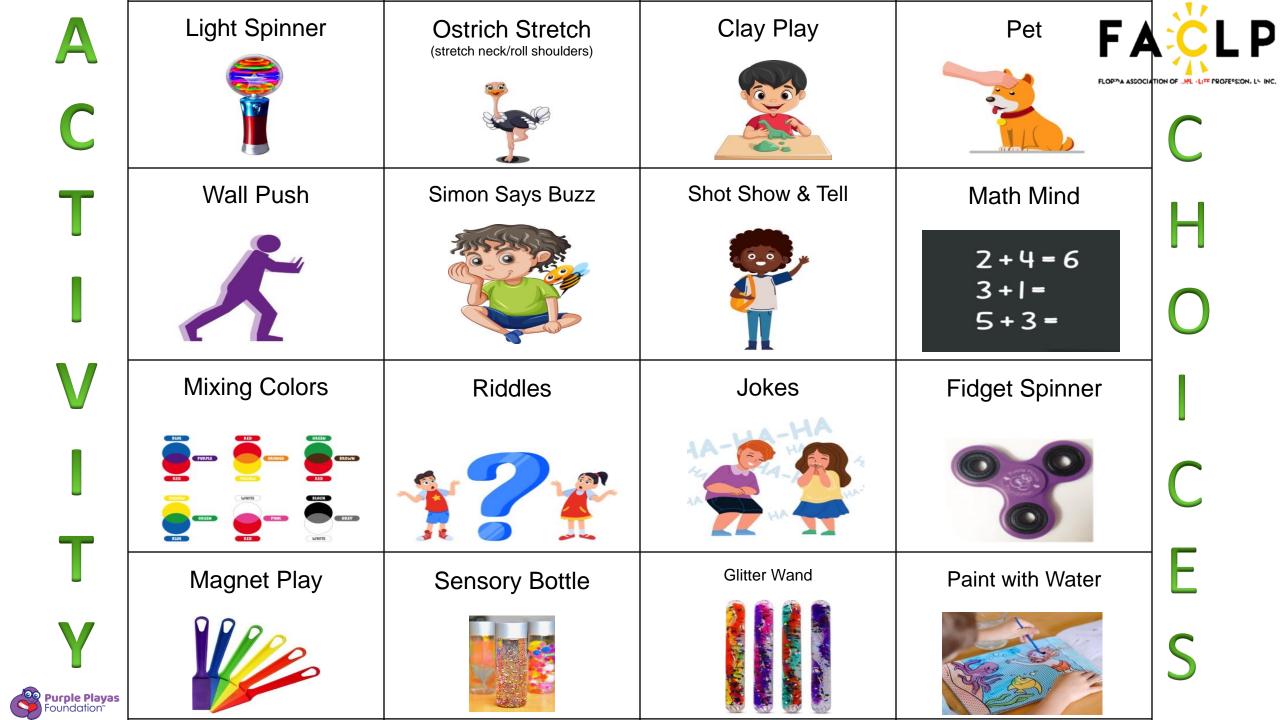


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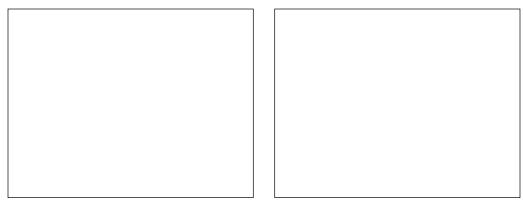
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S



I want to use...





to numb my shot spot.





to belly breathe.





as my activity today.





Purple Playas Coping Book Bundle Contents

FLOPYNA ASSOCIATION OF JUMP - LIFE PROFESSION, L' INC.

- Information booklet
- Book: When Purple Puff Gets Scared...Tucker Turtle Teaches Him How to Be Brave
- Pinwheel with Grape Scented Lip Balm
- Tucker Turtle & Coping Cues Wallet Cues (self regulation)
- Problem Solving & Solution Wallet Cues

2022 Pilot Study of Purple Playas Coping Book Bundle: St. Joseph's Children's Hospital



(32 children)

DEMOGRAPHICS/BASELINE

- 25% Hispanic, 28% were unknown ethnicity, 13% two or more races, 22% black, 38% white, and 31% unknown race
- 100% had at least one chronic illness, 50% had multiple health conditions, 22% had a disability in addition to chronic illness
- 19% received free or reduced lunch and
 22% had unknown lunch funding status
- Prior to use of materials
 - 97% had difficulty coping
 - 93% exhibited challenging behavior

RESULTS

- After use of materials
 - 97% of children coped better
 - 97% of children had reduction in challenging behavior
 - 97% of the child life specialist said the materials help them in their role

Comments from Child Life Specialists



- "Here for vaccine, very anxious, pacing in the room and stimming frequently. Reviewed Tucker Turtle book, practiced deep breathing, and he blew pinwheel during the procedure. Was able to remain still and focus."
- "He was obsessed with the pinwheel! Loved it!"
- "She LOVED the coping kit!!!! Very successful in helping her cope with her poke."
- "Pt is developmentally delayed cognitive function around 7 year old level. Coping kit helped her through immunizations."

In Conclusion, Remember to...



- Identify the skill you want to teach
- Teach the skills when the child is calm
- Give opportunities to practice role play, prompting children through an interaction (scaffolding), embedding instruction
- Model the new skills/behaviors
- Reinforce the skill use and behavior in context use positive descriptive feedback to comment on children engaging in the behavior
- Involve children in reflecting on the skills



Please remember to go on cvent and fill out the session survey!

