Long Island Jewish Medical Center
Northwell Health®

STRYDD

The Center for Supporting Trauma Recovery in Youth with Developmental Disabilities

Lessons Learned about Trauma with Youth who have Intellectually Developmentally Disabilities

George Wurzer, LCSW

Daniel Hoffman, PhD, ABPP

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Learning Objectives

- Describe impact of trauma on youth with developmental disabilities
- Explain how all behavior is communication, as well as the functional nature of behavior in terms of meeting our clients' needs
- List engagement strategies such as building rapport with verbal and non-verbal clients
- Describe Interventions to increase emotional awareness, help scaffold independence to empower clients to make healthy and self-regulating choices, and (re)build trust
- Learn and practice relaxation techniques for emotion regulation will be presented and practiced.

Impact of Trauma on Youth with Developmental Disabilities

Neurodiversity: Challenges for Learning, Assessment, Mental Heath Treatment

- Avoidance and anxiety
- Multiple co-occurring conditions
- Less emotionally and behaviorally regulated
- Concrete and present-focused
- Trouble with perspective taking
- Less aware of environmental or social safety cues
- Slower processing
- Language deficits
- Difficulty remembering and generalizing

Myths about Children with IDD

- Youth with IDD cannot engage in treatment
- Standard mental health treatment is ineffective for children with IDD
- Behavior modification is the only option
- Youth with intellectual disabilities do not experience trauma
- Working with this population requires *significant* specialized training
- A challenging behavior is explained by an intellectual disability
- Youth with IDD are protected from trauma because of their mental age (i.e., babies); they do not remember
- IQ scores tell you everything you need to know about a child

NOT TRUE

At-Risk for Trauma

2x as likely to experience emotional neglect, physical & sexual abuse

3x more likely to be in families with domestic violence

4x more likely to be victims of crime

2x more likely to be bullied

NCTSN The National Child Traumatic Stress Network

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At-Risk for Trauma

Subjected to traumatizing incidents of physical restraint & seclusion

Have significant higher rates of serious injury compared to non-disabled peers

Increased risk of psychological distress due to medical procedures

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Core Curriculum on Childhood Trauma

https://www.nctsn.org/sites/default/files/resources//the_12_core_concepts_for_understanding_traumatic_stress_responses_in_children_and_families.pdf

The 12 Core Concepts

Concepts for Understanding Traumatic Stress Responses in Children and Families

12 CORE CONCEPTS

1. Traumatic experiences are inherently complex.
2. Trauma occurs within a broad context that includes children's personal characteristics, life experiences, and current circumstances.
3. Traumatic events often generate secondary adversities, life changes, and distressing reminders in children's daily lives.
4. Children can exhibit a wide range of reactions to trauma and loss.
5. Danger and safety are core concerns in the lives of traumatized children.
6. Traumatic experiences affect the family and broader caregiving systems.
7. Protective and promotive factors can reduce the adverse impact of trauma.
8. Trauma and posttrauma adversities can strongly influence development.
9. Developmental neurobiology underlies children's reactions to traumatic experiences.
10. Culture is closely interwoven with traumatic experiences, response, and recovery.
11. Challenges to the social contract, including legal and ethical issues, affect trauma response and recovery.
12. Working with trauma-exposed children can evoke distress in providers that makes it more difficult for them to provide good care.

Core Concept 8: Trauma & Posttrauma adversities can strongly influence development.

- Trauma & adversities influence children's learning **developmental tasks**, and ability to reach important **developmental milestones**:
  - cognitive functioning
  - emotional regulation
  - interpersonal relationships.

- Trauma exposure and its aftermath can lead to **developmental disruptions** in the form of
  - regressive behavior
  - Reluctance
  - or inability to participate in developmentally appropriate activities,

- And **developmental accelerations**
  - leaving home at an early age
  - engagement in precocious sexual behavior.

- In turn, age, gender, and developmental period are linked to **risk for exposure** to specific types of trauma
  - sexual abuse
  - motor vehicle accidents
  - peer suicide

Core Concept 9: Developmental neurobiology underlies children's reactions to traumatic experiences.

- Children's ability to identify & respond to danger are based on the brain, nervous system, and endocrine systems
- The "**danger sensor**" brain sections allow us to identify danger, emotional and physical reactions, and protective actions.
- Traumatic experiences evoke strong, frequent, chronic biological responses that can affect maturation
- The impact of traumatic experiences depends in part on the developmental stage in which they occur.
- Exposure to **multiple traumatic** experiences carries a **greater risk** for significant impairments in **memory** & **emotional regulation**
- However, ongoing neurobiological maturation and **neural plasticity** also create continuing opportunities for recovery and adaptive developmental progress.

Diagnostic Overshadowing DSM-5 Symptoms & Associated Features

	PTSD	ID	ASD
Self-Regulation: Externalizing anger, aggression to self/others	· Irritable/angry outbursts (E1) · Reckless or self-destructive behavior (E2) · (could have ADHD pre-trauma)	• Difficulties regulating emotion • Motivation • Limited understanding of risk • Self-injury • Comorbid ADHD	· Self-injury · Disruptive behavior · Comorbid ADHD
Self-Regulation: Internalizing Emotional & physiological regulation	· Hypervigilance (E3) · Persistent negative beliefs, distorted cognitions (D2-3) · Persistent negative emotional state (fear, anger, guilt, shame) · Intense/prolonged Distress about internal/external cues (B4) · Marked physiological reactions to internal/external cues (B5) · Avoidance (C1-2) · Exaggerated startle response (E4)	• Deficits in self-management of emotions, behaviors, relationships (B) • Motivation • Difficulties regulating emotion •	• Prone to anxiety (social, GAD, phobias) • Prone to depression •

Diagnostic Overshadowing: Sample of DSM 5 Symptoms & Associated Features

	PTSD	IDD	ASD
Social	• Impaired social functioning (attachments, triggers)	• deficits in self-management of relationships (B) • social & communication deficits (B)	• Deficits in social-emotional reciprocity (A1) • Difficulties understanding relationships (A1)
Executive functioning, memory, attention, cognition	• Problems with concentration (E5) • Reckless or self-destructive behavior (E2)	• Executive functioning & Short term memory deficits (A) • Limited understanding of risk (A)	• High Comorbidity: ADHD, IDD
Behavioral or Anxious Avoidance	• Intense/prolonged Distress about internal/external cues (B4) • Marked physiological reactions to internal/external cues (B5) • Avoidance (C1-2)	• Difficulties regulating emotion • Rigidity + adherence to schedules	• Prone to anxiety (social, GAD, phobias) • Rigidity, adherence to schedules, extreme distress at changes to routine (B2)

https://www.nctsn.org/sites/default/files/resources/fact-sheet/children-with-intellectual-and-developmental-disabilities-can-experience-traumatic-stress-for-parents-and-caregivers.pdf

NCTSN The National Child Traumatic Stress Network

NADD An association for persons with developmental disabilities and mental health needs.

Children with Intellectual and Developmental Disabilities Can Experience Traumatic Stress

A Fact Sheet for Parents and Caregivers

https://www.nctsn.org/sites/default/files/resources/fact-sheet/the_impact_of_trauma_on_youth_with_intellectual_and_developmental_disabilities_a_fact_sheet_for_providers.pdf

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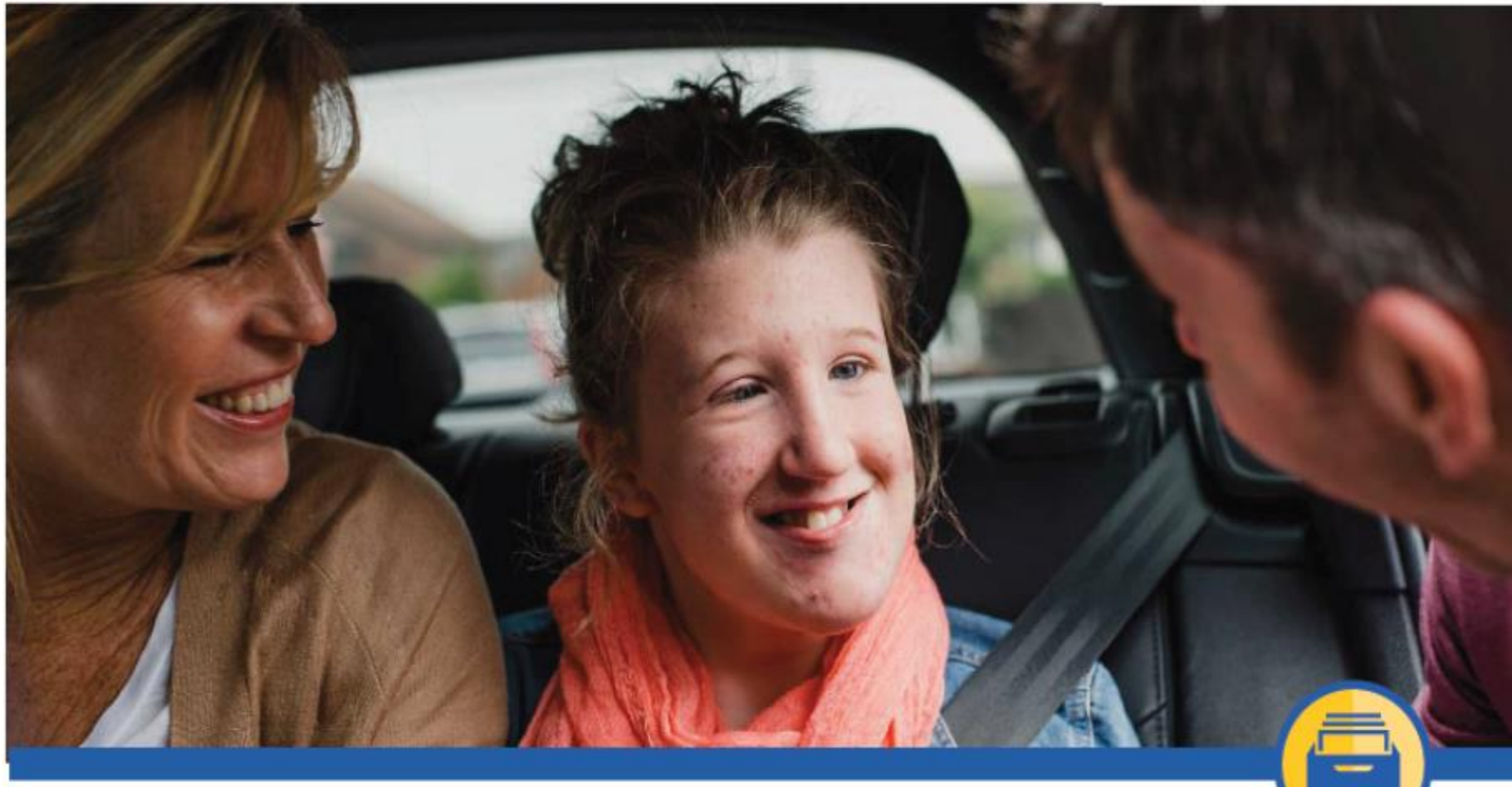


The Impact of Trauma on Youth with Intellectual and Developmental Disabilities:

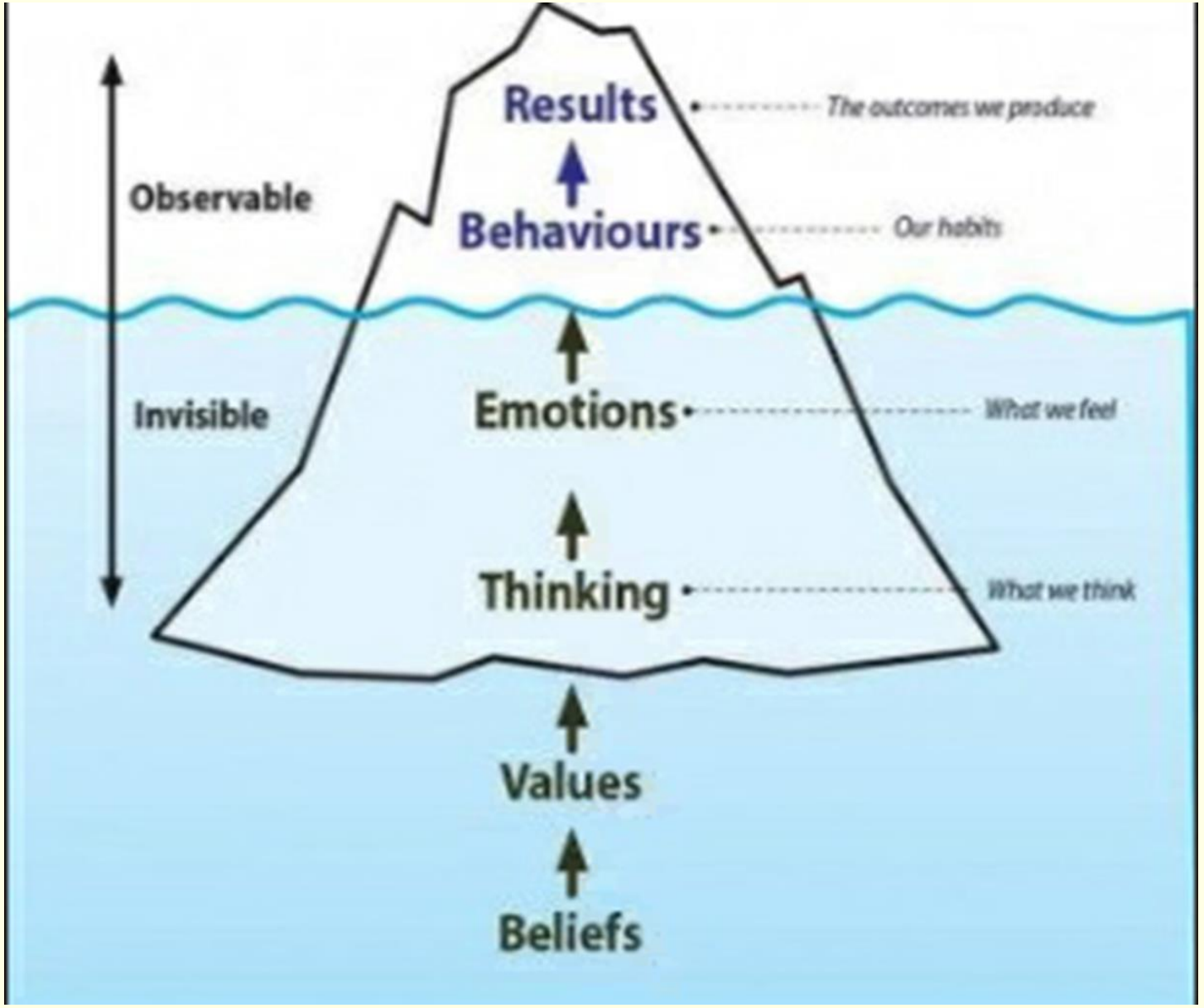
A Fact Sheet for Providers

All Behavior is Communication

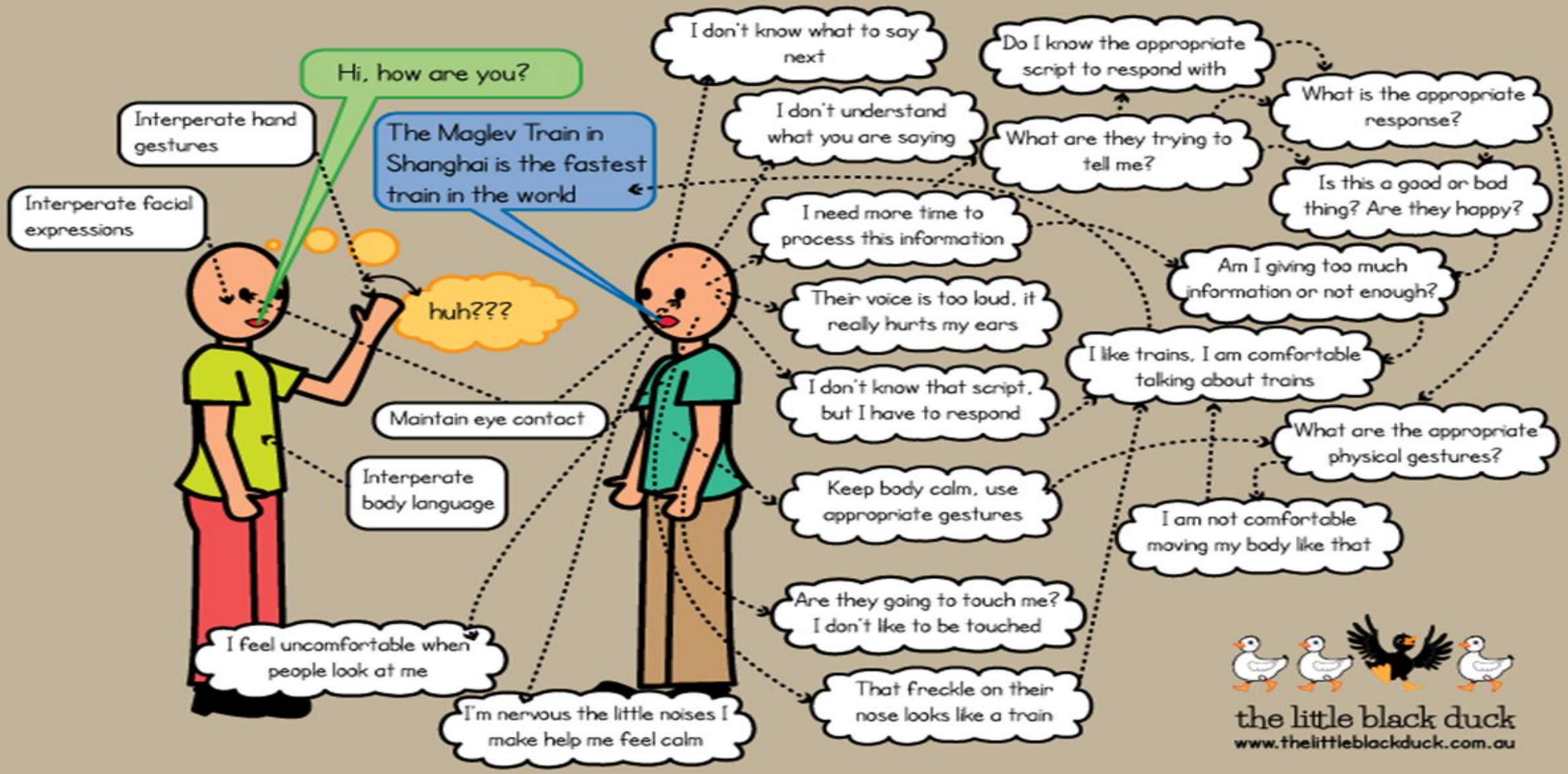
All Behavior is Communication!

Physiological Context
- Autonomic NS Arousal
- Fatigue/Tiredness
- Pain
- Hunger/Thirst
- Room Temperature
- Excretion Needs
- Over/Under Stimulation

Latency: Time Since…
- Attention
- Food/Drink
- Bathroom Use
- Affection
- (Good Quality) Sleep
- “Down Time” / preferred activities



communication and autism



https://www.youtube.com/@theautismhelper/about

Functions of Reinforced Behavior (Thorndike, Skinner)

- Everybody **EATS**!
- **E**scape/Avoidance – of something (subjectively) aversive
  - negative reinforcement
- **A**ttention (good or bad)
- **T**angible objects – things, possessions
- **S**ensory stimulation – increase/decrease in physical sensations, activities

- Where does "**control**" fit in? What about "**power**?"
- What about restraint?

Target/Problem Behavior

- Behavior to be modified by a behavior plan.
  - **Excesses**
    - too much of a problem behavior, we want to decrease it
  - **Deficits**
    - too little of an adaptive behavior, we want to increase it
  - **Non-Existent**
    - we want to teach it

Engagement & Rapport

Engaging Families in Treatment

- Treatment includes direct care, psychotherapy, OT, PT, SLP…
- Establish common ground/form an alliance
- Recognize concrete barriers to participating in treatment
- Emphasize importance/primacy of parental role
- Be flexible about scheduling
- Focus on what parents need and want from treatment
- Provide education about psychotherapy (what to expect: it occurs over time, not all at once, etc.) and other services
- Address such issues as stigma, cultural concerns, and previous experiences with therapists and direct care workers

Engaging Families in Treatment (cont'd)

NO SHAME

AND NO BLAME

Reinforce parents/caretakers for bringing child for treatment

- Labeled praise!
- Highlight benefits of treatment in general
- Explain why **now** is a crucial time for treatment
  - Risk factors of current diagnoses left untreated
  - Treatment as prevention of future adversity and symptoms

Foster Parent Reaction

"I never really get to a point where validation doesn't feel good"

Engagement Process

- Factors relating to therapeutic alliance
  - Detract:
    - Too Much Familiarity / too much Finding Common Ground related to trauma
    - Pushing child to talk
  - Enhance:
    - **Collaboration** with child (tx outcome)
    - **strong parent alliance** (tx continuation)
    - providers being casual

Collaboration Defined

- Engaging for exposure
- Use of rapport, preferred activities, etc.
- Explicit **therapeutic contract**
- The element of choice

Trauma Specific Engagement Factors for Clinicians:

Utilizing formal assessment & feedback

Psychoeducation in developmentally appropriate language is key variable for initial contract

Engaging for anxiety exposure

Expect and predict avoidance

Metaphor of cleaning out **infected wound**

Incorporating exposure throughout treatment: in intake, assessment, engagement, psychoeducation, skills building, etc…

Engagement & Rapport: Direct Care Staff

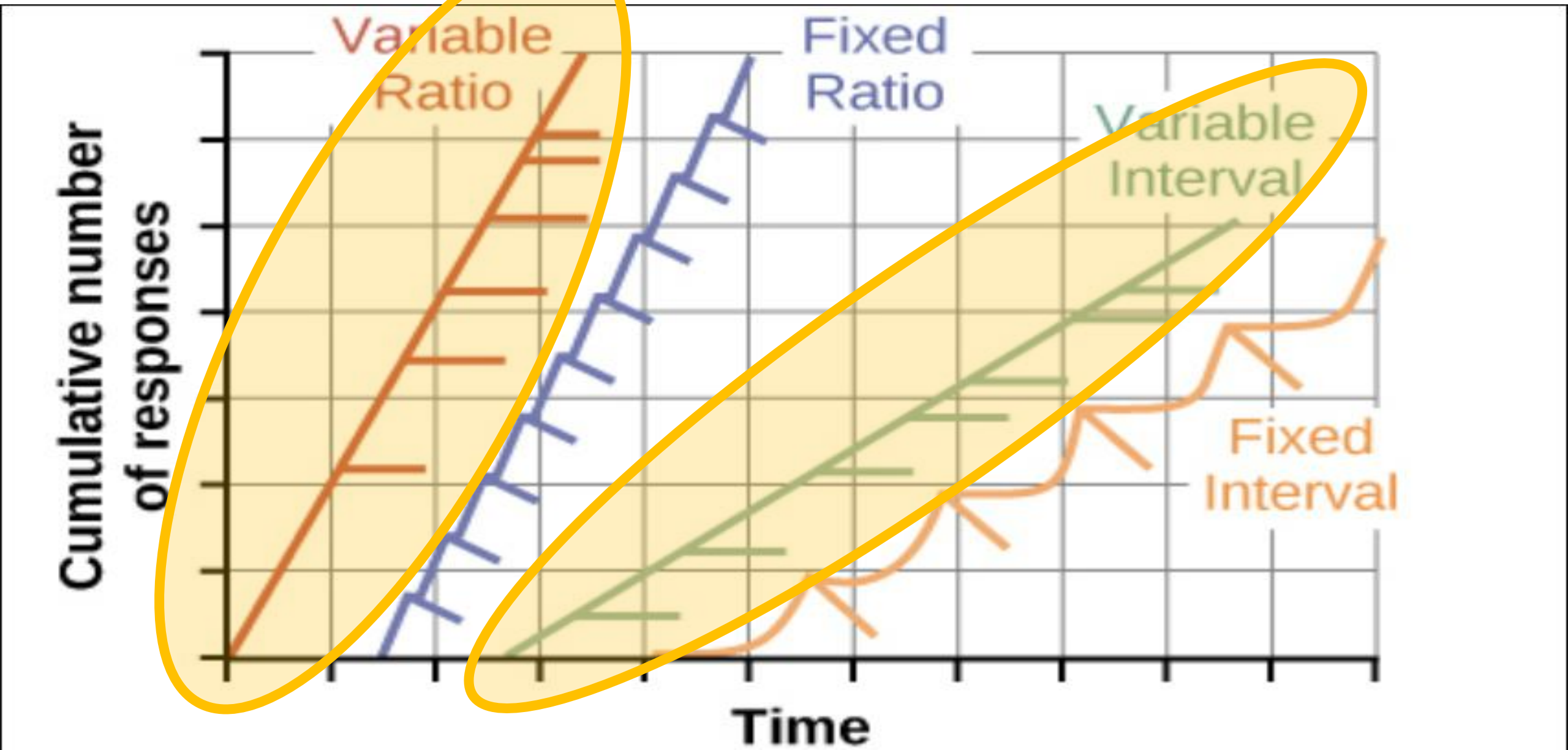
Getting to know the person

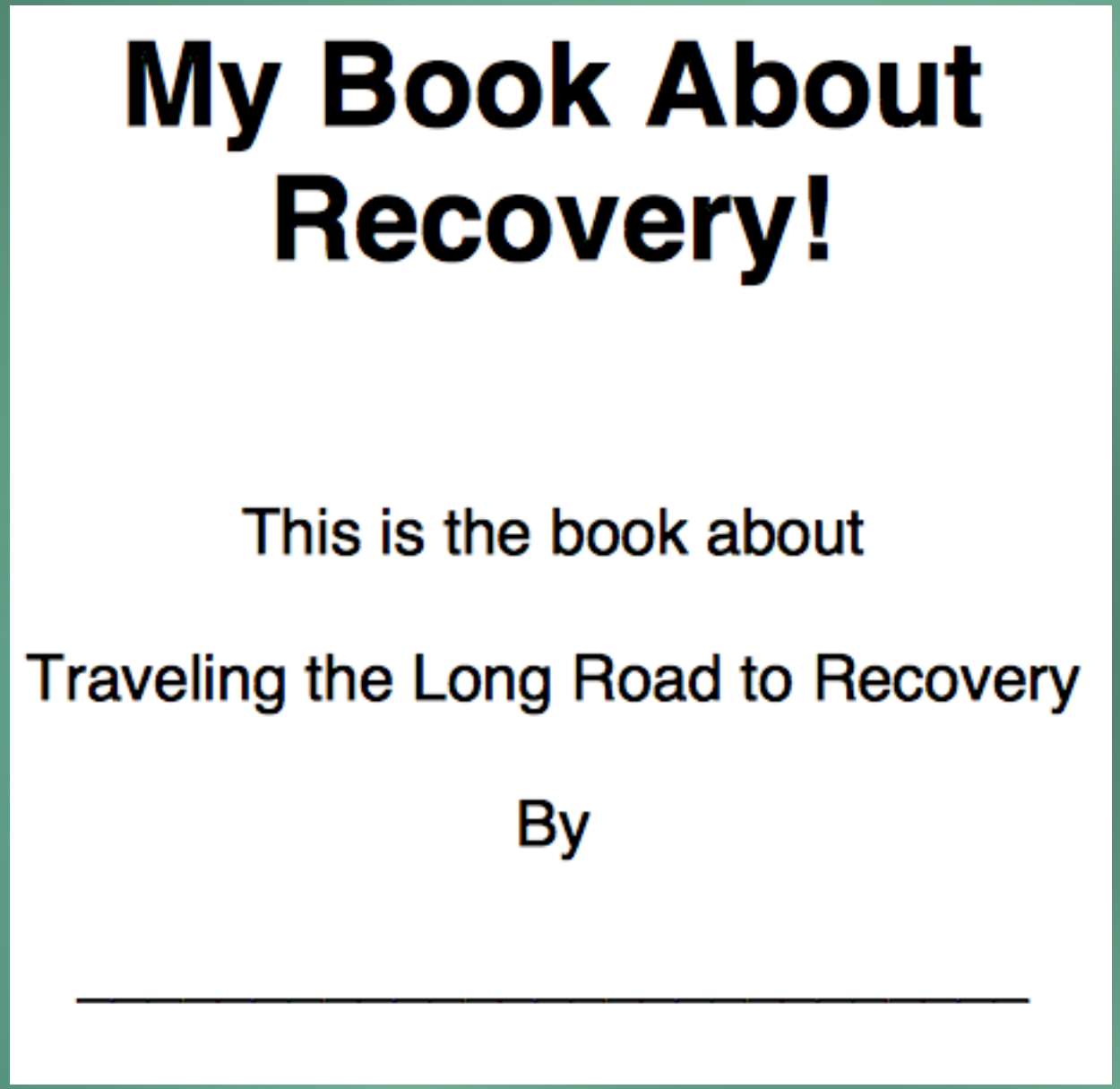
- Learn about their interests, values

What are their preferred reinforcers?

- Even if not age appropriate, or things not reinforcing to neurotypical people
- Talk with the person!
  - Ask what kind of things they like—e.g. sensory soothing, tangible objects/activities
  - Ask what things they dislike, find offensive, painful (e.g. tags on clothes)
- Observe what they do often (**Premack Principle**) –if they do it frequently, they likely enjoy it (also makes a good reward/positive reinfrorcer)
- Make sure to reinforce them for **ANY** and **ALL** prosocial & adaptive behavior

Intermittent/Variable Reinforcers





Materials accompany *Positive Identity Development: An Alternative Treatment Approach for Individuals with Mild and Moderate Intellectual Disabilities* (Harvey, 2009)

Available at pid.thenadd.org

https://thenadd.org/wp-content/uploads/2019/10/my-book-about-myself.pdf

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My best memory is:

Meeting a friend in his freshmen year

Graduating from high school in 2015

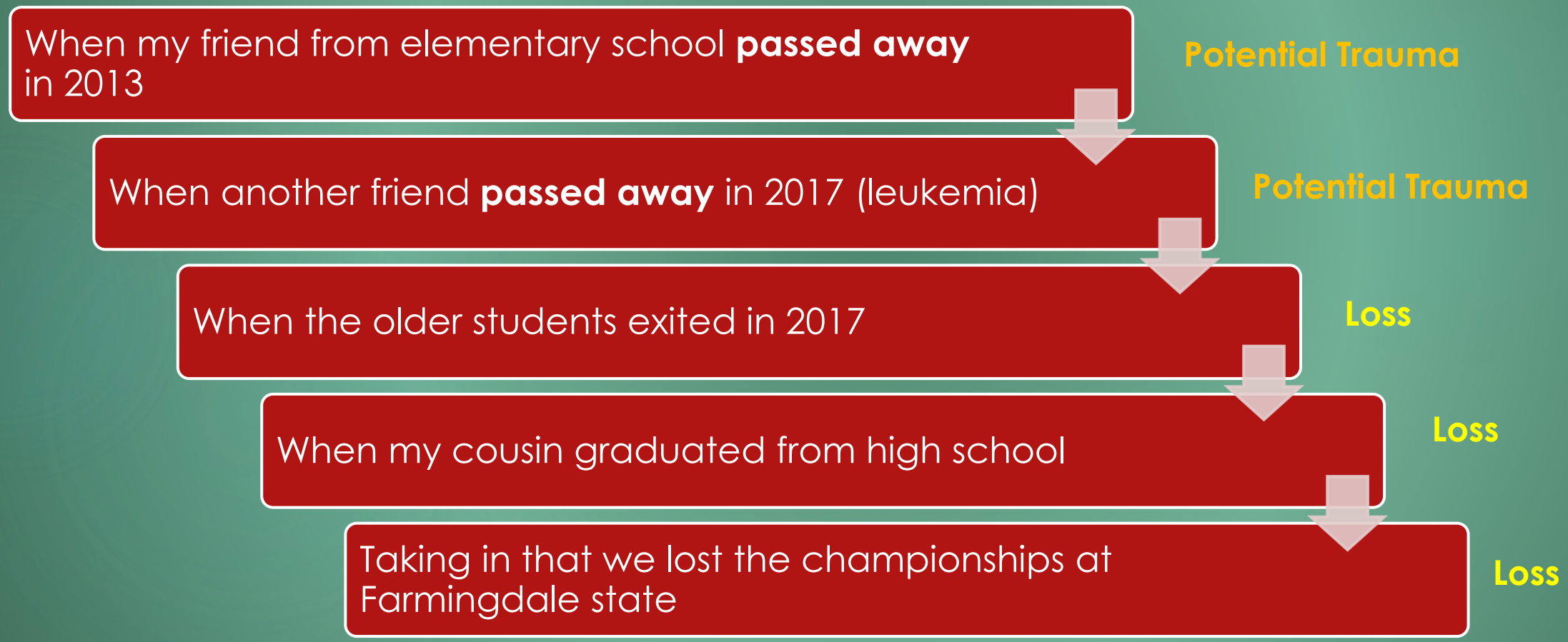
Meeting the new security guards

Graduating from middle school

Going to the prom

Starting unified basketball the first year

The hardest things I have overcome were



The best things I accomplished were:

- Making a three pointer at unified practice in April
- Making new friends my freshmen year
- Getting our medals at state university
- Winning every game this season

The hardest family issue to deal with for me was:

Loss — When I had to congratulated my cousins who graduated high school onto college

Loss — Taking in that my cousin is getting married

Potential Trauma — When my uncles dog died last month

Loss — Watching my cousin getting married

Interventions for Emotional Awareness, Independence & Trust

Supplementary Reproducible E for Elementary Ages

THE ZONES OF REGULATION

The ZONES of Regulation

Blue Zone	Green Zone	Yellow Zone	Red Zone
Sad	Happy	Worried	Overjoyed/Elated
Bored	Focused	Frustrated	Panicked
Tired	Calm	Silly	Angry
Sick	Proud	Excited	Terrified

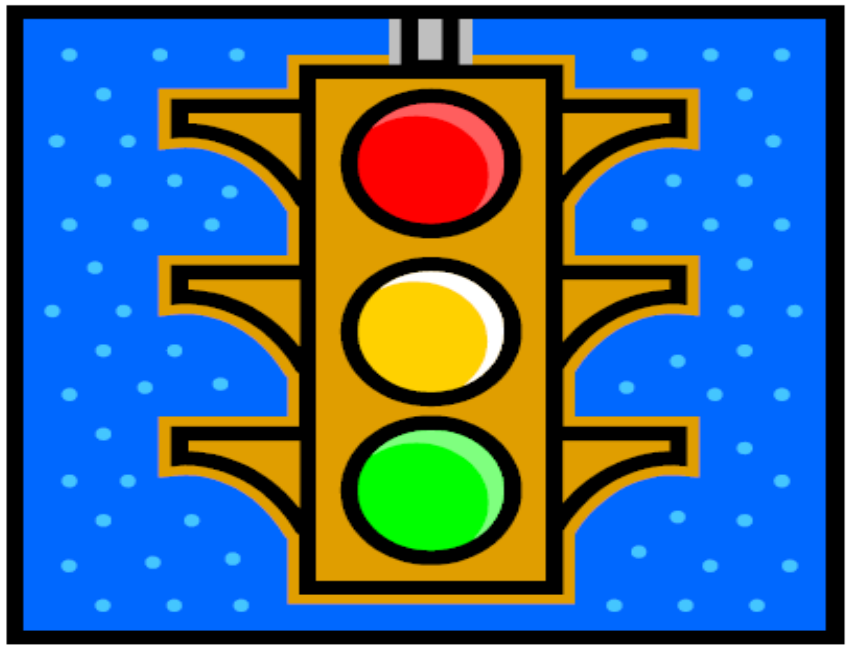
Adapted from *The Zones of Regulation 2-Storybook Set* | Available at www.socialthinking.com

Zones of Regulation

https://www.youtube.com/watch?v=pqJVC29LVI8

SELF-REGULATION

- The ability to adjust level of alertness AND direct how emotions are revealed behaviorally in socially adaptive ways in order to achieve goals.
- Encompasses:
- Self-control
- Resiliency
- Self-management
- Anger management
- Impulse control
- Sensory regulation



What Are The ZONES?

There are four zones to describe how your brain and body feel.

BLUE Zone – Your body is running slow, such as when you are tired, sick, sad or bored.

GREEN Zone – Like a green light, you are "good to go." You body may feel happy, calm and focused.

YELLOW Zone – This zone describes when you start to loose control, such as when you are frustrated, anxious, worried, silly or surprised. Use caution when you are in this zone.

RED Zone – This zone is for extreme emotions such as anger, terror and aggression. When you are in this zone, you are out of control, have trouble making good decisions and must STOP!

Goals of the Zones Curriculum

To teach the students:

- Indentify their feelings and levels of alertness
- Effective regulation tools
- When and how to use the tools
- Problem solve positive solutions
- Understand how their behaviours influence others' thoughts and feelings

And ultimately…

- Independent Regulation!

What Zone are you in?

Blue Zone:

Running Slow

sad
sick
tired
bored
moving slowly

Green Zone:

Good to Go

happy
calm
feeling okay
focused
ready to learn

Yellow Zone:

Caution

frustrated
worried
silly/wiggly
unfocused
loss of some control

Red Zone:

STOP

mad/angry
hands on
yelling
refusing to work
out of control

ZONES BINGO: WHAT ZONE IS IT?

BINGO: The ZONES of Regulation		
		
		
		

Zones

Chapt. 4 Lesson 10
Sensory Support Tools to Calm & Alert

ZONES Tools Worksheet					
Name of Tool	Circle the zone(s) you think the tool would help				
Fidget Stretchy Stress Ball	Blue	Green	Yellow	Red	None
Silly Putty	Blue	Green	Yellow	Red	None
Bean Bag Fidget	Blue	Green	Yellow	Red	None
Yoga Poses	Blue	Green	Yellow	Red	None
Exercise Cards	Blue	Green	Yellow	Red	None
Life Moves/Me Moves DVD	Blue	Green	Yellow	Red	None
Go Noodle website Movements	Blue	Green	Yellow	Red	None
Listening to Upbeat Music	Blue	Green	Yellow	Red	None
Listening to Calming Music	Blue	Green	Yellow	Red	None

LET THE ZONES FLOW THROUGH YOU….

BLUE

Sick, Tired, Sad, Bored, Moving Slowly

Jedi Toolkit

_____

_____

_____

_____

_____

_____

GREEN

Calm, Happy, Focused, Ready to Learn

Jedi Toolkit

_____

_____

_____

_____

_____

_____

YELLOW

Worried, Frustrated, Silly, Excited, Loss of Some Control

Jedi Toolkit

_____

_____

_____

_____

_____

_____

RED

Angry/Mad, Mean, Yelling, Hitting, Out of Control

Jedi Toolkit

_____

_____

_____

_____

_____

_____

Relaxation Exercises

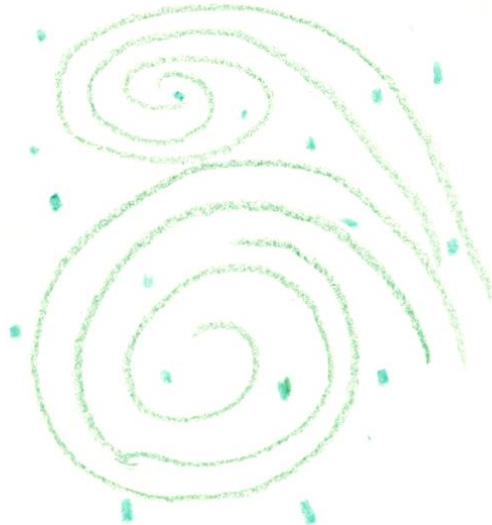
Relaxation

- Reduce physiologic manifestations of stress and PTSD
- **Reduce distress related to trauma reminders**
- Can help to lower the body's alarm reactions
- Can be used at anytime so child will probably need more than one skill to use
- Can be coupled with other skills like feeling expression or cognitive coping

Relaxation (cont'd)

- Develop individualized relaxation strategies for manifestations of stress (headache, stomach ache, dizzy, racing heart, etc.)
- Focused breathing/mindfulness/meditation
- Progressive muscle relaxation
- Physical Activity
- Yoga, singing, dance, blowing bubbles
- "If it's not fun, you're not doing it right"
- **Relaxation strategies for trauma reminders**

4/26/04



exhale

inhale

BrEaThInG iN bLuE,
bReAtHiNg OuT dAnIeL.

InHaLe= BLUE!

ExHaLe=DANIEL!

Daniel= Stinky
Blue= Good

Relaxation
(Stress Management)

Teach deep breathing, deep muscle relaxation

Mindfulness and meditation- yoga

Resources Online for all Developmental Levels

Belly Breathing with Rosita

https://youtu.be/Xq3DwzX6MUw

Relaxation for Teens

- http://mindfulnessforteens.com/guided-meditations/

Relaxation Skills: Lazy 8 Breathing

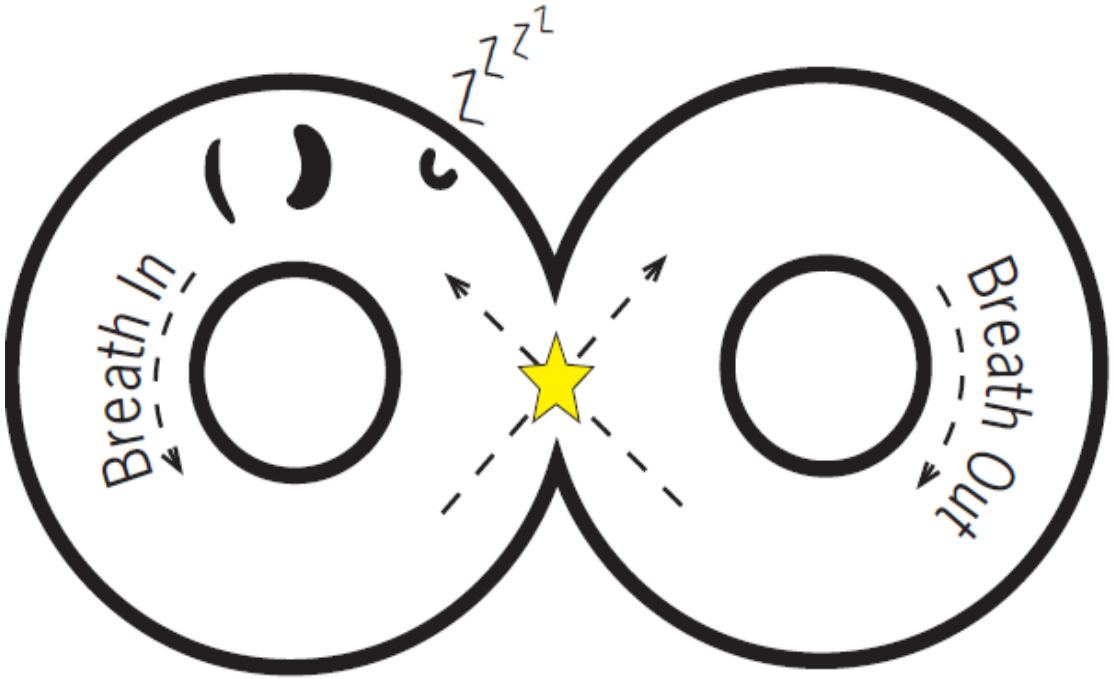
Trace the Lazy 8 with your finger starting at the star and taking a deep breath in.

As you cross over to the other side of the Lazy 8, slowly let your breath out.

Continue breathing around the Lazy 8 until you have a calm body and mind.

The **ZONES** of Regulation™ Reproducible T

Lazy 8 **Breathing**



Progressive Muscle Relaxation

Dry and Cooked Spaghetti Exercise

Modifications to Relaxation

Deep Breathing

- More relevant use of imagery

Progressive Muscle Relaxation

- More culturally relevant use of examples
  - (tortilla vs. spaghetti)

Prayer

- If spirituality is important

FOCUSing for Emotional Resilience

Families OverComing Under Stress (FOCUS): Overview

- FOCUS works with families to increase resilience and strengthen family skills in meeting the **challenges** and **stressors** commonly experienced during times of **trauma** and **adversity**.
- **Resiliency** is the ability to effectively cope with, adapt to, and overcome adversity, stress, and challenging experiences.
- All families possess unique strengths and skills. FOCUS helps families to build on those strengths to improve their ability to deal with stressful events.

- Originally designed for military families, adapted for use with other populations
- Helps each family member understand one another's perspectives on hardships they each faced when apart and together
- Saltzman, Lester, Pynoos, Mogil, Green, Layne, & Bearslee. (2007) **Focus Family Resiliency Training** Manual, 2nd Edition.

Goals of FOCUS

1

Helping families to **identify** and **build upon** their **existing strengths** and **positive coping** strategies

2

Increasing parents' and children's **understanding** of how different family members might react to stressful events

3

Helping family members **communicate** and **better understand** how each was affected by their experience of the event

4

Working with parents to better **support one another** in dealing with the stressors that can arise from **long separations** and the **aftereffects of trauma**

5

Assisting parents to work **more effectively as a team** in **caring for their children** both during and after stressful experiences

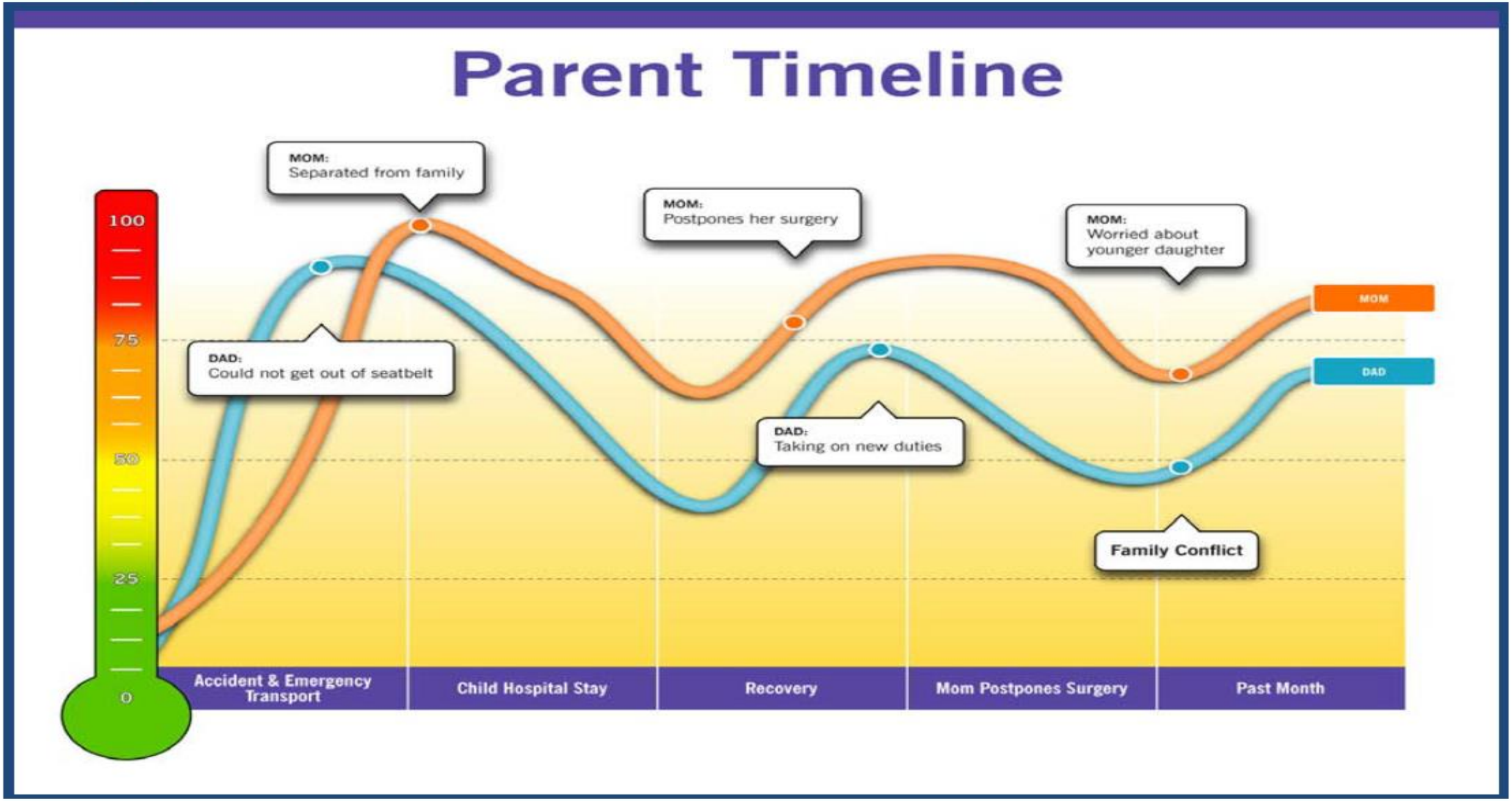
FOCUS Modules

- Session 1: Introducing Parents to FOCUS
- Session 2: Constructing Parents' Narrative Timelines
- Session 3: Introducing Children to FOCUS
- Session 4: Constructing Children's Narrative Maps
- Session 5: Preparing Parents for the Family Sessions
- Session 6: Developing a Family Narrative
- Session 7: Building Family Resiliency Skills
- Session 8: Preparing for the Future

- Parent & family sessions ~90 minutes
- Child Sessions 30-60 mins

- For more in depth information:
- https://focusproject.org/sites/default/files/FOCUS%20Outreach%20Packet2_OSD-SM03.24.16-aj3.pdf

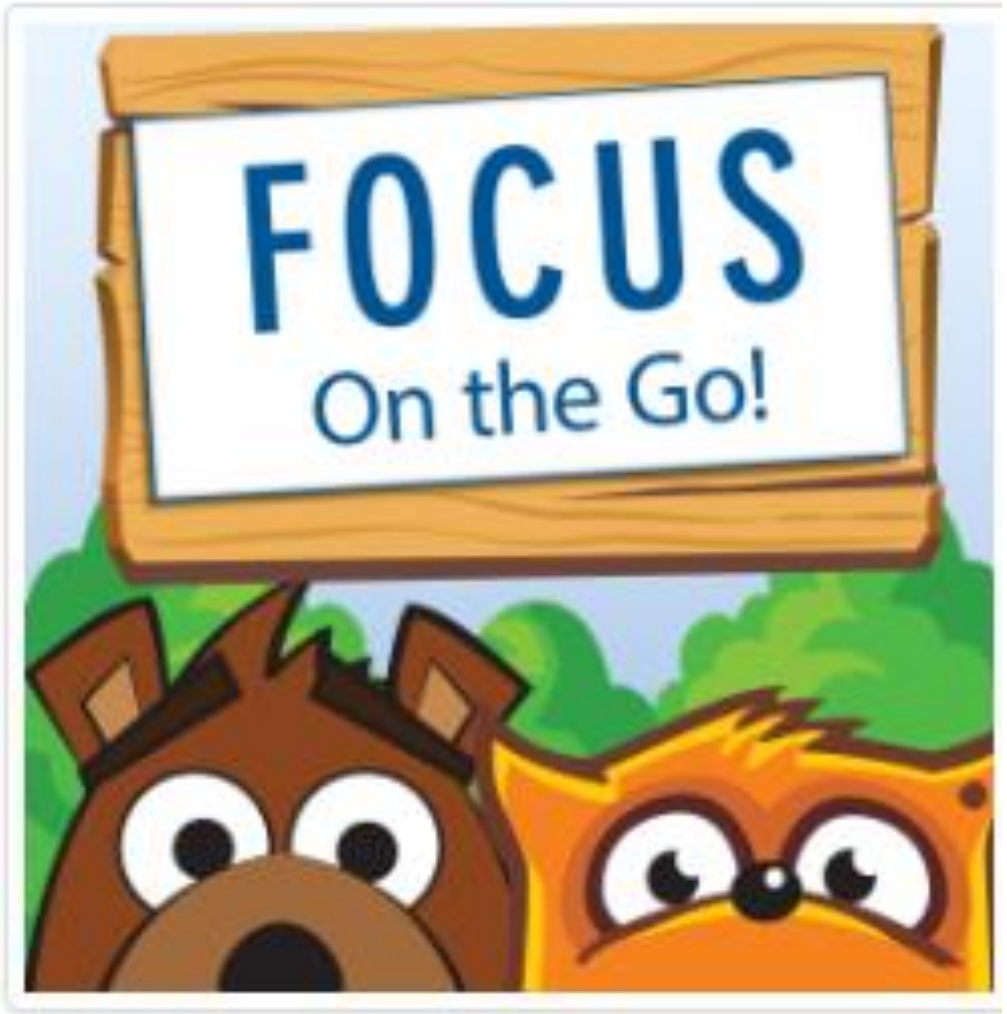
Sample Parent Timeline



Focus Website & App

https://nfrc.ucla.edu/focus-on-the-go-bk

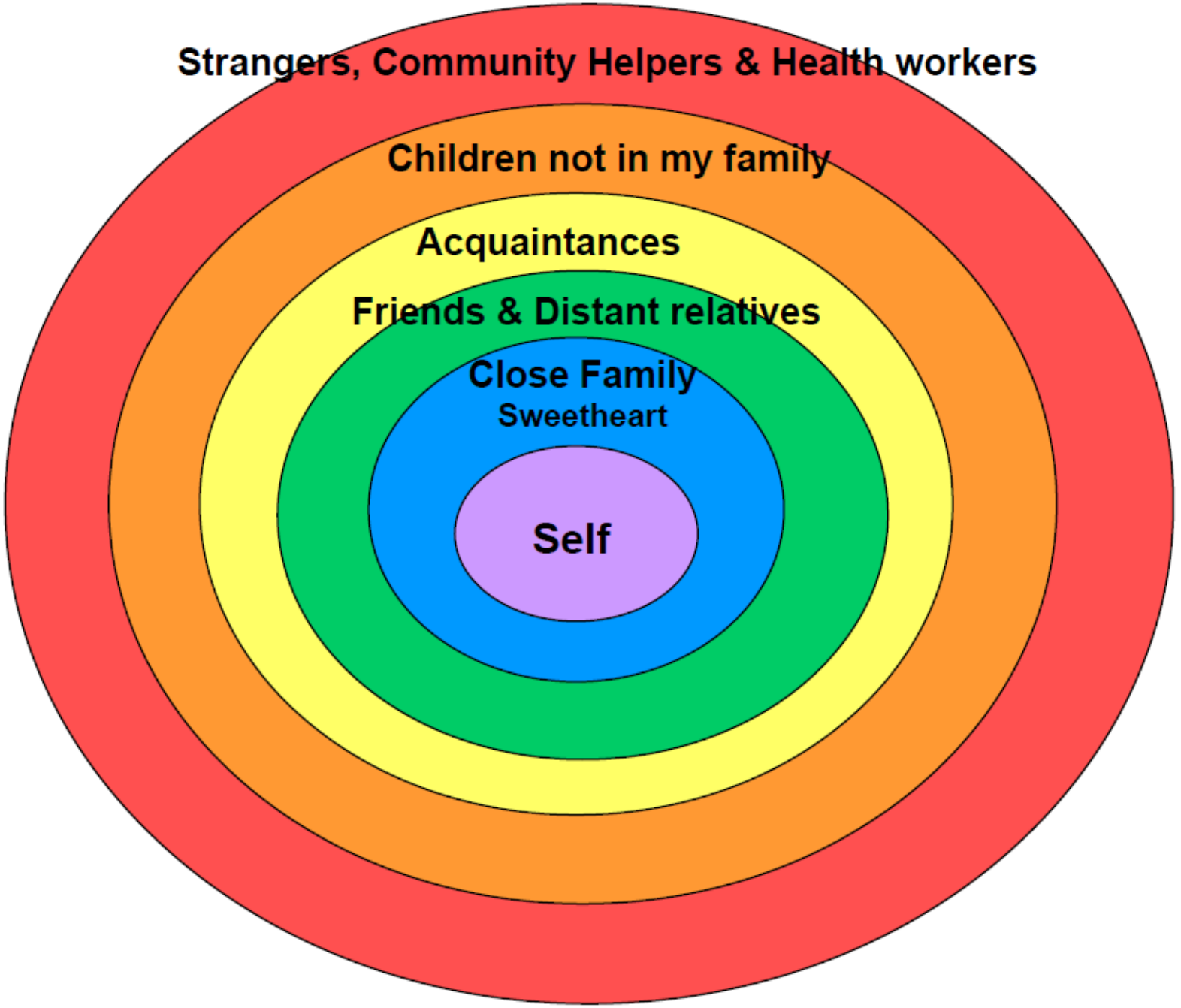
- Trainings
- Manuals
- App
- Therapist Finder
- And more!



Empowerment through Assertive, Healthy Choices: Circles Curriculum

Circles- What is it?

- The Circles Curriculum, developed by James Stanfield Co., focuses on teaching social and relationship boundaries, interpersonal skills and relationship-specific social skills.
- The program uses a simple multi-layer colored circle diagram to demonstrate the different relationship levels students will encounter in daily life.
- Starting from the center circle, which is self, each new color represents behaviors, feelings, and actions appropriate to the distance from the center or self.



RELATIONSHIP CIRCLES

Teaches Boundaries of
Talk, Touch, Trust

Circles- Why it's useful

- Circles is a concrete, organizational paradigm for students with special educational needs that helps them learn to act and interact in self-enhancing ways.

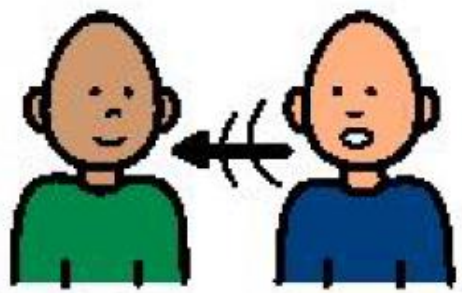
- This curriculum uses principles of behavioral psychology and proven techniques in special education that help students to generalize their learning across many settings: school, home, social and vocational.

Benefits of implementing Circles

- common language utilized across settings
- opportunities to teach appropriate social boundaries across settings
- provides a context to discuss difficult issues
- provides students with the tools to advocate for themselves.
- can easily be incorporated with school-wide PBIS expectations as it teaches appropriate social skills

The 3 T's of Circles

talk



touch

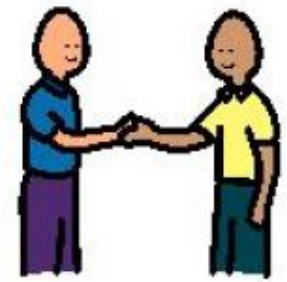
trust

purple circle

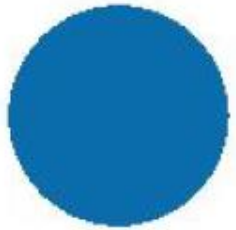
your own body

yellow circle

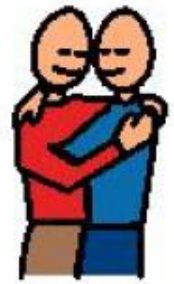
hand shake



blue circle



close hug

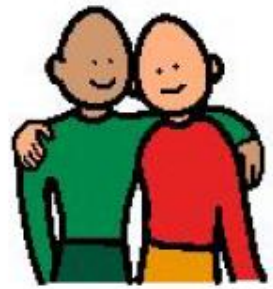


orange circle

wave

green circle

far away hug

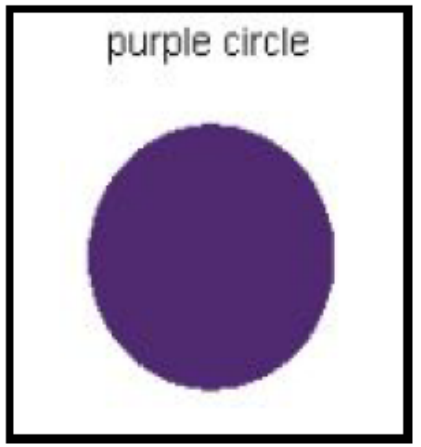


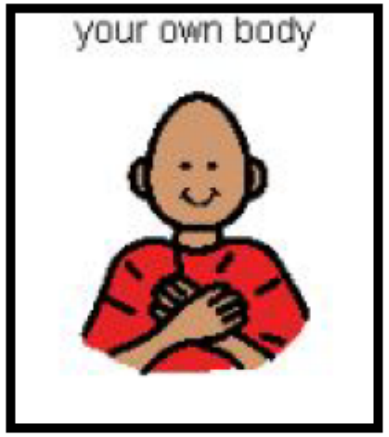
red circle

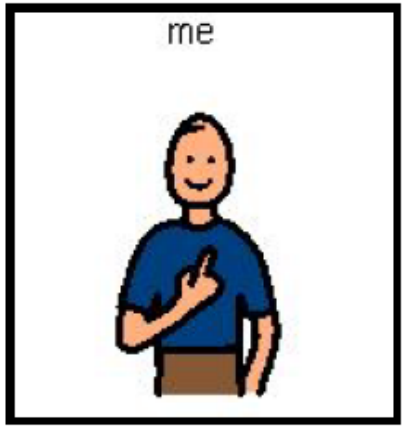
no touch

Purple Private Circle

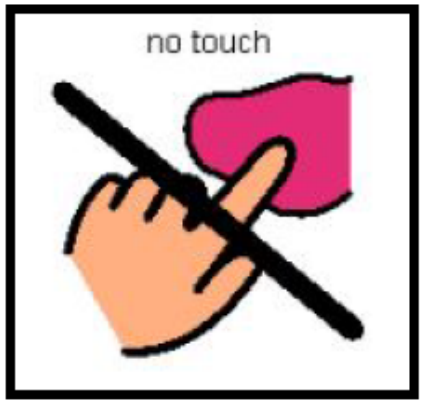
- The center circle
- Key Concepts:
  - Everyone has their own purple private circle
  - You are the most important person in your world
  - No one touches you unless you want to be touched
- Places for privacy
  - Bedroom & Bathroom
- Extending the curriculum:
  - Public vs. private (places & activities)
  - Personal Hygiene
  - Self- Advocacy
  - Appropriate sexual expression

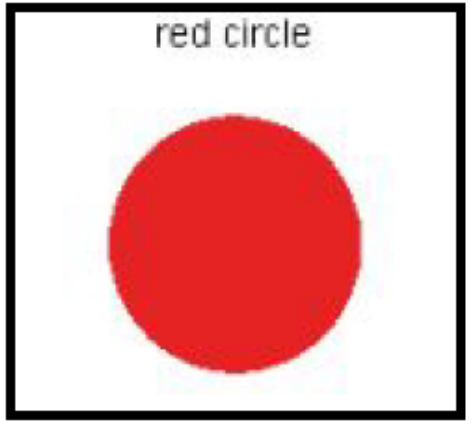




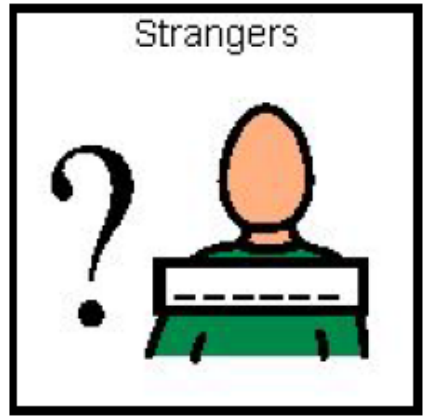


Red Circle

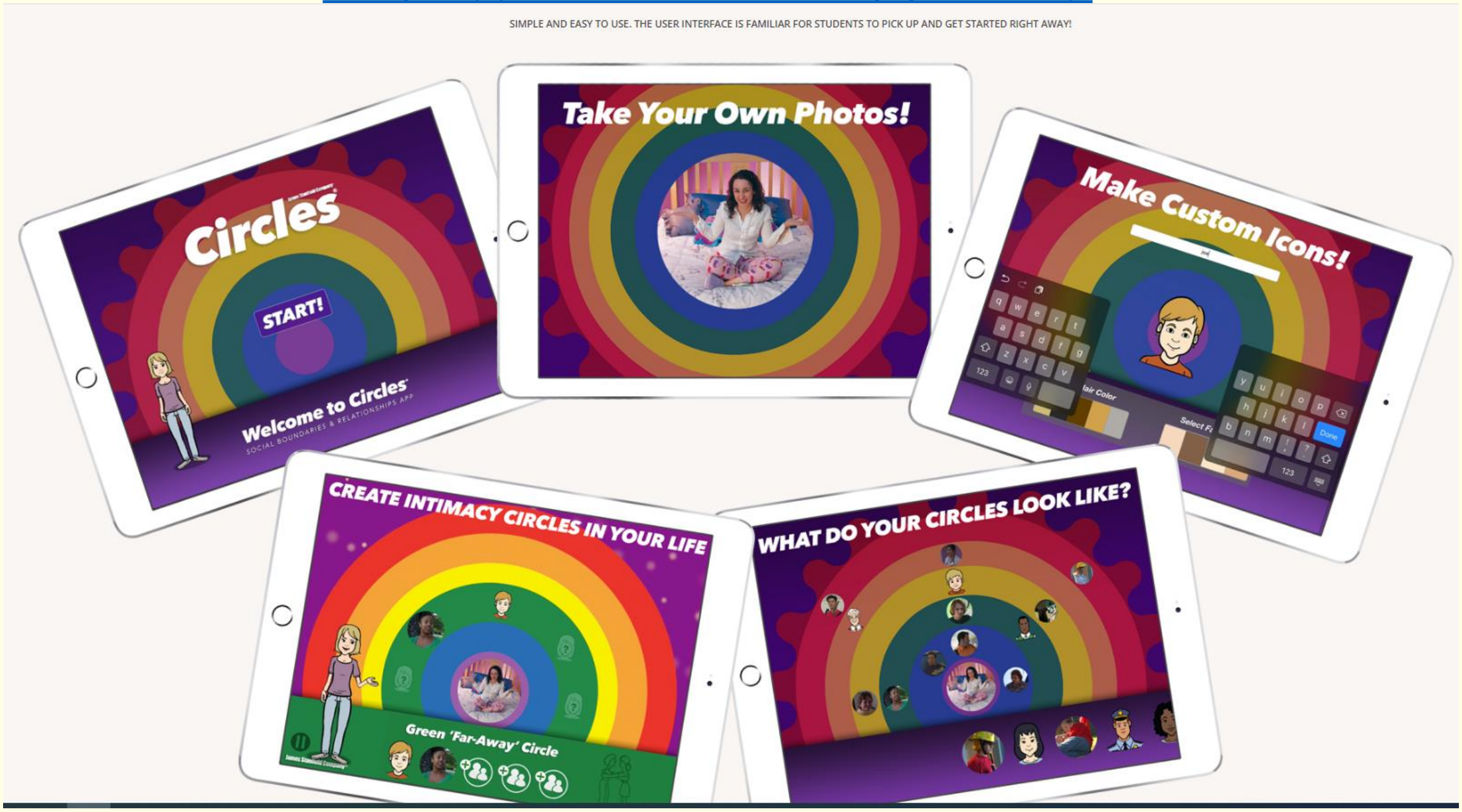




- Who: Strangers (Community Helpers, Health Care Workers, Total Strangers)
- Talk: No talk (Total Strangers) or business talk (Community Helpers & Health Care Workers)
- Trust: No trust (Total Strangers) or limited trust (Community Helpers & Health Care Workers)
- Touch: No touch (Total Strangers) or business touch only (Community Helpers & Health Care Workers)
- Extending on the curriculum
  - Self-Advocacy
  - Relationship Development
  - Interpersonal Communication



https://www.circlesapp.com/



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Take Aways & Conclusions

Adapting/Tailoring Existing Interventions & Learning

(Based on Grosso, 2012; Avrin, Charlton & Tallant, 1998; Hoover, 2018)

Collaterals	Building Rapport Looks a Different	Pacing of Sessions	Content of Sessions
More people involved (E.g., caseworkers)	Allow more time for rapport-building	Shorten sessions to match attention span/capabilities	Concrete language
Increased involvement from caregivers	Use restricted interests to build rapport	More frequent sessions to promote review and consolidation	Use frequent checks for understanding
Recruitment of more supports (e.g., family support)	Adjust expectations for what strong rapport looks like (e.g., eye contact, smiling)	More sessions will be needed to make gains	Use frequent checks for understanding
		During sessions, slow down the pace	Use games or other interactive methods to promote engagement
		Involve caregivers in session itself	Use visual modalities/arts
			Measure changes in micrometer vs yardstick

https://www.nctsn.org/sites/default/files/resources/fact-sheet/children-with-intellectual-and-developmental-disabilities-can-experience-traumatic-stress-for-parents-and-caregivers.pdf

NCTSN The National Child Traumatic Stress Network

NADD An association for persons with developmental disabilities and mental health needs.

Children with Intellectual and Developmental Disabilities Can Experience Traumatic Stress

A Fact Sheet for Parents and Caregivers

https://www.nctsn.org/sites/default/files/resources/fact-sheet/the_impact_of_trauma_on_youth_with_intellectual_and_developmental_disabilities_a_fact_sheet_for_providers.pdf

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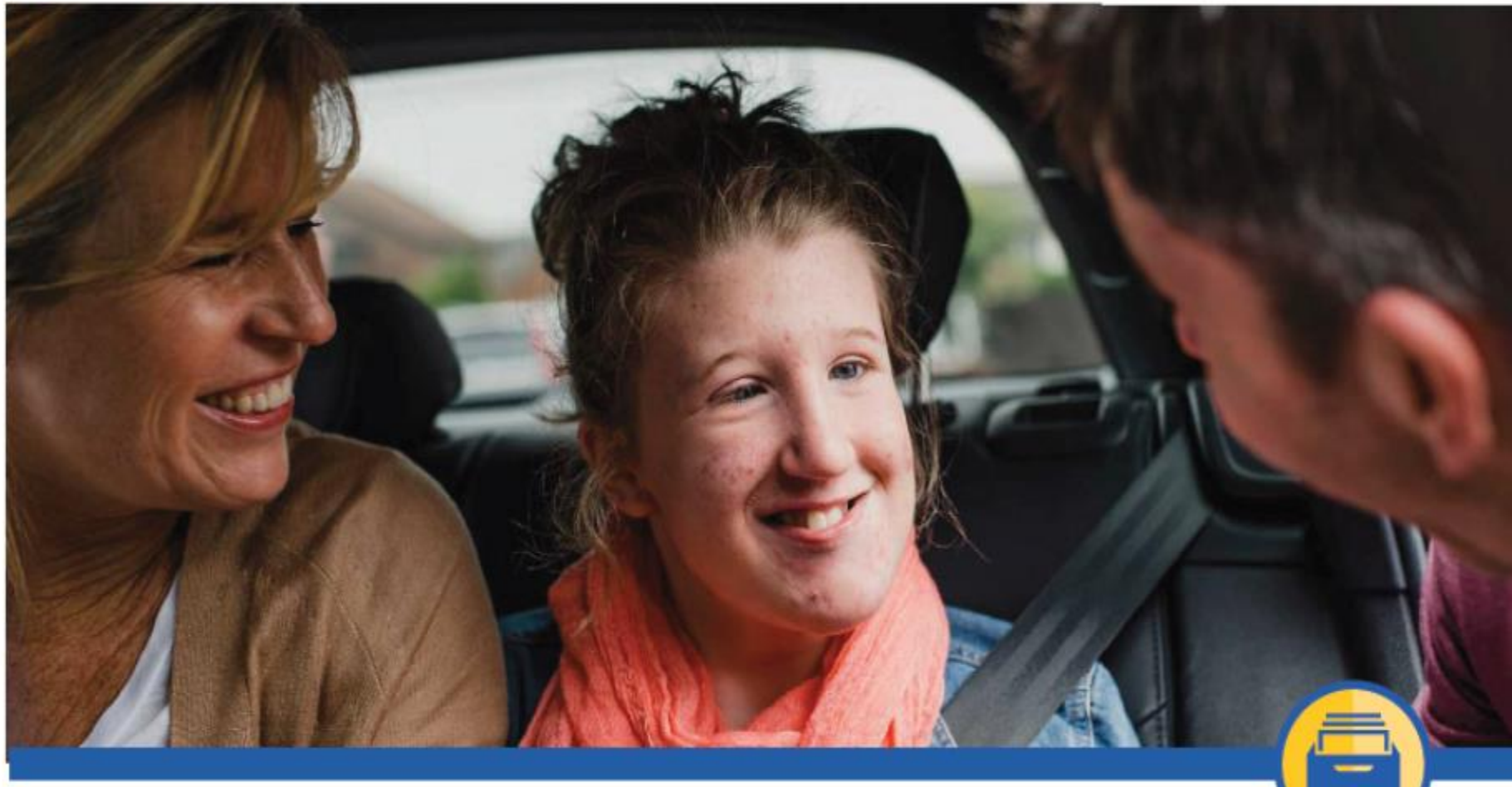

The Impact of Trauma on Youth with Intellectual and Developmental Disabilities:

A Fact Sheet for Providers

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Thank you!

Questions?

Answers!