Long Island Jewish Medical Center
Northwell Health®

Center for Child and Family Traumatic Stress
at Kennedy Krieger Institute

# Treating Traumatized Children Who Have Intellectual and Developmental Disabilities

## Tailoring Trauma-Focused Cognitive Behavior Therapy

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The National Child Traumatic Stress Network

# CME Commercial Disclosure

The presenters - Peter D'Amico & Daniel Hoover
have no pertinent commercial relationships to disclose.

# GRATITUDE & CREDIT

This presentation is partially based on the work

of

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# The Center to Support Trauma Recovery for Youth with Developmental Disabilities (STRYDD Center)
# Northwell Health System

## NCTSN Category II Treatment & Services Adaptation (TSA)

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# Outline

- Scope of the Problem
- Assessment and diagnosis with IDD + Trauma
- Trauma Response & Neurodiversity
- Results of TF-CBT Therapist Survey
- Treatment considerations tailoring TF-CBT to children and families with IDD
  - Case Example: youth with ID
- Applications of Adaptations to PRACTICE Modules
  - Case Example: youth with ASD

# DAY 1 Schedule

| | |
|---|---|
| • 10:30-11:30 | Scope of the Problem |
| • 10 Min BREAK | Break |
| • 11:40-12:30 | Assessment & Diagnosis |
| • 1 Hr LUNCH | Lunch |
| • 1:30-2:30 | Trauma Response & Neurodiversity |
| • 10 Min BREAK | Break |
| • 2:40-3:30 | Relevance of TF-CBT Model: Clinician Survey |

# Reflections

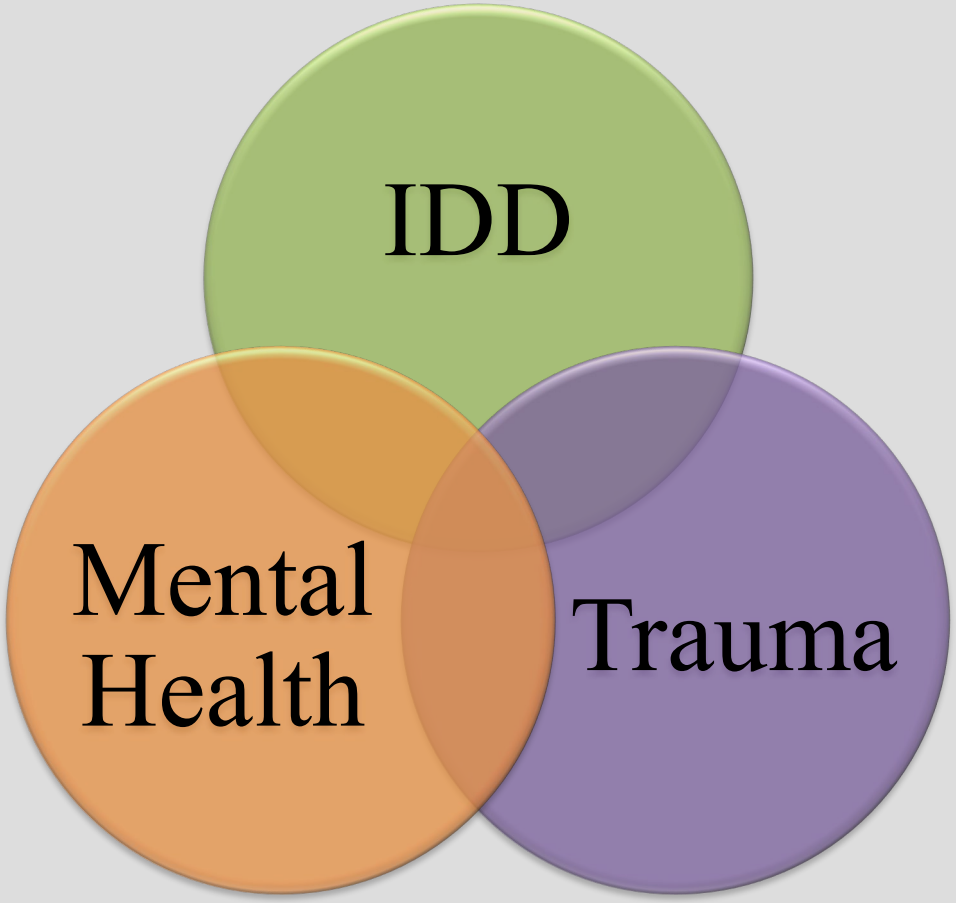
- Our collaboration-follow-up consultation and leadership engagement
- Case complexity the rule
- Significant case management
- Clinician burnout, self-care
- COVID-extra burden placed on parents of children with special needs
- Telehealth and the world of technology

# The Road to Recovery:
## Supporting Children with IDD Who Have Experienced Trauma

NCTSN The National Child Traumatic Stress Network

Hogg Foundation *for* Mental Health
ADVANCING RECOVERY AND WELLNESS IN TEXAS

# Interacting Influences




What are the frameworks you use in your work?

# Genetic Disabilities

A disability caused by an absent or defective gene or chromosomal aberration.

- **Down Syndrome**
- **Fragile X Syndrome**
- **Prader-Willi Syndrome**
- **Angelman's Syndrome**
- **Williams Syndrome**
- **Phenylketonuria**

# Neurological Disabilities

A disability caused by a neurological/medical condition with a severe impact in functioning.

- **Autism**
- **ADHD**
- **Lead Poisoning**
- **Fetal Alcohol Syndrome**
- **Epilepsy**

# Intellectual Disability

A disability pertaining to significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 18.

**Intellectual Functioning**

**Adaptive Behaviors**

# Scope of the Problem

- Approximately 1 in 6 youth in U.S. have intellectual & developmental disorders
- Affects learning, thinking, language & adaptive functioning
- Increases vulnerability to behavioral, social, & emotional difficulties including trauma
- There are gaps in services; siloed services are a problem
- Trauma has been virtually invisible

# At-Risk for Trauma

2x as likely experience emotional neglect, physical & sexual abuse
(Sullivan, 2006)

2x more likely to be in families with income insufficiency, divorce
(Kerns et al., 2016)

More likely to be bullied (Zeedyk et al. 2014)

# At-Risk for Trauma

Subjected to traumatizing incidents of physical restraint & seclusion
(Sullivan, 2006)

Have significantly higher rates of serious injury compared to non-disabled peers
(Sedlak et al, 2010)

Increased risk of distress due to medical procedures

# IDD & Trauma

- Neglect
- Physical and sexual abuse
- Restraints and seclusion
- Changes in living and educational placements
- Increased risk for bullying and exploitation by peers
- Higher number of medical procedures/med trauma
- Comorbid conditions
- Misattribution of problems (Overshadowing)

# Youngsters with DD Who Experience Trauma

- More likely to experience “restrictive” care that can be traumatizing
- Interaction of impairment with processing of trauma: Cognitive, neurodevelopmental, language/communication, social/emotional, motor, adaptive functioning
- Less likely to spontaneously recover
- At times hard to distinguish DD and trauma symptoms, which can lead to inappropriate treatment
  - Autistic: sensory sensitivity vs. trauma triggered symptoms?
  - Severe neglect impact vs. autistic spectrum?

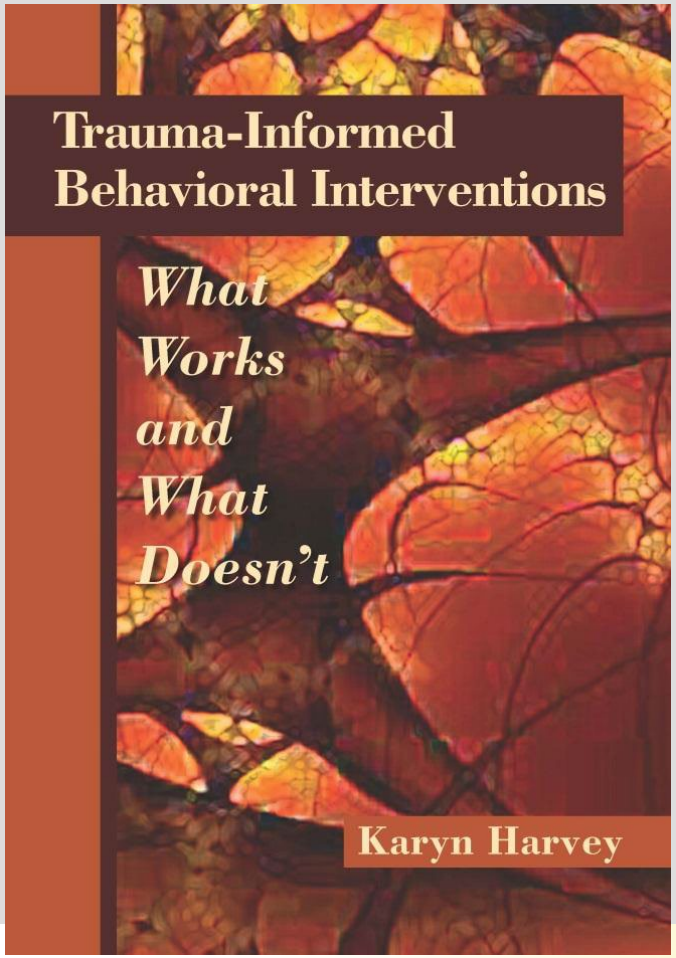
# IDD &Trauma-Related Behavior

- Behavior is communication
- Behavioral regression (functional, language, hygiene, stereotypies)
- Self injury
- Aggression
- Need trauma informed approaches

# IDD & Systems of Care

- Siloed systems for IDD and mental health
- In mental health reluctance to treat IDD
- In IDD over-reliance on behavior management-compliance orientation
- Trauma field: typically less knowledge of IDD

# Trauma Informed Care



# Screening & Assessment

- Evidence that children with IDD are more commonly exposed to trauma*
- Crucial to screen or assess for trauma – often not considered or well understood by front line staff
- Ask the Questions!

https://www.youtube.com/watch?v=o1cW8Pzzu4U&t=11s

*Dinkler L, Lundstrom S, Gajwani R, Lichtenstein P, Gillberg C, Minnis H. Maltreatment-associated neurodevelopmental disorders: a co-twin control analysis. J Child Psychol Psychiatry. 2017;58(6):691-701.

*Ohlsson Gotby V, Lichtenstein P, Långström N, Pettersson E. Childhood neurodevelopmental disorders and risk of coercive sexual victimization in childhood and adolescence - a population-based prospective twin study. Journal of Child Psychology and Psychiatry. 2018;59(9):957-965.

# Break!

"We went to them and they had no idea how to help us."

# The Diagnostic Complexity of Trauma & IDD

- Situational stressors vs. known developmental challenges
- Medical Issues
- Co-occurring conditions
- Traumatic experiences
- Communication challenges

- Challenges Accessing Services

# Diagnostic Overshadowing

Symptoms are inaccurately attributed to developmental disability rather than to mental or physical health problems that arise from other sources.

Kerns et al., 2015

# Diagnostic Overshadowing
# DSM 5 Symptoms & Associated features

| | PTSD | IDD | ASD |
|---|---|---|---|
| **Development** | • Leads to Impaired developmental functioning | • Adaptive functioning deficits, failure to meet milestones (B, C) | • signs soon after birth, assessment begins 1.5-2 years |
| **Social** | • Impaired social functioning<br>• Feelings of estrangement & detachment (D6)<br>• Poor relationship functioning<br>• (If comorbid with depression, oversharing with people whom they are not close) | • deficits in self-management of relationships (B)<br>• Difficulties regulating emotion<br>• social judgment, assessment of risk (A)<br>• social & communication deficits (B)<br>• Being easily led by others, risk for exploitation | • Deficits in social-emotional reciprocity (A1)<br>• Difficulties understanding relationships (A1)<br>• Deficits in non-verbal behavior, expressing emotions verbally, & facial expressions (A2) |
| **Executive functioning, memory, attention, cognition** | • Inability to remember (D1)<br>• Problems with concentration (E5)<br>• Reckless or self-destructive behavior (E2) | • Executive functioning & Short term memory deficits (A)<br>• Limited understanding of risk (A) | • High Comorbidity: ADHD, IDD |

# Diagnostic Overshadowing
# DSM 5 Symptoms & Associated features

| | PTSD | IDD | ASD |
|---|---|---|---|
| **Repetition** | • Recurrent intrusive memories / repetitive play (B1) | • Intellectual functioning: Deficits in reasoning, problem solving, judgment, learning from experience (A)<br>• Perseveration | • Repetitive & fixated interests, behavior (inflexibility, sensory sensitivities) (B2,3,4)<br>• Perseveration |
| **Altered state of consciousness/ responsiveness** | • Dissociative reactions (B3) | • Perseveration | • Catatonia<br>• Perseveration |

# Diagnostic Overshadowing
# DSM 5 Symptoms & Associated features

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

# Diagnostic Overshadowing
# DSM 5 Symptoms & Associated features

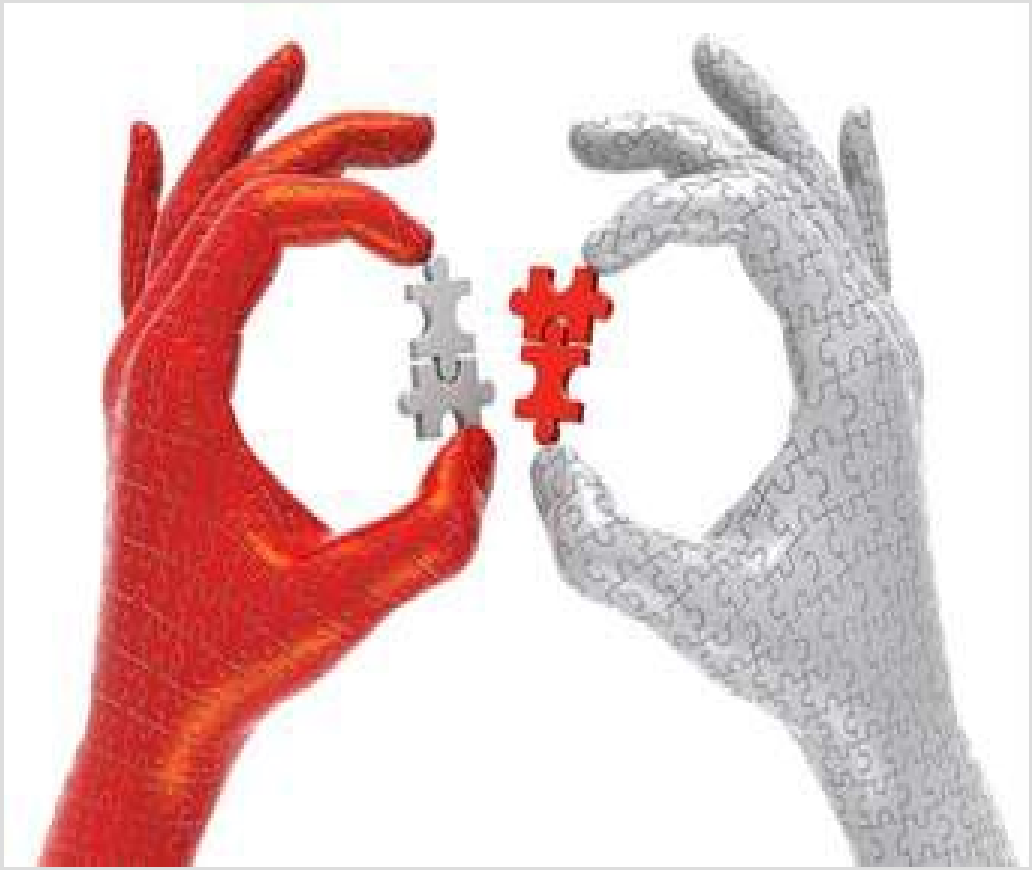
| | PTSD | IDD | ASD |
|---|---|---|---|
| **Behavioral or Anxious Avoidance** | • Intense/prolonged Distress about internal/external cues (B4)<br>• Marked physiological reactions to internal/external cues (B5)<br>• Avoidance (C1-2) | • Difficulties regulating emotion<br>• Rigidity + adherence to schedules | • Prone to anxiety (social, GAD, phobias)<br>• Rigidity, adherence to schedules, extreme distress at changes to routine (B2) |
| | | | |
| | | | |

# 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

# Dual Diagnosis



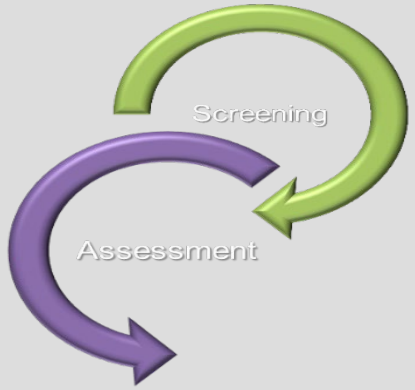
# Special Issues Assessing trauma in Youth with IDD

- **Who should be involved?**
  - Multiple reporters- caregivers, teachers, providers

- **Problems with Measures for IDD**
  - High false negative and false positive rates in ASD
  - Others need norms for IDD
  - Items may not be understood
  - Differences in response styles
  - May not be valid for ASD/IDD (Mazefsky et al. 2011)
  - Adaptive behavior measures (Vineland, ABAS)

# Trauma Screening & Assessment: Adaptations for Children with IDD

- Involve a wide range of caregivers in the assessment process (e.g., parents, school/daycare teachers)
  - Provide psychoeducation on responses to trauma




- Providers should pay attention to
  - Pace *(e.g., slow down speech)*
  - Complexity *(e.g., use simple language)*
  - Timing *(e.g., present one concept at a time)*
  - Sequencing *(e.g., rearrange questions to build on strengths)*

- May need to make use of an intermediary *(e.g., sign language interpreter, professional familiar with assistive devices)*

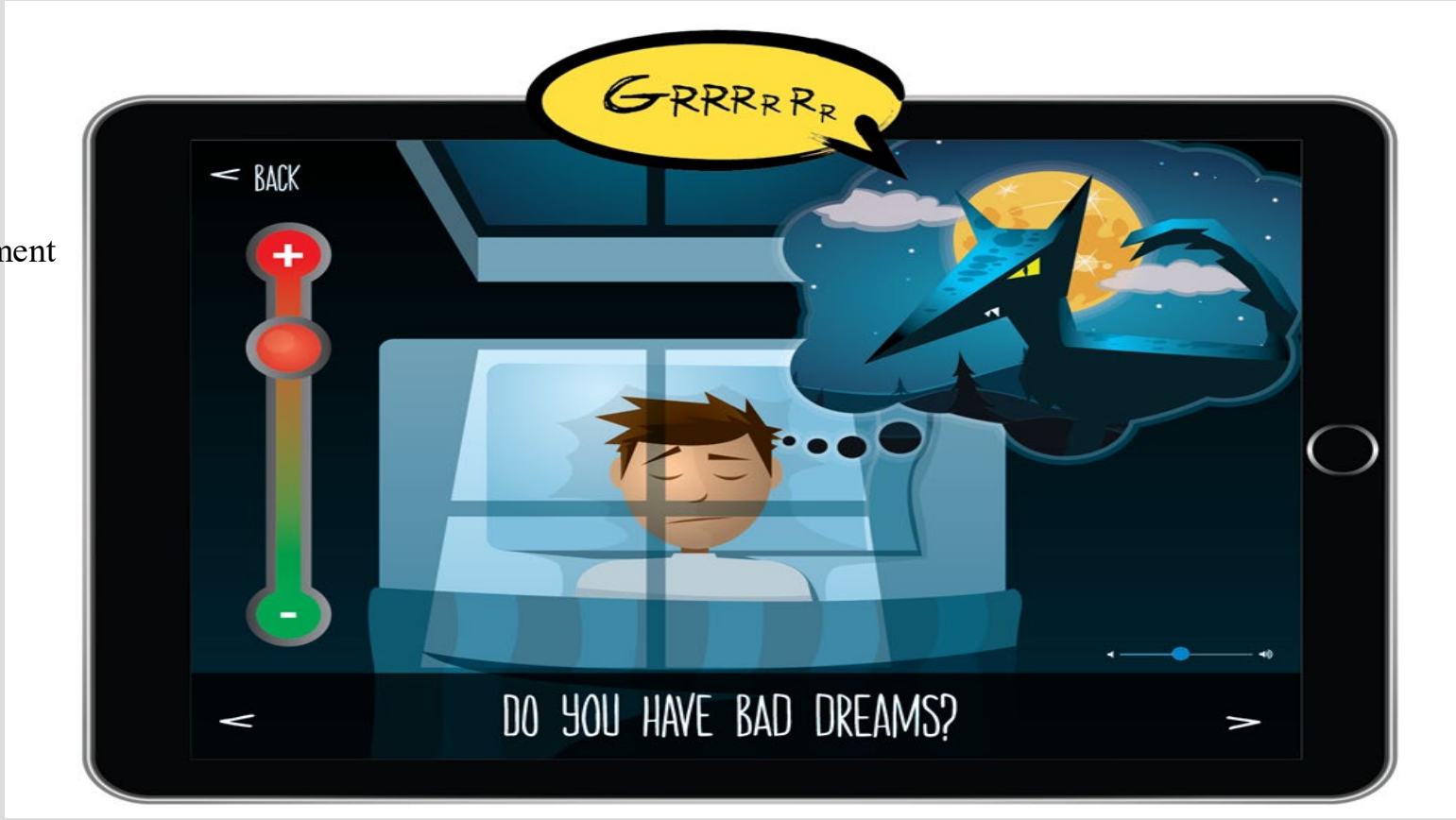
# Trauma Screening Measures

| Measure | Description | References |
|---|---|---|
| **Child Stress Disorders Checklist-Short Form;(parent report)**<br><br>**Obtain from Glenn.Saxe@nyumc.org** | 8 exposure items; 4 symptom items; predicts CSDC overall score. | Enlow, M.B., Kassam-Adams, N., & Saxe, G. (2010). The Child Stress Disorders Checklist-Short Form: a four-item scale of traumatic stress symptoms in children. *General Hospital Psychiatry 32*, 321–327. |
| Young Child PTSD Screen (parent report)<br><br>YCPS | For ages 6 and under- 6 items; If 2 items endorsed as present a little or a lot refer for treatment; 1 item endorsed: evaluate further | Scheeringa, M. (2019). Development of a Brief Screen for Symptoms of Posttraumatic Stress Disorder in Young Children. *J Dev Behav Pediatr 40, 105-111.* |
| THE CHILD PTSD SYMPTOM SCALE FOR DSM-V (CPSS-V SR): 6 screening items | Emotionally upset when reminded of trauma; Avoiding thoughts/feelings about the trauma; strong upset feelings (e.g. fear, anger, shame, guilt); Being very careful/on the lookout (hypervigilance); | Foa, Asnaani, Zang, Capaldi & Yeh (2018) |

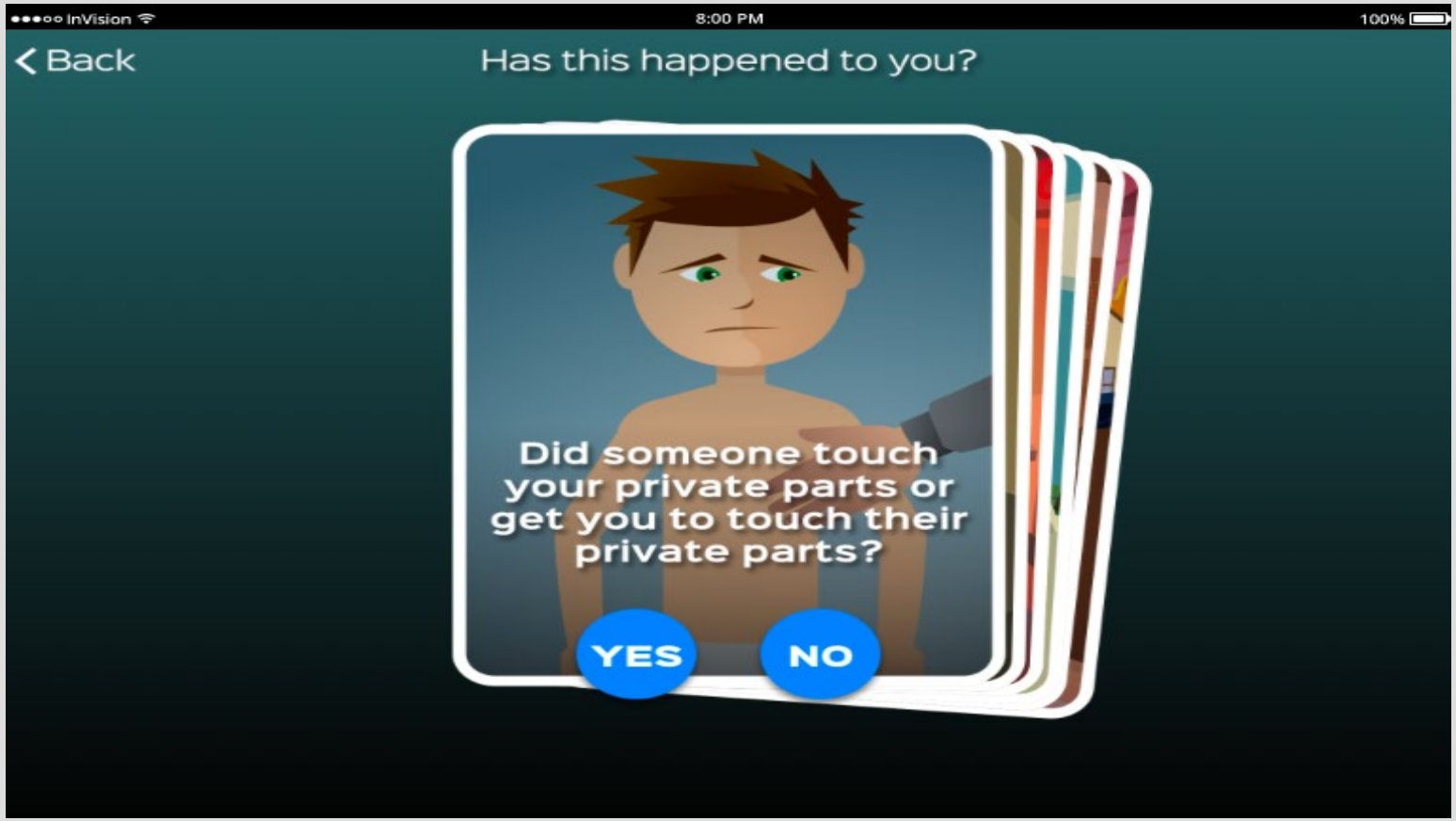
# The Interactive Trauma Scale (ITS)

Tablet-based app in development

Hoover & Romero, 2019



# Interactive Trauma Scale



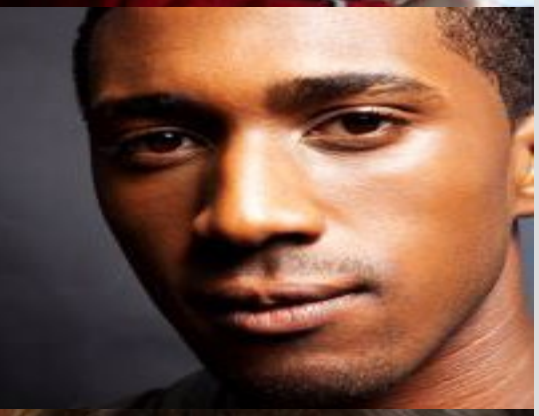
# Interactive Trauma Scale

# Interactive Trauma Scale

# Trauma Reminders

*"For the longest time we couldn't understand why Billy was always acting out and seemed unhappy on our holiday trips to the mountains. We didn't realize that the smell of wood burning in a fire was a reminder of the the ski trip to Colorado, during which Billy was assaulted."*

# Lunch!



# Responses to Traumatic Experiences

# Discussion Points

- In this case, what is trauma and what is IDD?  How do you tell the difference?
- What might be an example of diagnostic overshadowing in this case?
- What do you need to know/what further assessment do you need in order to treat?
- How does knowing about disability status in this case matter?

# Neurodiversity: Challenges for 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

# Neurodiversity:
# Benefits and Strengths for Treatment

- Supportive caregivers
- Willingness to follow rules and routines
- Unique talents and interests
- Respond to concrete and simple strategies
- Respond to incentives in a relatively straightforward way
- Often charming, engaging, resilient

# Break!

# TF-CBT as a model for treatment of youth with IDD

- Recognition of trauma in lives of youth w IDD
- Follows well established methods of coping skills development
  - Fosters language and understanding of problems (trauma, anxiety and associated difficulties)
  - Develops skills for emotional competence & self-regulation
  - Gradual exposure
- Flexibility
- Emphasizes caregiver(s) involvement
- Clear stepwise pattern
- Strong empirical base with demonstrated applications for special populations

# Treatment of Trauma in IDD

- Common issues
  - Do we or “I” have enough expertise?
  - Proceeding with “business as usual”
  - Screening for clinic appropriateness
  - Risk
  - What adaptations to EBTs are needed?

# NCTSN TF-CBT Survey Spring, 2018

- Purpose: To learn about how clinicians were already conducting TFCBT with patients who have disabilities

- Surveyed certified TF-CBT therapists  N=391

- Format: Online survey, ~15 minutes to complete

- Questions
  - Length of treatment overall, session length & frequency
  - Style of treatment: individual, dyadic/family
  - Applications to IDD

- Many therapists are already using TFCBT with individuals with IDD

# TF-CBT Therapist Characteristics N=391

- >50% LMHC, MA Counseling;  32% SW; 13% Psych ****NC>75% SW + LMHC**
- Approximately 2/3 less than 10 Y licensed
- Approximately 2/3 less than 5 Y practicing TF-CBT, 2-4 Y certified
- Majority have treated more than 10 TF-CBT cases ****NC>30+**
- Approximately 2/3 Outpatient/Private Practice setting;  20% Milieu
- Full range of youth served 0-18+
- 16% of cases seen are Youth with DD ****NC=16**
- 70% of therapists report some or a lot of experience working with youth with **DD**NC=24**
- More than 65% state need for extra consultation ****NC> 80%**
- 83% of therapists-treated at least one case with DD****NC=83**

# 17% of Settings (NC=11%) Limited Access for Youth with IDD

- Lack of specialized training and resources
- Cognitive readiness for therapy (IQ>70)
- DD cannot be primary diagnosis/Insurance
- Exclude IDD or ASD from intake process
- Refer on if cannot complete PTSD index or not comprehend the triangle
- Depends on level of functioning/severity
- Cognitive model of treatment

# Exclusion in Order of Clinician Discomfort

1. Low Verbal functioning
2. Autism Spectrum
3. Intellectual Disability
4. Hearing and Vision Impaired
5. Speech and Language delays
6. Learning Disability

# Selected Comments on Exclusion

"I find that TF-CBT was extremely difficult with kids with IDD as TF-CBT (and CBT in general) requires cognitive flexibility which kids with ASD/ID often do not have."

"I, myself, actively seek out these children to work with as I know they are underrepresented. My hospital is apathetic and does not actively support working with them but does not actively discriminate working with them."

"We have been cautious in engaging in TF-CBT with clients on the autism spectrum as we have not received a great deal of training or guidance in adapting the model to meet client needs"

# 83% of therapists have treated at least one case of trauma in IDD

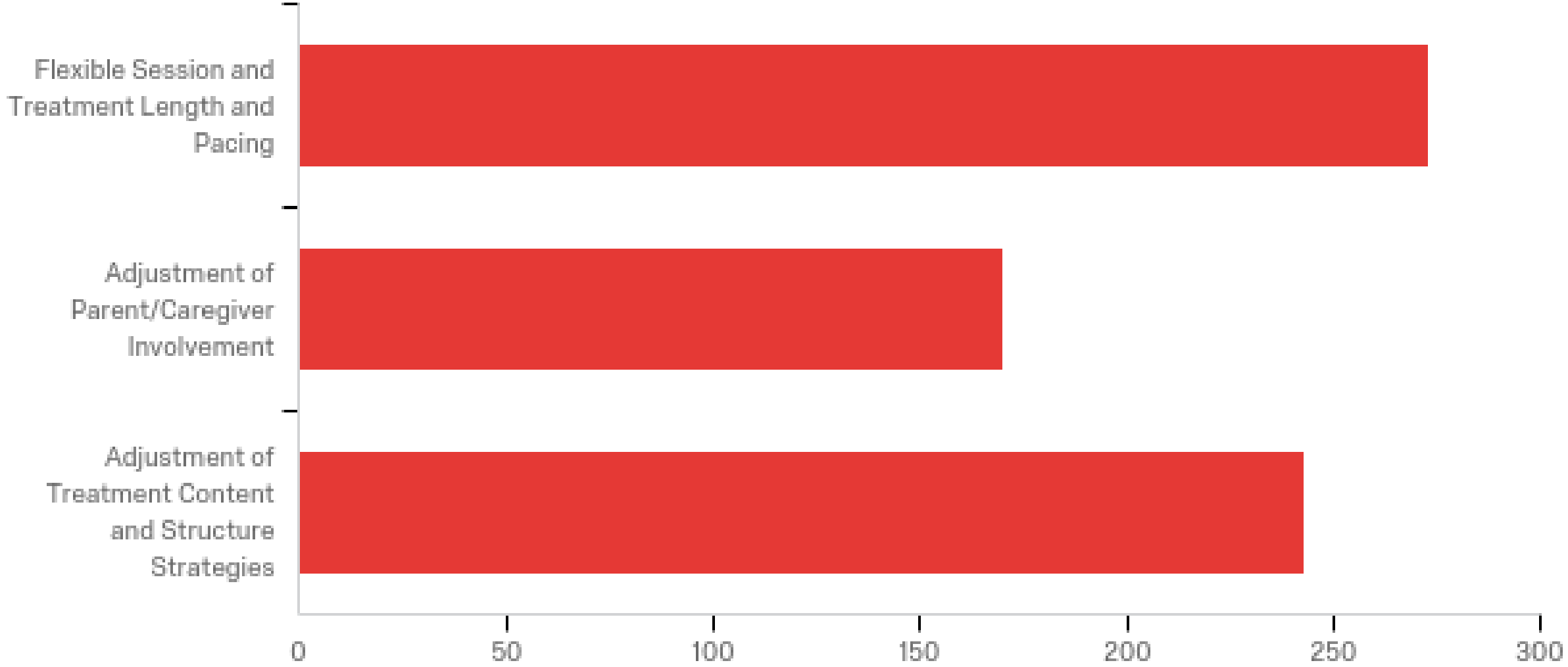
## In order of most case assignments

- Learning Disability
- Intellectual Disability
- Autism spectrum
- Speech & Language delays

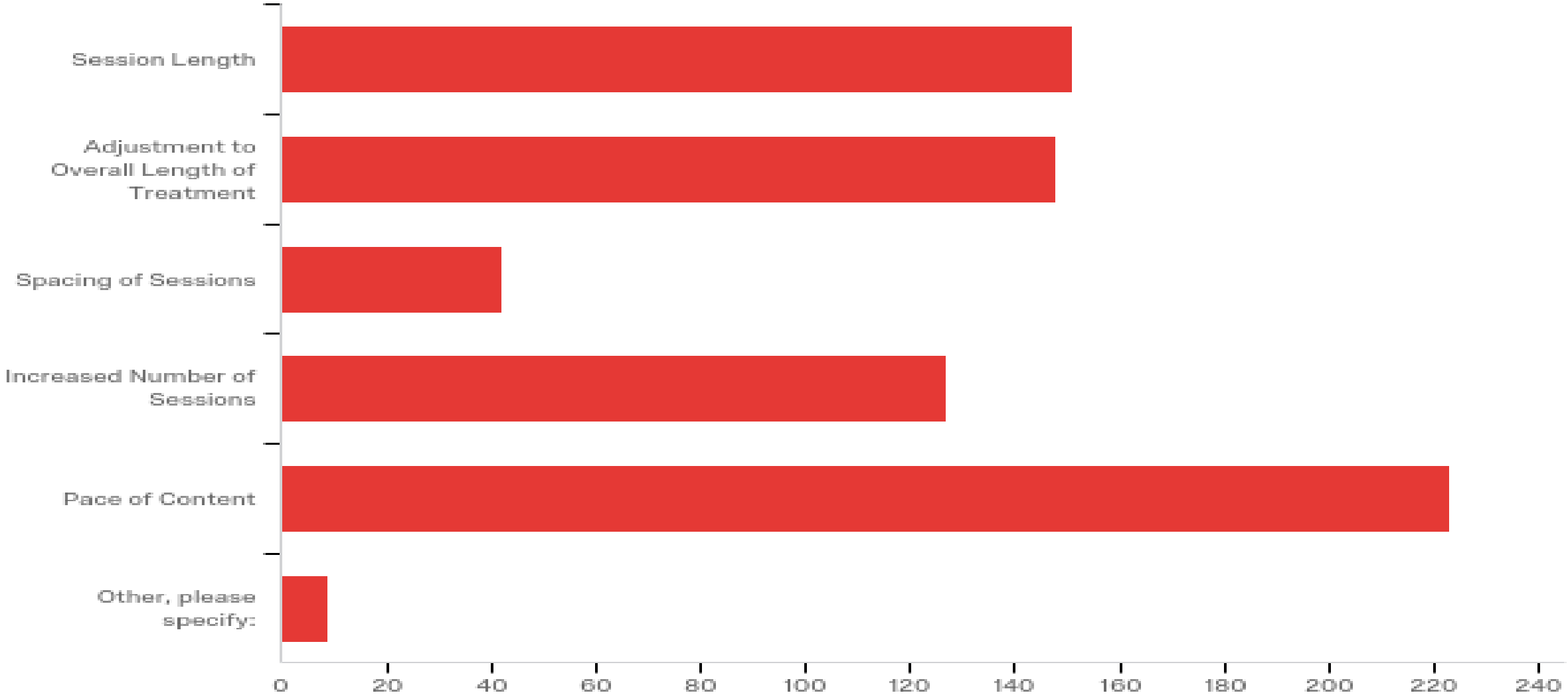
# Therapist Reported Comfort and Experience Relating to Flexibility Variables

- Those reporting use of increased flexible session length and pacing had **more background experience and comfort with DD**
- Those reporting adjustment in parent/caregiver involvement had **more background experience** but not comfort with DD
- Those reporting adjustments to treatment content and structure had **more background experience** but not comfort with DD

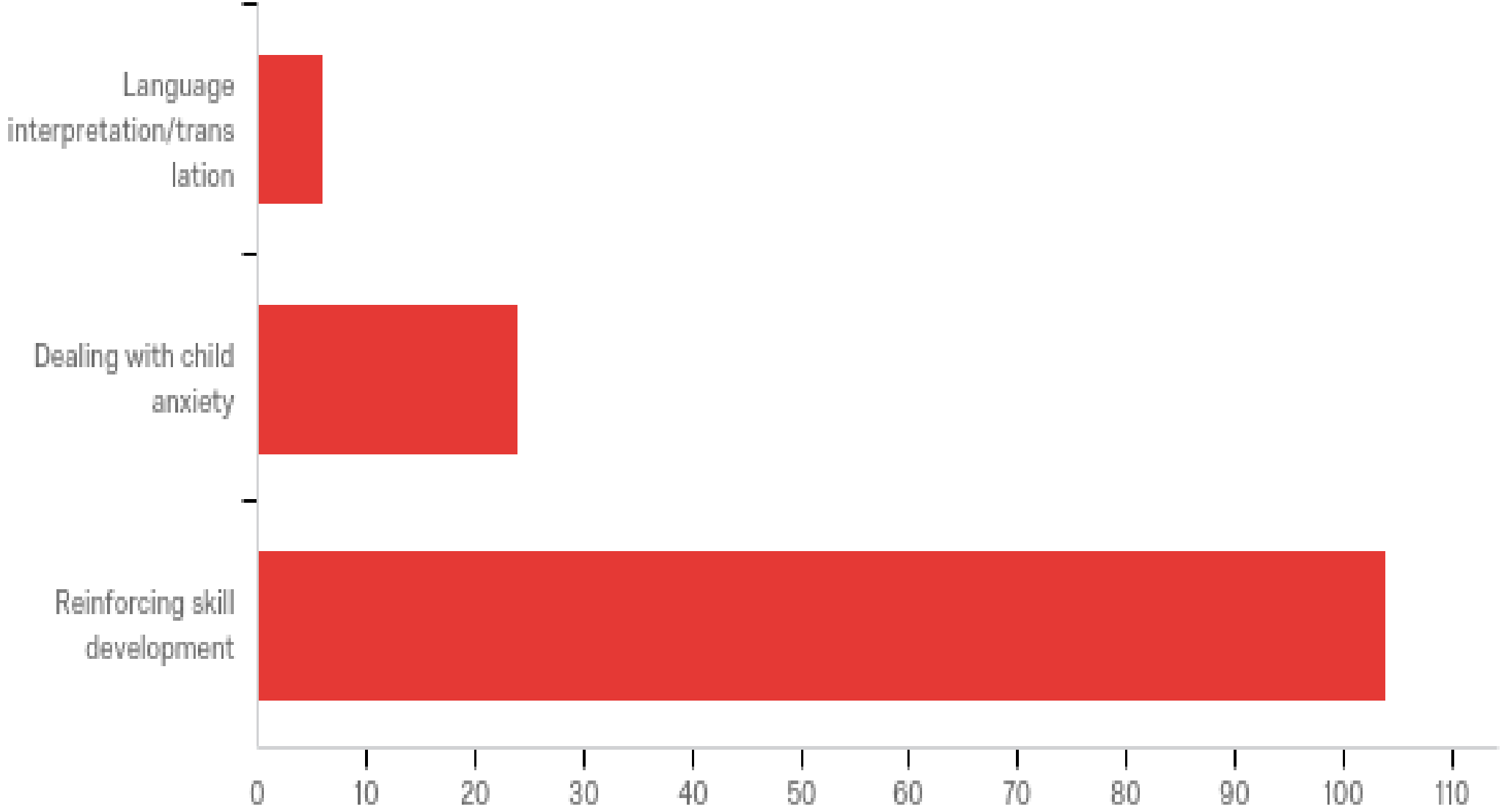
# Q25 Compared to most of your TF-CBT patients, which of the following have you found helpful for youth with developmental disabilities?



# You chose "Flexible Session and Treatment Length and Pacing" as a type of flexibility needed in treating youths with developmental disabilities. Which of the following strategies have you found most helpful?



Q33 - You chose "Inclusion of Parent/Caregiver with Child in Portion of Sessions for Child Sessions" as a strategy useful in treating youth with developmental disabilities.
What aspect of this strategy is most helpful?




| | |
|---|---|
| | 4.48% |
| | 17.91% |
| | 77.61% |
| | 100% |

# Most Utilized Flexibility Strategies by Category

- **Session, Treatment Length and Pacing:**
  - **Slower pace ****NC#2A, Shorter session***NC#4**
  - **Additional sessions per week, Longer treatment ****NC#3**

- **Parent/Caregiver Involvement:**
  - **Inclusion of the parent in child sessions ***NC#1 & more caregiver sessions**
  - **More between session contact with parent**
  - **Reinforcing skill development ***

- **Treatment Content & Structure:**
  - **Use of visuals****NC#2B, simplifying language, check for understanding**
  - **Tailoring PRACTICE components specific to the disability**
  - **Focusing on non-trauma specific issues (i.e. behavior, case management)****NC**
  - **Use of session schedule ***NC, rewards and more playtime**

# Therapist Reflections

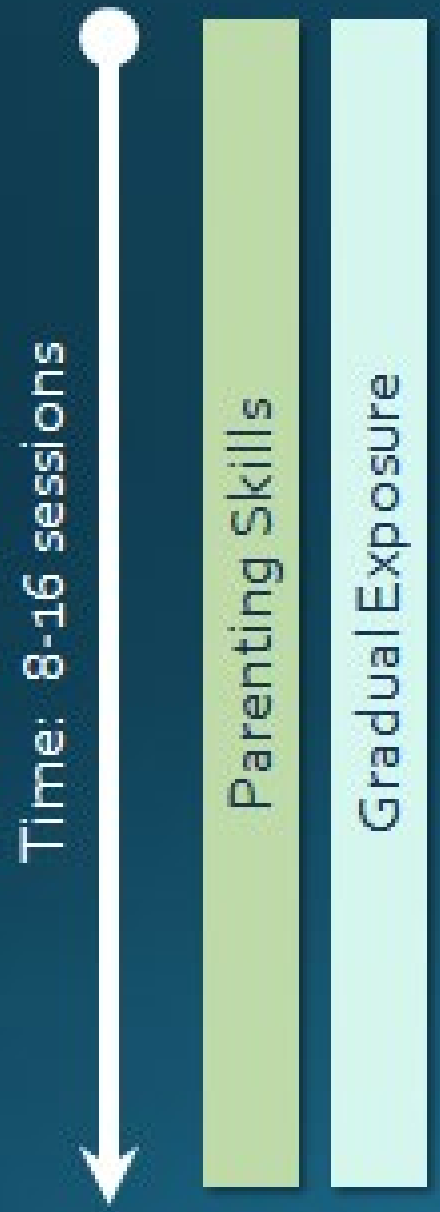
"I think that some people are overthinking this challenge. The vast majority of youth in residential care (my setting) have learning/developmental needs.

The application of CBT with this population is well supported and the modifications I have made with TFCBT reflect strategies and integration of the science of ABA to help support skills acquisition, manage session, and enhance learning."

"Behavioral strategies, especially related to physical aggression, seem to be a significant need for parents and child that are developmentally delayed.

This must, at times, be addressed and stabilized before being able to move through TF-CBT.
TF does have a parenting skills component but is brief and does not adequately address behaviors exhibited by children who suffer from a developmental disability."

# TF-CBT Pacing--Single Trauma




Pscyhoeducation
Relaxation
Affective Modulation
Cognitive Coping

**Stabilization Phase** 1/3

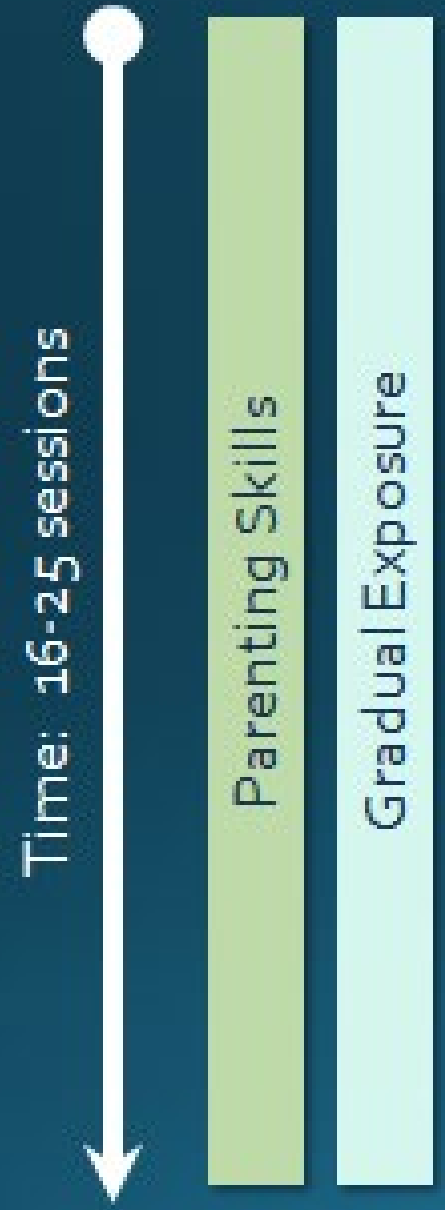
Trauma Narrative and Processing

**Trauma Narrative Phase** 1/3

In vivo
Conjoint sessions
Enhancing safety

**Integration/ Consolidation Phase** 1/3

# TF-CBT Pacing – Complex Trauma




Pscyhoeducation
Relaxation
Affective Modulation
Cognitive Coping

**Stabilization Phase** 1/2

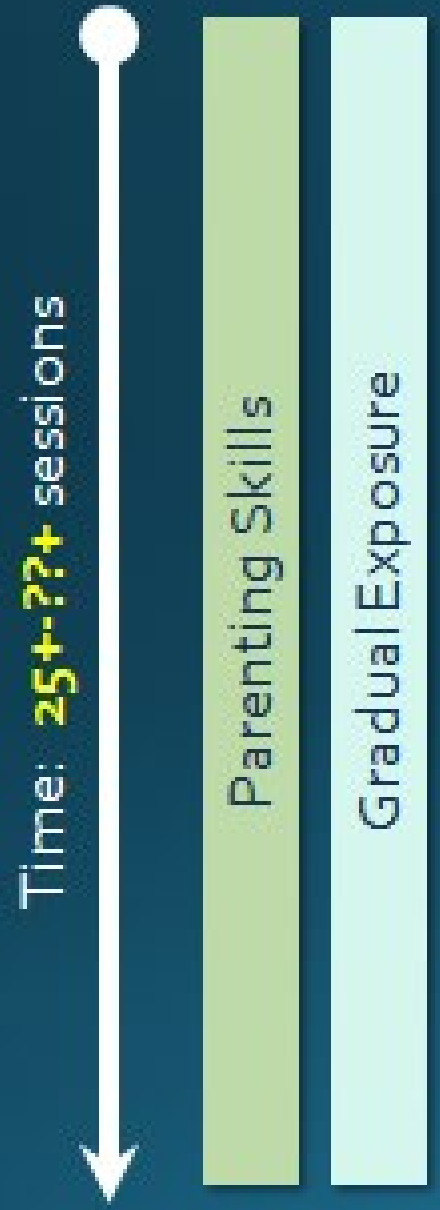
Trauma Narrative and Processing

**Trauma Narrative Phase** 1/4

In vivo
Conjoint Sessions
Enhancing Safety

**Integration/ Consolidation Phase** 1/4

# TF-CBT Pacing – Developmental Disabilities & Trauma




Pscyhoeducation
Relaxation
Affective Modulation
Cognitive Coping

**Stabilization Phase** 1/2?

Trauma Narrative and Processing

**Trauma Narrative Phase** ¼?

In vivo
Conjoint Sessions
Enhancing Safety

**Integration/ Consolidation Phase** ¼?

# Adapting/Tailoring Existing Treatments

**(Grosso, 2012; Avrin, Charlton & Tallant, 1998)**

- Involve a wide range of caregivers, more education/support for families
- Allow more time for rapport development/emphasize strengths
- Provide more structure, create routines
- Shorten sessions
- Use concrete language examples, translations
- Slow down, check for understanding, be specific in making suggestions
- Use art/visuals & play
- Provide repetition, extend treatment modules/goal time frames
- Utilize special interests, reinforcement approaches
- Focus on building coping skills over insight
- Increase involvement of caregivers, more conjoint session time
- Measure change with a micrometer rather than a yardstick

# Group Discussion

- What are you doing already to tailor TF-CBT for youth with IDD that affords flexibility of the model?

- As individual therapists/supervisors, what are the most significant challenges/barriers in implementing TF-CBT with youth w/IDD?

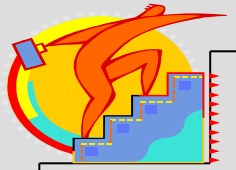
TF-CBT

# Steps of Therapy


Celebration and Future Planning

Safety Skills and Assertiveness Training

Sharing Trauma Story



Creating and Discussing Trauma Story

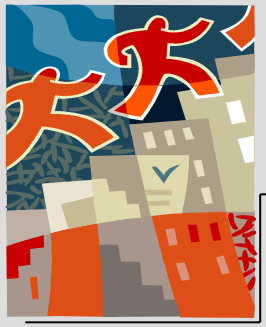
Changing Behaviors

Learning New Ways of Thinking

Figuring Out and Talking About Feelings

Managing Stress

Learning About Trauma



# Flexibility within Fidelity

- Prior research—assumed at least avg level of functioning required for standard EBT's

  "Effectiveness may depend on the cognitive capacity of the child"

- Summary from Kendall and colleagues
  - Adapted vs nonadapted tx's generally comparable
  - Protocols not as fragile as sometimes suggested
  - Rigid adherance (ticking off of items) is likely associated with poorer outcomes
  - Alliance is necessary but not sufficient
  - Flexible therapists make adjustments based on underlying principles of the treatment protocol
  - Therapist can and should adjust expectations of session and/or treatment structure to address developmental capacities of children across development
  - Non-adherance occurs when components are not addressed or new elements are introduced inconsistent with the aim of the treatment component or the overall theoretical model
  - Non-adherance may be in the best interest of child-when an alternate treatment is indicated (primary dx of disruptive behavior)

Conclusion: Tailoring is a therapist competence

# A Yeoman's Try

A Case of Extraordinary Therapist Flexibility

& the Elusive Narration

When did I stop doing TF-CBT?

# Enhancing Safety First
# Behavioral Stabilization Questions

- Is TF-CBT the right intervention?  PCIT first?
- How much is enough?
- Can I start TF-CBT now or am I already doing it?
- What if trauma narration leads to escalating behavior problems?
- Can I facilitate a collaborative treatment approach with a trauma-informed ABA specialist?

# Case Vignette: Joshua

- 18 YO male with ID in moderate range abused at group home
- 21 Sessions of TF-CBT before subpoena and deposition
- Most sessions included visits to the volunteer fire house & therapist's office, both parents at majority of sessions
- Concerns of isolation, nightmares, fears of leaving the house

# Context: Outpatient Treatment

- Joshua is an 18 year old white male.
- Moderate intellectual disability (IQ=45; higher than expected adaptive functioning age 10).
- Presenting for treatment following a reported sexual violation which occurred 6 weeks prior at a community independent living facility where he resided for 2 months before returning home with his parents.
- Joshua is described by his parents (his father a retired naval officer and his mother a paralegal) as in good health, good looking, good character/personality, trusting and sociable.
- His history prior to moving into the independent living facility was rather unremarkable as Joshua obtained an Individual Educational Plan (IEP) diploma at his home high school with intensive support services (OT, speech, 1:1 aid) in a self-contained setting.
- He has been taking Adderall for attention problems since age 9.

# Case Vignette

- Prior to and post graduation, Joshua and his parents spent considerable time researching together possible living facilities where Joshua could live on his own with supports as was his wish.
- Joshua recalls the interview with the director at his chosen facility to be the deciding factor as he was assured of the excellent blend of staff supervision and resident freedom.
- Almost immediately after moving into his shared apartment (2 other adult males in their early 20's), Joshua described a gradual intensifying pattern of bullying and sexual predation from one of the male residents. This started with sexualized talk, teasing and uncomfortable touching while clothed, peeking in the shower, walking around naked. This progressed to requests and dares to perform sexual favors, oral sex while patient was sleeping, joining patient in shower, and to attempts at anal sex.
- This last escalation prompted the patient to call and request to come home. Parents picked him up that evening, which is the last time patient was in residence.
- Joshua reported that he tried on several occasions to ask for help from staff and that they did not take seriously his accusations.
- Joshua had difficulty remembering important parts of what had occurred and was often inconsistent with small details.
- On evaluation which included UCLA PTSD reaction index, Joshua and parents describe persistent anxiety ("I am afraid it will happen again"), sadness ("not happy so much anymore"), intrusive recollections, social withdrawal, fear of leaving the house, and almost constant "butterflies in my stomach." Joshua repeatedly stated that he felt like he was "put in a strait jacket" and could not stop what was happening. He did not think what happened was his fault (because his father told him so). As one of his 3 wishes, Joshua stated "for the bad stuff to go away."
- Joshua's parents state they are both devastated by this and feel responsible for allowing it to happen.

# IDD Cultural/Resource Broker

"interpreter or intermediary who engages in the act of bridging or linking between groups of differing cultural backgrounds for the purpose of producing change"

- Legal Guardianship
- OMRDD registration
- Caseworker
- Able ride
- Social Skills groups
- Special Olympics
- Alternative placement options , independent living

# Service Delivery Systems

EDUCATION

- School team:
  - Principal or director
  - Teacher and aides
  - OT, PT, speech, counselor
  - ABA in school
- Committee on Special Education (oversees)
- Education Lawyer (if contesting placement)
- Medical:
  - Pediatrician
  - Developmental pediatrician (evaluations, medication)
  - Child Psychiatry
  - Pediatric neurology
- Neuropsych. or psychoeducational evaluator (outside of school)

- OFFICE OF PERSONS WITH DEVELMENTAL DISABILITIES
  - Case manager & self-direction broker
    - Home care workers/community habilitiation workers

- ABA services (in home)
  - Clinical director, supervisor, worker in home

- Family
  - Parent(s)
  - Father's extended family
  - Mother's extended family

# Assessment Broker

- You are likely to need & benefit from expert consultation regarding how to decide about the need for further evaluation and/or how to interpret assessment results and translate them into therapy accommodations
  - Can be experts from other agencies, schools, MH centers, DD agencies, regional & academic centers
  - Or you can marry a Pediatric Neuropsychologist

# IDD Profile (review)

**Individualized Therapy Accommodations Planning: IDD Profile**

| Issues | Strengths in each of the areas | Age/Grade Level* | Therapy Accommodations |
|---|---|---|---|
| **Language issues** | **Language strengths** | | |
| __ Limited expressive vocabulary | | | |
| __ Limited ability to express ideas in words | | | |
| __ Speech unclear/hard to understand | | | |
| __ Limited receptive vocabulary | | | |
| __ Limited understanding of complex language forms (e.g, multi-phrase sentences, etc) | | | |
| __ Limited pragmatic skills (understanding and use of verbal and nonverbal cues for interpersonal communication) | | | |
| **Cognitive issues** | **Cognitive strengths** | | |
| __ Difficulty with abstract concepts (more difficult than expected for age) | | | |
| __ Difficulty with generalizing | | | |
| __ Difficulty with immediate memory (e.g. ability to remember multiple instructions) | | | |
| __ Difficulty with long-term memory retrieval on demand | | | |
| __ Limited attention span for at least some kinds of materials (specify) | | | |
| __Limited visual/spatial skills—may affect organizing of information | | | |
| __ Uneven skills (specify—e.g. visual spatial skills much stronger than verbal or the opposite) | | | |
| **Sensory/motor issues** | **Visual/spatial & motor strengths** | | |
| __ Low vision (for near, far, both?) | | | |
| __ Hearing issues (any aids?) | | | |
| __ Fine motor issues (e.g. affecting writing, drawing) | | | |
| __ Gross motor issues | | | |
| __ Sensory sensitivities (specify) | | | |
| **Academic skills that can impact treatment**<br>___ Reading decoding<br>___ Reading comprehension<br>___ Writing skills<br>___ Understanding basic numbers | **Academic strengths** | | |
| **Other issues**<br>___ Willingness and Motivation<br>___ Obsessive about sameness<br>___ Hyperfocus on _____<br>___ Difficulty with transitions<br>___ Limited emotional coping strategies | **Special characteristics**<br>___ Special interests<br>___ Tends to follow clear routines<br>___ Has mastered coping strategies of _____<br>___Other_____ | | |

*If available

# Types of information from evaluations

- General level of functioning:  overall, verbal, nonverbal
- Functioning in different domains, including memory, attention, social relatedness
- Adaptive behaviors (ability to deal with practical domains: communication, daily living, social/emotional)  particularly – if ID suspected
- Academic skills
- Qualitative information—e.g. about flexibility/rigidity or special interests

# Sources of Information for Profile of Developmental Issues and Strengths

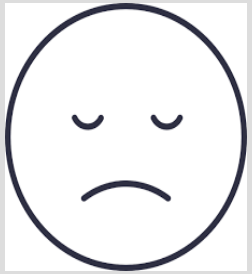
- Early Intervention (EI) and Committee of Preschool Special Education (CPSE) Assessments
- School Evaluations
  - Formal: For Individualized Education Program (IEP) classification or 504 accommodation
  - Periodic evaluations:
    - Formal: standardized testing
    - Informal: report card levels and comments
- Other evaluations (if autism suspected, may include specialized measures)
  - Neuropsychological, psychoeducational
  - Developmental pediatrics
  - Specialists: speech/language, occupational therapy, physical therapy
- Your own screening instruments; updating based on case information and progress

# Neuropsychological Profile Assessment Broker

- **FSIQ =45-54,** in the moderately deficient range; subscales **uniformly depressed;** Estimated **cognitive age=6-7**
- **Weaknesses:** Fund of knowledge (days of the week), working memory, multimodal or integrative tasks
- **Strengths:** Receptive vocabulary; rote verbal learning; basic visual perception (identifying details missing in pictures)
- BASC-2: Self: Depression, Inadequacy, Attitude to Staff and Placement; Mom: Anxiety & Withdrawal; Dad: No significant problem area
- RI-Only 2 items with high ratings, parents slightly higher
  - RI-identified **bullying** and **unwanted sexual touching**
  - Only sig **items-stay by myself** and **trouble remembering important parts**

# “Be Concrete”

- What would you like help with?
  - “I want the bad stuff to go away”, “I’m not happy so much”



- Assessment-Use of fire flames for 0-4 none to most

- What did it feel like?
  - “Like a strait jacket”

- Take the power out of the memories?
  - No, “Make it (the residence) smaller”, “put it (the fire) out”

# “Be Concrete”

- False Alarms
  - “The ghost of Larry”
  - “Ghosts can’t pull fire alarms or light fires”

- Homework-turn on your DVD to make the memory smaller-say boo to your fear
  - “I said Boo to the DVD” “and it helped me turn it on when mom reminded me”


- Tell me what happened

## –“NO, DON’T WANT IT!!”

# Accommodations

- **Graphomotor**-don't like to write or draw pictures
- **Session structure** and therapy course-Visual Activity Schedule
- **Parenting-In** room 80% of the time
- **Psychoed-CBT** triangle-"it can go anyway Dr D", -concrete connections 1:1
- **Inadequacy-not** my fault I couldn't stop it
- **Role Playing-do** you know how to pretend-to be a fireman
- **Repetition**, rote verbal role plays
- **Problem solving-3** choices then pick one
- **Triggers-**sparks become fire**:** being taken advantage of; anniversary call from residence, sleeping away from home
- **Narrative-scribing** in sentences—not a timeline or story
- **Relaxation-Butterflies** to stop flapping
- **Cog**-Go away, get out, its gonna be alright
- **InVivo**-Say boo to your DVD, interview the next residence program

# “He learns like he’s 6 but remember he’s 18”

- Independence:
  - Explore new placement wants to live in his own apartment
  - Wants to drive- able ride
  - Use of phone, texting
  - Own money & checkbook, bankcard
  - Cooking skills when home alone
- Computer time: teletubbies & sexual education
- Social skills group: assertiveness-saying stop, no & dating
- Volunteering vs paid position
- Candy cottage $ vs purchasing his own flat screen TV
- Preparing for deposition

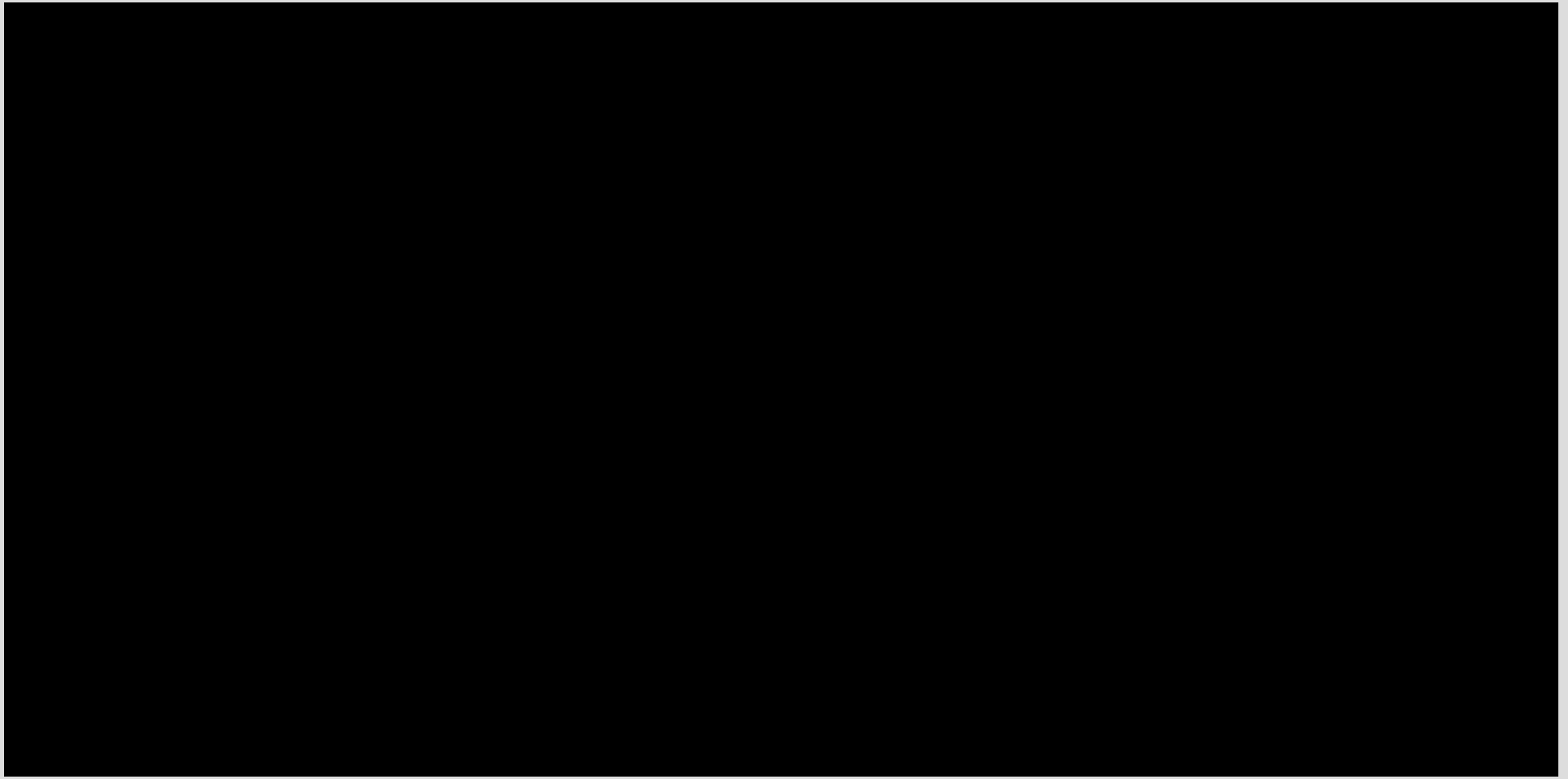
# Joshua's idea for narrative: Interview Questions for Next Residence

- How many people apply to your school?
- Are you allowed to ride a bike?
- Is it safe to lock the bike outside?
- How many people in the bathroom?
- Does the bathroom have a lock?
- How many classes do I have to take?
- Who is in charge watching outside at night?
- Are you allowed to bring candles?
- Do you have a medical kit and a nurse?
- Do other residents just come in or need special permission?
- Are you going to fix the facilities?

# Group Activity

Completing Individualized Therapy Accommodations Planning Tool on Joshua

# Autism TMI Virtual Reality Experience



https://www.youtube.com/watch?v=DgDR_gYk_a8

# The “Big 4” foundations
# Assess at each TF-CBT step:

1. **Visual-spatial competencies**

   Will the clients benefit from pictures and other visual and activity-based illustrations of trauma, its effects, and parenting skills?

2. **Verbal comprehension/conceptual understanding**

   Do the clients understand key terms inherent in treatment (e.g., “trauma,” “trigger,” “physical, sexual, psychological abuse,” “relaxation,” etc.)?

# The “Big 4” foundations
# Assess at each TF-CBT step:

**3. Generalization skills**

- Are the clients able to recognize potentially traumatic situations or reminders of past traumas and integrate into current events?
- Can the clients remember information that was presented in the step?
- How able are caregivers to implement recommendations for parenting skills, including consistently tracking, reminding, and rewarding child’s behavior, homework, coping skills?

# The “Big 4” foundations
# Assess at each TF-CBT step:

**4. Willingness and Motivation (meta-cognitive skills)**

- How willing and motivated are the clients to engage in therapy that requires gradual exposure to anxiety-arousing stimuli?
- How willing is the child to stop, think, and use relaxation and other skills before, during, or after a stressful reminder?
- What is the level of the caregivers’ willingness to change parenting styles if needed?

# Other factors to consider in assessing & adapting

- **Sensory differences**

  Are there visual, auditory, tactile, or other sensory hyper-sensitivities that may impact response to the treatment environment or tasks?

- **Special interests**

  What particular preoccupations or interests might be used to enhance or reinforce treatment responses?

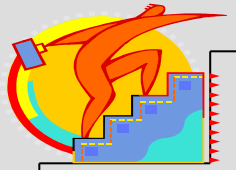
TF-CBT

# Steps of Therapy


Celebration and Future Planning

Safety Skills and Assertiveness Training

Sharing Trauma Story



Creating and Discussing Trauma Story

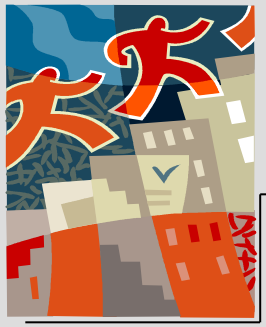
Changing Behaviors

Learning New Ways of Thinking

Figuring Out and Talking About Feelings

Managing Stress

Learning About Trauma



# TF-CBT Components

- **P** - Psychoeducation and parenting skills
- **R -** Relaxation techniques
- **A -** Affective expression and regulation
- **C -** Cognitive coping
- **T -** Trauma narrative and processing
- **I -** In vivo exposure
- **C -** Conjoint parent/child sessions
- **E -** Enhancing personal safety and future growth
- **Traumatic Grief Components as needed**

# IDD/ASD Differences and Challenges

| The "Matrix" | Verbal Language Comprehension | Visual-Spatial Competence | Willingness/ Motivation | Generalization of Skills | Sensory Differences |
|---|---|---|---|---|---|
| TF-CBT Skills | | | | | |

# IDD/ASD Differences and Challenges

| The "Matrix" | Verbal Language Comprehension | Visual-Spatial Competence | Willingness/ Motivation | Generalization of Skills |
|---|---|---|---|---|
| TF-CBT Skills: Psychoeducation/ Parenting Skills | In-range books and stories; flash cards | Behavior charts; trauma picture cards "What Do You Know" game | Visual schedule, routine, move slowly at first | Provide psycho-education to other systems (i.e., school, social services) |
| Relaxation | "Pizza" breathing; "noodle" practice | Movement-based Yoga practice; videos and apps | Interest-based alternatives; substitute distraction | Video modeling; practice yoga at home; chart progress with reinforcers |
| Affect Regulation | Emotion game apps, emoji charts; Zones of Regulation | "Check your engine" Alert Program; Parking Space game; feelings thermometers | M&M emotions game; Power Cards | Practice in school, community settings |
| Cognitive Coping | Thought bubbles, "worry bugs"; "true-false game" | Thought bubbles; Comic-Strip Conversations | Triangle of Life app; Playing CBT game | Stop sign at home/ school: "Stop and Think"; "When" reminders |
| Trauma Narrative | Have parent/caregiver in session as "interpreter" | Draw cartoon narrative/ use pictures/ collage | Short narrative session followed by special interest play | Consider keeping the narrative in "safe space" or clinician's office |
| In-Vivo Desensitization | Use roller coaster or child-specific analogies | Habituation chart | Reinforce small "ladder rungs" | Hierarchies for home, school, community |
| Safety Skills | In-range books and stories; Circles Curriculum/app | Pictures, tables, charts; Circles app | Address parents' concerns about topics; reinforce practice | Use Circles colors for door, bathroom, wear reminder bracelet; engage school personnel |

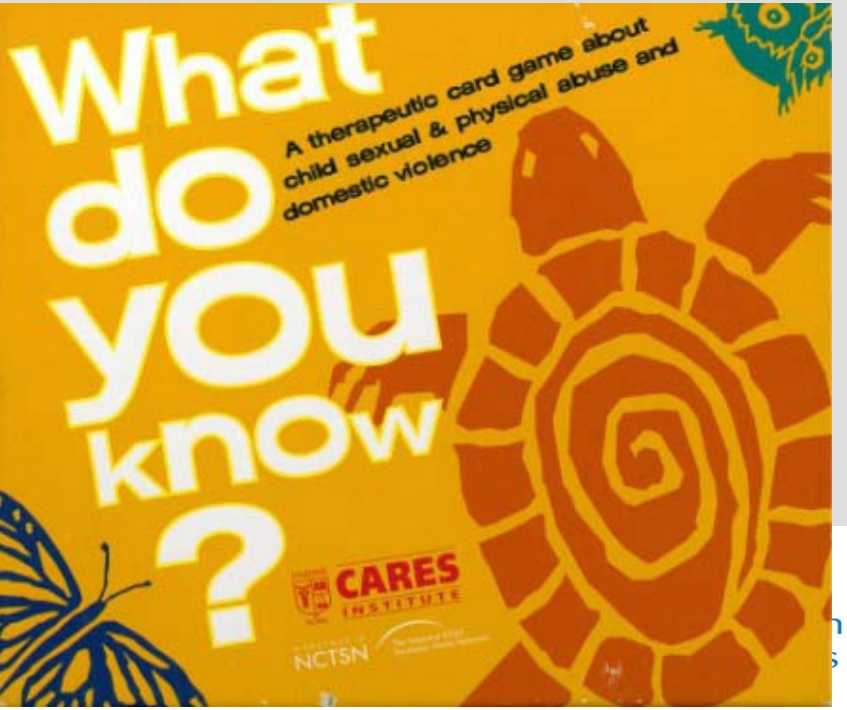


Daniel Hoover, PhD
Center for Child and Family Traumatic Stress

# Break!

# 1. Psychoeducation and Parent Training

- Teach functional behavior assessment to parent
- Educate about IDD/ASD
- Expected development for IDD
- *What do you know? game*



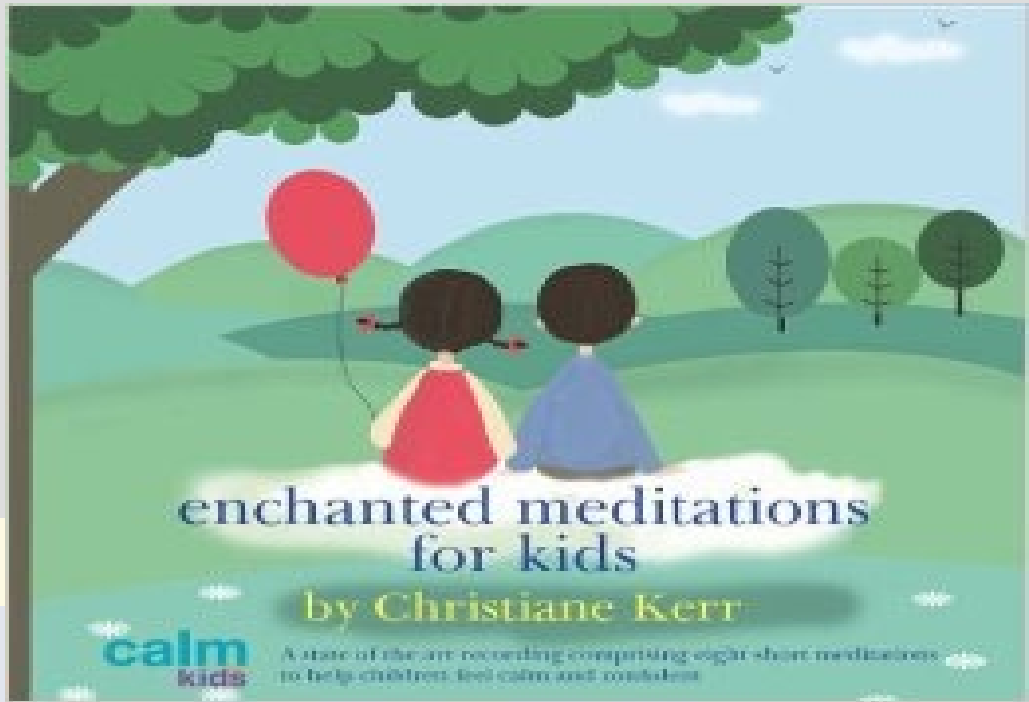

# 2. Relaxation (Stress Management)

Teach deep breathing, deep muscle relaxation

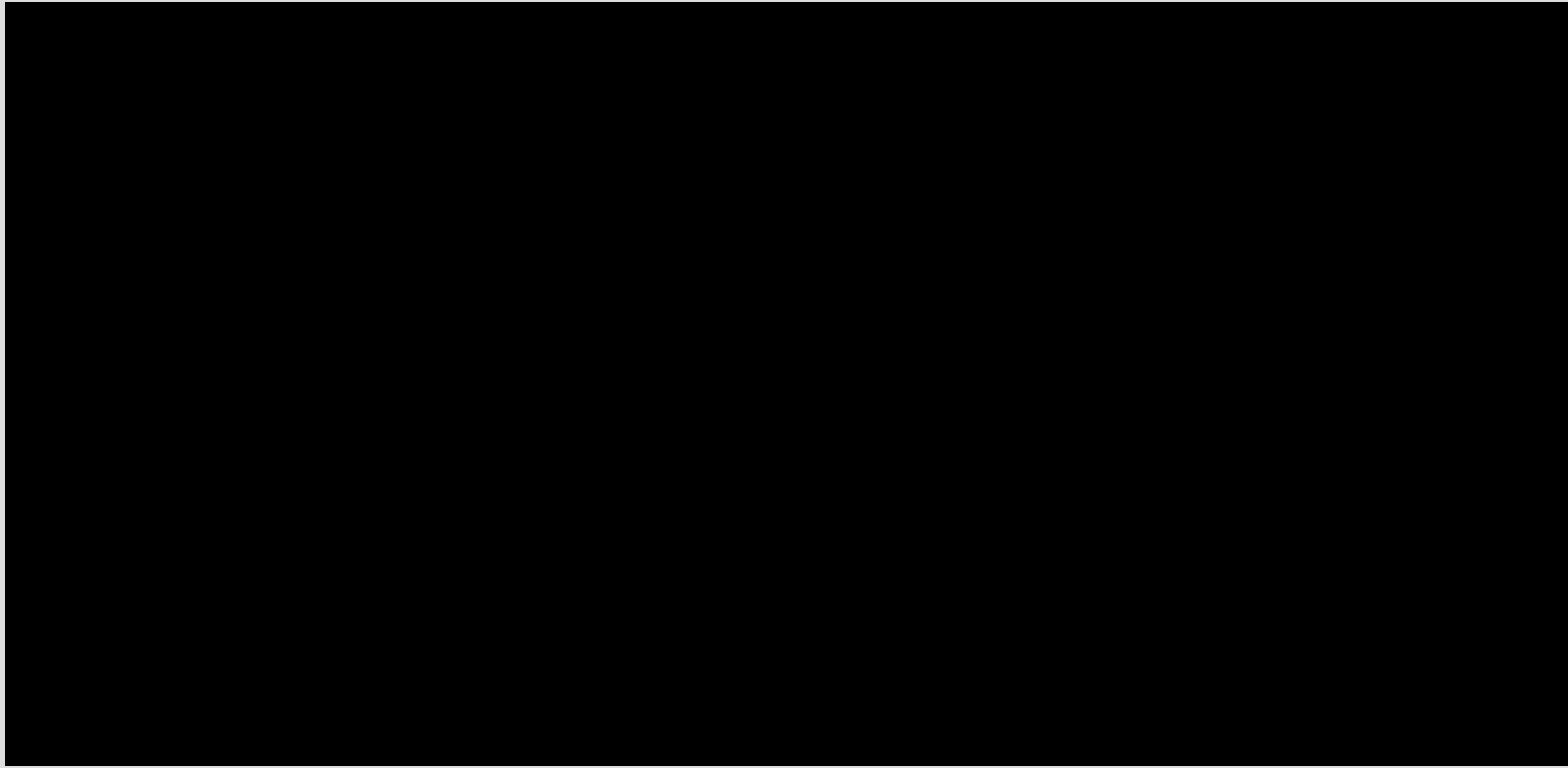
Mindfulness and meditation- yoga

Relaxation

- Elmo Sesame Street belly breathing
- Go Noodles https://www.youtube.com/watch?v=XXH0EAKzPcM
- Zones of Regulation calming exercises
- Distraction-based coping
- Use Special Interests
- Tablet/phone apps



# Relaxation



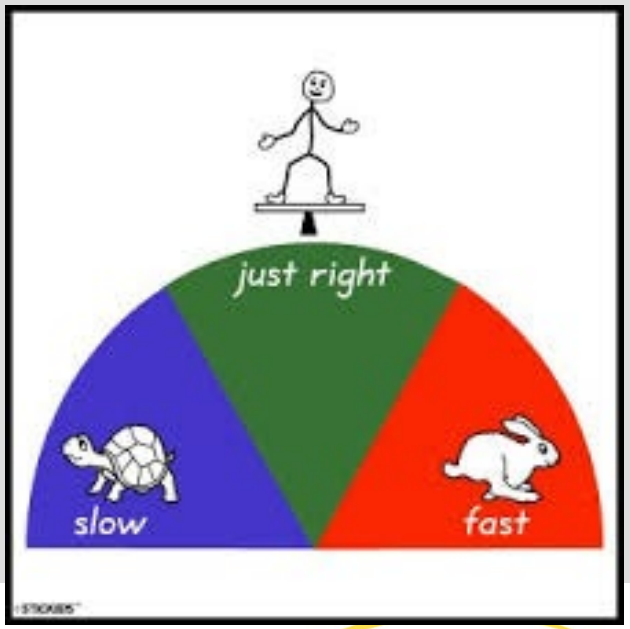
https://sesamestreetincommunities.org/activities/comfy-cozy-nest-video-provider/

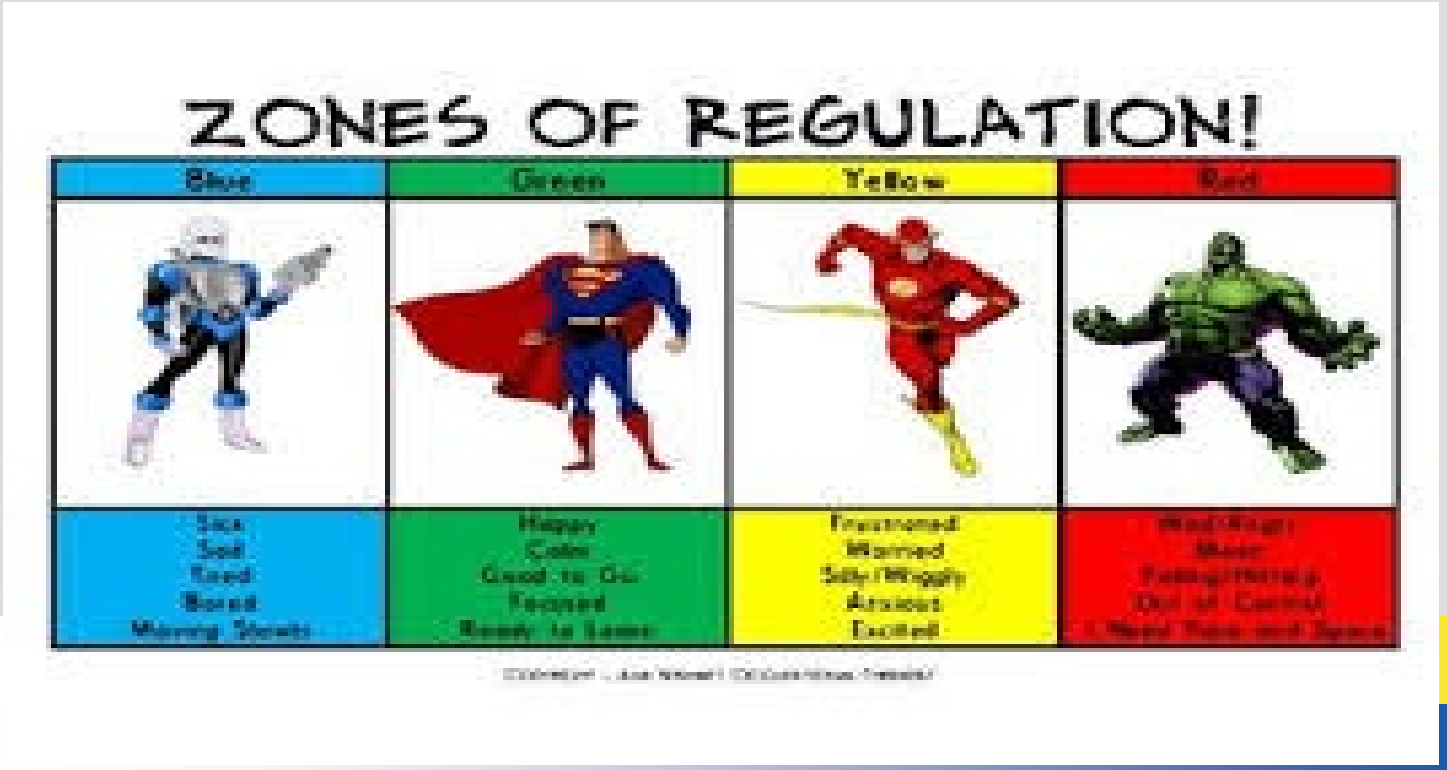
# 3. Affect Expression and Regulation

- Emotion identification is important work
  - Charts, games, Therapist Aid, emojis
  - https://www.youtube.com/watch?v=dOkyKyVFnSs&t=106s


# 3. Affect Regulation

- Secret Agent Society
- How Does Your Engine Run?
- Zones of Regulation https://www.youtube.com/watch?v=NnIz0u0K-h4



# 4. Cognitive Coping

## Cognitive Coping

- Superflex https://www.youtube.com/watch?v=Ck0Hfn5ZHoU&list=PLZ-iOh4DDwXSRyavCdoauzEqZJ8enwnZ

- Triangle of Life app
- Incredible 5-Point Scale

# Cognitive Coping

## Worry bugs



# Cognitive Coping

Externalize:

"My anxiety is telling me…"

"Worries are getting in the way by…"

"My brain would like to keep me thinking about this.."

"My worries are holding me back from…"

Learn to TALK BACK TO ANXIETY

# 5. Trauma Narration

Tell the story-

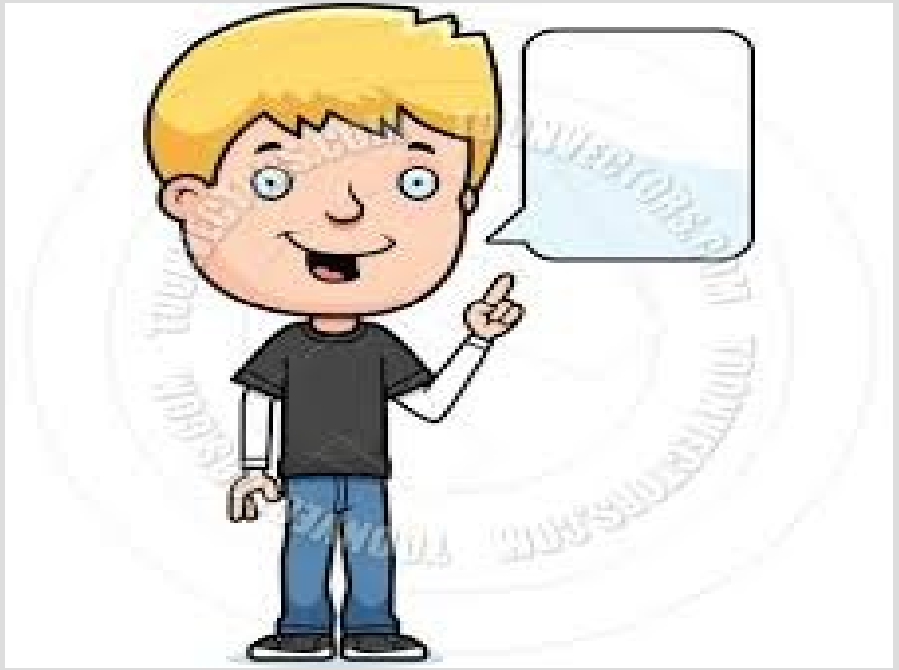
Play

Talk about it

Draw it out

Sing it

Make a book



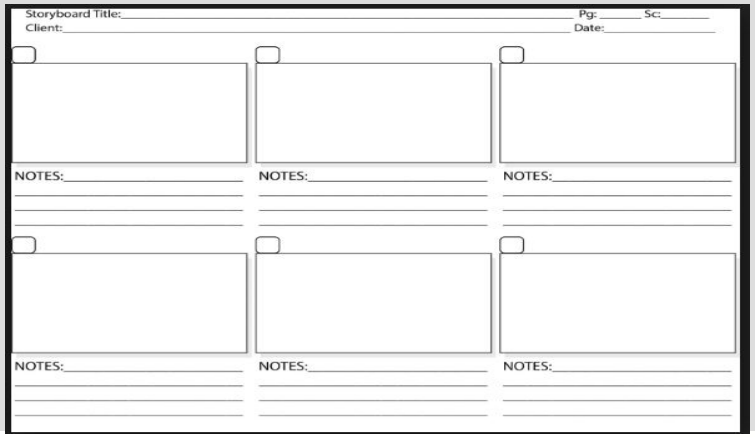
whatever works for you

# Narration

- *She was going somewhere else then when everyone was all in the shallow end I fell in the deep end.*
- *The water was blowing me and other students were pushing the water everywhere and I fell in to the deep by mistake.*
- *And my goggles fell off my face.*
- *I was looking at my foot because it got scraped on the sidewalk. And my foot was red and it really hurt.*
- *I knew then I was in the deep water. I tried to escape- tried to swim out of the deep end.*
- *I couldn't get my head above water because it used to be an old skateboard park it was 9 feet down.*
- *Then my goggles fell off because I pulled them off because I thought it would help a little.*
- *I breathed in a little bit then held my breath again and I died.*
- *I was very scared- a lot scared.*
- *I was crying when I woke up--* ***I thought I was dead****.*

# Role of Play in Trauma Narration
## (Grosso, 2012)

- Consider other methods
  - Story boarding
    - Can use index cards/post its
    - Drawings on separate pieces of paper
    - Can be Autobiographical




Series of short videos

- Consider using spoken narrative as narrator for video
- Singing, dancing, rapping…
- Recording play – sand table, role play

# 6. In Vivo Desensitization

## In Vivo Desensitization

- Power Cards
- Video modeling
- Reinforcement strategies

# In vivo mastery of trauma reminders

- Can make part of BIP with ABA therapist
- Manage overstimulation
  - Prompt to use PRAC skills to tolerate distress
- use concrete examples (And special interests!) to create hierarchy
- Provide a specific schedule, plan, and reinforcement system
- Provide social coaching by school staff, teacher, or parent
- Make the In Vivo practice into the child's own movie for video feedback (as in Facing your Fears session 7)

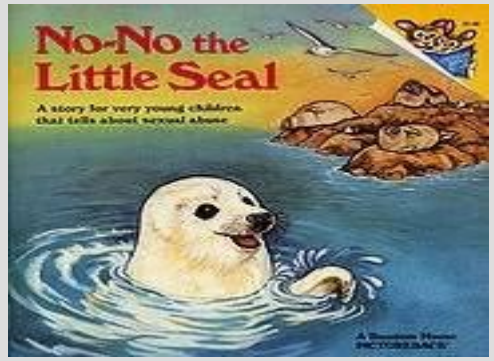
# 7. Conjoint Parent-Child Sessions

- Review narrative together
- Educate caregiver
- Practice safety skills
- May be most useful for kids with IDD if most or all sessions are conjoint family sessions

# Conjoint Sessions: Youth & Parent

- Have sessions with each caregiver, but do not share narrative with every caregiver (e.g. 1:1 at school, every teacher…); may become overwhelming for Pt (G)
- Instead, offer a trauma informed consultation to each provider or in a team meeting
- Respect caregiver's knowledge of youth (G)
- Create a new contract of safety & privileges for independence
- Celebrate the accomplishment

# 8. Safety and Personal Skills




- Safety Skills
  - May need to come first in order
  - Educate about ok and not ok touch
  - Coping with bullies (Autism Talk TV 24)
    - http://www.youtube.com/watch?v=UfznHlLcl7w
    - https://www.youtube.com/watch?v=ZDfvsjho-z8&list=PLMIyjKun9zTMmIL0uR-BH-jQjyYT_Uk-E
  - Practice setting boundaries

Circles Program

# Resources: Organizations

- NCTSN
  - https://www.nctsn.org/
- NADD
  - http://thenadd.org/
- Autism Speaks
  - https://www.autismspeaks.org/
- National Autism Society
  - https://www.autism-society.org/

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