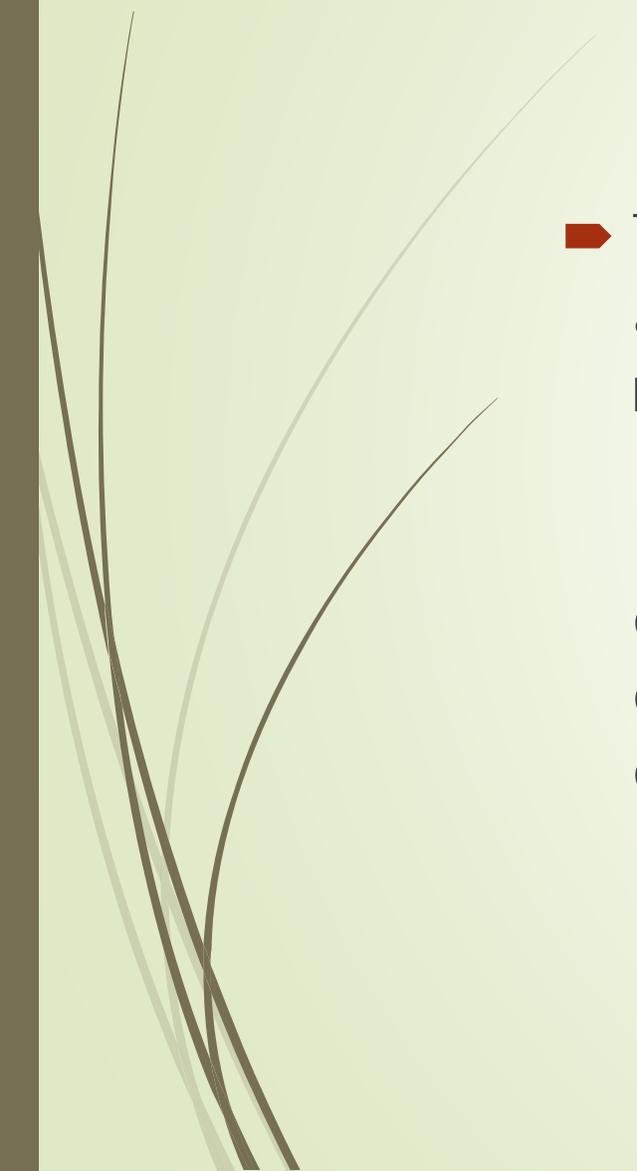




# Trauma- and Stressor- Related Disorders and Trauma Informed Care in IDD

*Jill Hinton, PhD*

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- ▶ Trauma refers to intense and overwhelming experiences that involve serious loss, threat or harm to a person's physical and/or emotional well being.
  - ▶ These experience may occur at any time in a person's life. They may involve a single traumatic event or may be repeated over many years.
  - ▶ These trauma experiences often overwhelm the persons coping resources. This often leads the person to find a way of coping that may work in the short run but may cause serious harm in the long run.

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- ▶ Trauma has an impact on the maturation of biological as well as psychological processes. It has been found repeatedly that traumatic exposure disrupts the maturing organism's development of self-regulatory processes, leading to chronic affect dysregulation, destructive behavior toward self and others, learning disabilities, dissociative problems, somatization, and distortions in concepts of self and others.



# Examples of Trauma

- Physical, emotional and/or sexual abuse in childhood or adulthood
- In Childhood
  - neglect or abandonment (food insufficiency, lack of money to met basic needs, homelessness)
  - death of a parent
  - divorce
  - family life that includes drug addiction, alcoholism, parental incarceration, violence
- Rape
- Serious medical illness or disease (disabling conditions, loss of function, invasive and distressing procedures)

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- 
- ▶ War, combat and civil unrest conditions including torture affecting soldiers and refugee civilians
  - ▶ Catastrophic losses of one's home, livelihood, people, pets due to flood, tornado, hurricane or other disasters of nature
  - ▶ Involved in or witnessing horrific events involving violence, gruesome accidents or death/serious injury

# What is the Adverse Childhood Experiences (ACE) Study?

Center for Disease Control and Kaiser Permanente (an HMO) Collaboration

Over a ten year study involving 17,000 people

Looked at effects of adverse childhood experience (trauma) over the lifespan

Largest study ever done on this subject



People enrolled in the Kaiser Permanente health plan were asked ten questions related to the following adverse childhood experiences....

- ▶ Physical, emotional and/or sexual abuse
- ▶ Neglect or abandonment
- ▶ Divorce
- ▶ Alcoholism or drug addiction in the family
- ▶ Family violence
- ▶ Poverty, homelessness, lack of food and basic needs
- ▶ Family member in prison
- ▶ Family member with mental illness

The 17,000 people who answered these questions were....

- 80% White, including Hispanic
- 10% Black
- 10% Asian
- > About 50% men, 50% women
- > 74% had attended college
- > 62% age 50 or older

# What They Found

## Of the 17,000 respondents

- ▶ 1 in 4 exposed to 2 categories of ACEs
- ▶ 1 in 16 was exposed to 4 categories.
- ▶ 22% were sexually abused as children.
- ▶ 66% of the women experienced abuse, violence or family strife in childhood.
- ▶ Women were 50% more likely than men to have experienced 5 or more ACEs

# Impact of Trauma Over the Lifespan

Are neurological, biological, psychological and social in nature. They include:

- ▶ Changes in brain neurobiology;
- ▶ Social, emotional & cognitive impairment;
- ▶ Adoption of health risk behaviors as coping mechanisms (eating disorders, smoking, substance abuse, self harm, sexual promiscuity, violence); and
- ▶ Severe and persistent behavioral health, health and social problems, early death.

*(Felitti et al, 1998)*

# Multiple trauma experiences raise the risk for.....

- ▶ Anxiety problems and fears
  - > Avoiding people, places and things that are similar to or reminders of the traumatic event(s)
- ▶ Physical health problems
- ▶ Sleep problems
- ▶ Emotional problems such as feeling numb and/or disconnected from oneself or environment
- ▶ Memory problems
- ▶ Flashbacks

## Multiple trauma experiences raise the risk for.....

- ▶ Alcoholism and alcohol abuse, substance use/abuse
- ▶ Obesity
- ▶ Respiratory difficulties
- ▶ Heart disease
- ▶ Multiple sexual partners
- ▶ Poor relationships with others
- ▶ Smoking
- ▶ Suicide attempts
- ▶ Unintended pregnancies

Trauma experienced in adulthood may also affect a persons emotional and physical well-being

- ▶ Combat related trauma
- ▶ Physical or sexual assault
- ▶ Witnessing or experiencing violence
- ▶ Catastrophic loss (natural disasters)
- ▶ Terrorism

Bottom line findings: These experiences raises the individuals risk for severe emotional distress, suicide, physical illness, substance abuse and a host of other life difficulties

# Trauma- and Stressor- Related Disorders (DSM-5)

- ▶ Reactive Attachment Disorder
- ▶ Disinhibited Social Engagement Disorder
- ▶ Posttraumatic Stress Disorder
- ▶ Posttraumatic Stress Disorder for Children 6 and under
- ▶ Acute Stress Disorders
- ▶ Adjustment Disorders

# PTSD

- ▶ Exposure to actual or threatened death or serious harm (direct, witnessing, learning of violent event for close family member/friend)
- ▶ Intrusive Symptoms
- ▶ Avoidance
- ▶ Alteration on cognition and mood
- ▶ Alterations in arousal and reactivity

# Intrusive Symptoms

## “reliving”

- ▶ Intrusive memories images, or perceptions;
- ▶ Recurring nightmares;
- ▶ Intrusive daydreams or flashbacks;
- ▶ Exaggerated emotional and physical reactions;
- ▶ Dissociative experiences (feeling disconnected from one's body and environment)

# Avoidance Symptoms

- Avoidance of memories, thoughts, and feelings
- Avoidance of external reminders – people, places, activities, objects

# Cognition and Mood

- ▶ Inability to remember event
- ▶ Negative beliefs about oneself or others - "I am bad", "no one can be trusted"
- ▶ Negative emotions – fear, anger, guilt, shame
- ▶ Difficulty experiencing positive emotions – happiness, satisfaction, love
- ▶ Reduced interest in activities
- ▶ Feelings of detachment from others

# Arousal and Reactivity

- ▶ Exaggerated startle response
- ▶ Irritability and angry outbursts
- ▶ Reckless behavior
- ▶ Being on guard much of the time/hypervigilant
- ▶ Insomnia and other sleep disturbances,
- ▶ Difficulties in concentrating

## PTSD in IDD:

- ▶ ***Intrusive Symptoms – Memories, flashbacks, dreams, physiological symptoms***  
***Reliving the experience***
  - ▶ In IDD, re-experiencing the traumatic event may manifest in symptoms that are more overtly behavioral (concrete) and may include self-injurious behavior and trauma-specific re-enactments. Re-enactments can look quite bizarre and it is important to distinguish such symptoms from psychotic disorder symptoms
- ▶ ***Avoidance and emotional numbing***
  - ▶ IDD, this can sometimes be seen or described as non-compliance
- ▶ ***Alteration in cognition and mood – negative beliefs about self or others, negative emotional state.***
  - ▶ In IDD, negative emotional state may present in externalizing behaviors.
- ▶ ***Alterations in arousal – hypervigilance, irritable behavior, exaggerated startle response, aggression.***
  - ▶ In IDD, aggressive behavior is often described as ‘coming out of nowhere’

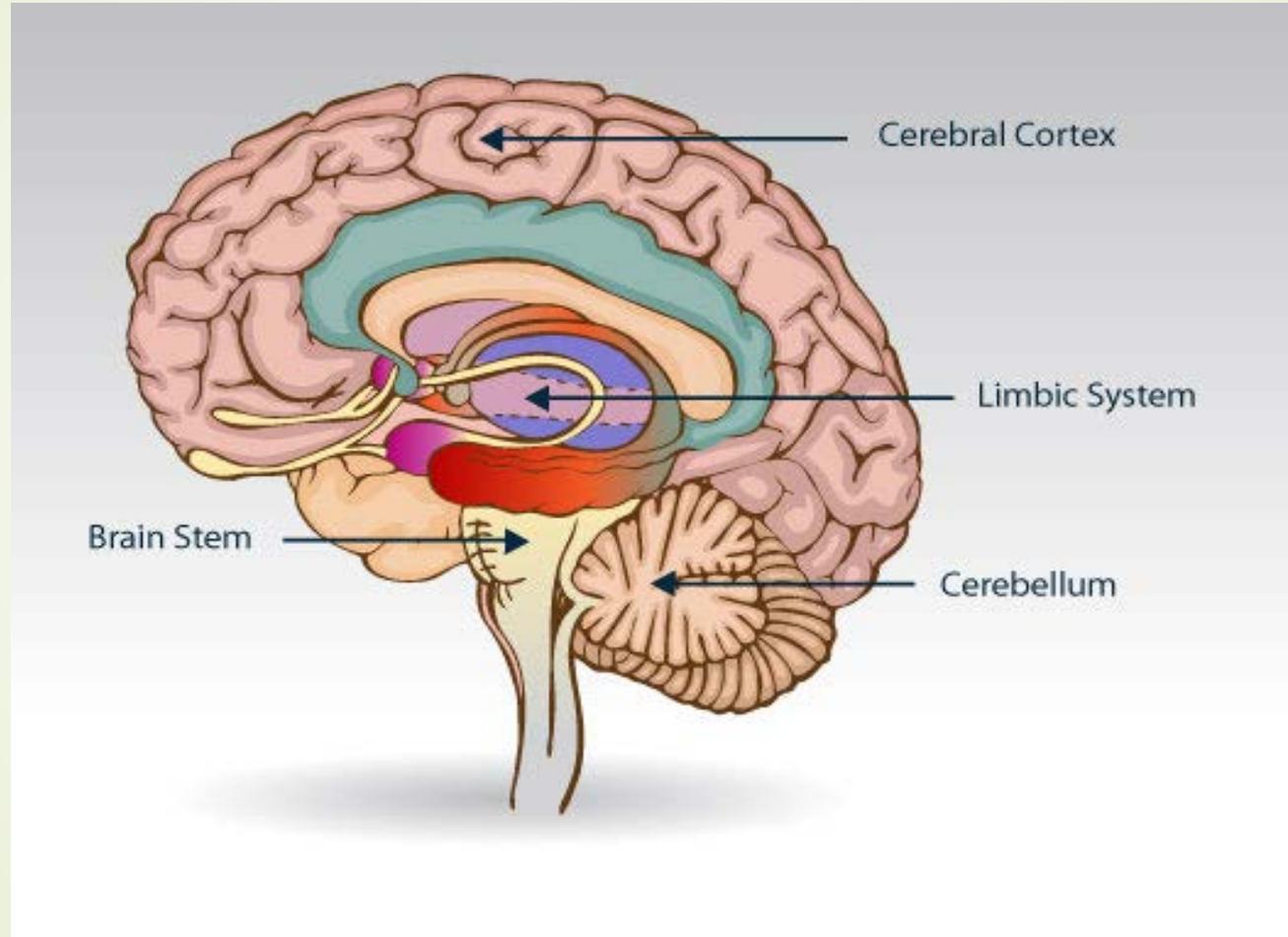
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- ▶ “We need to presume the clients we serve have a history of traumatic stress and exercise “universal precautions” by creating systems of care that are *trauma-informed*.” (Hodas, 2005)

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- ▶ 90% of public mental health clients in have been exposed to trauma
  - ▶ Estimated a rate of 83% of females with developmental disabilities and 32% of males have been sexually or physically abused
  - ▶ Up to two-thirds of men and women in SA treatment report childhood abuse & neglect (*SAMSHA CSAT, 2000*)
  - ▶ As many as one third of women and 14% of men are survivors of childhood sexual abuse



We don't know what kinds of experiences individuals have had when they present for services, so we need to approach them in a universally sensitive manner

- > If we assume that their presenting issues are not related to trauma, then we miss a great opportunity to help
- > If we assume trauma may be playing a role, then we begin to pay attention to signs of trauma and ask the right questions
- > The steps we take to create a safe and trusting environment benefits everyone



- 
- ▶ Brainstem – core regulatory functions such as body temperature, heart rate, respiration, blood pressure
  - ▶ Cerebellum – motor control and motor memory
  - ▶ Limbic System – emotional responses such as fear, hatred, love, joy
  - ▶ Cortex – complex human functions such as speech/language, abstract thinking, planning, decision making, rational thoughts

- 
- ▶ When we are calm, it is easy to live in our cortex, using the highest capacities of our brains to contemplate abstractions, make plans, dream of the future, read, make rational decisions. But if something intrudes on our thoughts, we become more vigilant and concrete, shifting the balance of our brain activity to subcortical areas to heighten our senses in order to detect threats.

- 
- ▶ As we move up the arousal continuum toward fear, then we necessarily rely on lower and faster brain regions. In complete panic, our responses are reflexive and under virtually no conscience control. Fear quite literally makes us dumber, a property that allows faster reactions in short periods of time and helps immediate survival. But fear can become maladaptive if it is sustained or intense; the threat system becomes sensitized to keep us in this state constantly.



# What does it mean to provide Trauma Informed Care?

A definition of trauma-informed approach incorporates three key elements:

- *Realizing* the prevalence of trauma
- *Recognizing* how trauma affects all individuals involved with the program, organization, or system, including its own workforce
- *Responding* by putting this knowledge into practice

A program, organization, or system that is trauma-informed realizes the widespread impact of trauma and understands potential paths for healing; recognizes the signs and symptoms of trauma in staff, clients, and others involved with the system; and responds by fully integrating knowledge about trauma into policies, procedures, practices, and settings.

(SAMHSA 2012) -

<http://www.samhsa.gov/traumajustice/traumadefinition/approach.aspx><sup>28</sup>



# Why



- ▶ To provide effective services we need to understand the life situations that may be contributing to the persons current problems
- ▶ Many current problems faced by the people we serve may be related to traumatic life experiences
- ▶ People who have experienced traumatic life events are often *very sensitive* to situations that remind them of the people, places or things involved in their traumatic event.
- ▶ These reminders, also known as triggers, may cause a person to relive the trauma and view our services as a source of distress and not as a healing and welcoming environment

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- ▶ Recognition of high prevalence of trauma
  - ▶ Recognition of primary and co-occurring trauma diagnoses
  - ▶ Assess for traumatic histories & symptoms
  - ▶ Recognition of culture and practices that are re-traumatizing

## TRAUMA-INFORMED

- ▶ Lack of education on trauma prevalence & “universal” precautions
- ▶ Over-diagnosis of Schizophrenia & Bipolar D., Conduct D. & singular addictions
- ▶ cursory or no trauma assessment
- ▶ “Tradition of Toughness” valued as best care approach

## NON TRAUMA INFORMED



## TRAUMA INFORMED

- ▶ Power/control minimized - constant attention to culture
- ▶ Caregivers/supporters – *collaboration*
- ▶ Address training needs of staff to improve knowledge & sensitivity

## NON TRAUMA INFORMED

- ▶ Keys, security uniforms, staff demeanor, tone of voice
- ▶ Rule enforcers – compliance
- ▶ “Patient-blaming” as *fallback* position without training



## TRAUMA INFORMED

- ▶ Staff understand function of behavior (rage, repetition-compulsion, self-injury)
- ▶ Objective, neutral language
- ▶ Transparent systems open to outside parties

## NON TRAUMA INFORMED

- ▶ Behavior seen as intentionally provocative
- ▶ Labeling language: manipulative, needy, "attention-seeking"
- ▶ Closed system – advocates discouraged

- 
- ▶ The question changes from

“what is wrong with you?”

to

“What happened to you?”



# What does all this mean for people with IDD?

- ▶ Many people experience trauma. People with developmental disabilities are at greater risk for being victimized or abused.
  - ▶ They are also more likely to have “everyday” stresses or losses that build up and become traumatic.
  - ▶ They are more vulnerable to trauma so incidence of PTSD is higher
  - ▶ We see the effects of trauma in the people with IDD we support
- 

## Trauma in IDD

- Individuals with IDD are more likely to experience traumatic events
- Individuals with disabilities are 2-10 times more likely to be sexually abused
- More likely to experience negative life events, such as serious illness or injury
- Life losses may result in complicated or traumatic grief

## Factors that Contribute to Risk

- ▶ People with IDD are:
  - ▶ Trained to be compliant
  - ▶ Dependent on caregivers for longer; often have multiple caregivers
  - ▶ Isolated from resources to report
  - ▶ Sometimes impaired in ability to communicate
  - ▶ Sometimes impaired in mobility
  - ▶ Often not provided with general sex education

- ▶ People with IDD may also experience:
  - ▶ Cognitive and processing delays that interfere with understanding what is happening in abusive situations
  - ▶ Feelings of isolation and withdrawal which may make them more vulnerable to manipulation

## Predisposing Factors In Exposure to Trauma & PTSD

Breslau, et al.

- ▶ Predisposing factors are more significant in the development of PTSD than the type of trauma
- ▶ IQ influences the likelihood both of exposure to traumatic events, and the development of PTSD if exposed
- ▶ Children with IQ above 115 had significantly less exposure to traumatic events and were significantly less likely to develop PTSD following exposure

## Traumatic Events vs. Negative Life Events

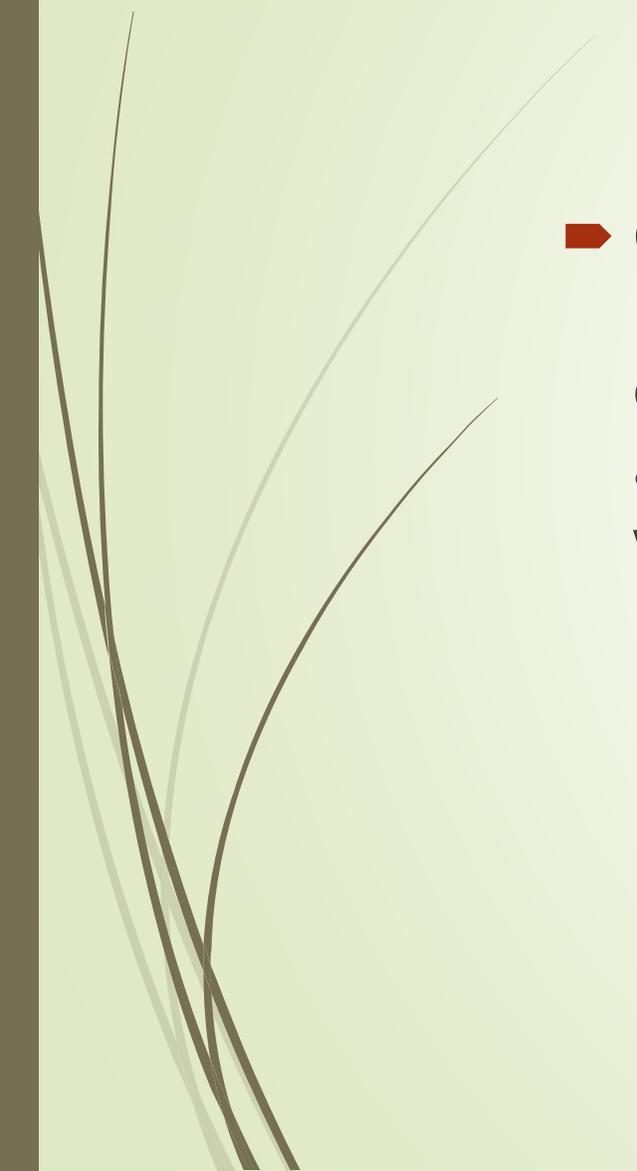
- ▶ NLE: bereavement, moves, illness, injury, serious interpersonal difficulties (Big T vs. Little T)
- ▶ Children with ID report more NLEs than non-ID
- ▶ NLEs have been determined to be significantly related to a broad range of psychopathology

## Effects of Trauma

- ▶ The effect of trauma is increased for people with IDD due to:
  - ▶ A predisposition toward emotional problems and impaired resiliency
  - ▶ A belief that people with IDD cannot benefit from therapy
  - ▶ A lack of trained professionals who are comfortable working with IDD in processing traumatic experiences



# “Fight, Flight, or Freeze” moments

- ▶ Once triggered, the limbic system may ‘hijack’ the brain. Initiating the stress response results in hypo-arousal, or dissociation. Or, an individual may go into hyper-arousal, and become frantic or aggressive. These responses are what we usually associate with “fight or flight”.
- 



# Trauma and Sensory Processing

- ▶ The first stops for primary sensory input are the lower regions of the brain – e.g. brainstem – which are incapable of conscious perceptions.
- ▶ If sensations are perceived as a threat (because of past experiences), it allows the individual to respond in a reflexive fashion.
- ▶ So..
  - asking someone to interpret a sensation (hand on shoulder) as neutral, when it is coded into the lower brain as a threat is like asking you to think through whether or not you should remove your finger from a hot stove burner before you move your hand.



# Bruce Perry

- ▶ Persistent trauma leads to a “dysregulated” brain stem – which manifests with symptoms such as impaired cardiovascular regulation, extreme affective lability, and poor impulse control.
  - ▶ People who are aroused from fear cannot take in cognitive information. They are too busy watching for threatening gestures, and not able to listen to what is being said.
- 



# “the state becomes a trait”

- ▶ Rather than recognizing a fear-based brain state, or attempt to manage or prevent fear, a person may be diagnosed incorrectly with:
  - ▶ Obsessive Compulsive Disorder
  - ▶ Psychotic Disorder
  - ▶ Bipolar Disorder
  - ▶ Borderline Personality Disorder
  - ▶ Intermittent Explosive Disorder
  - ▶ Oppositional Defiant Disorder
  - ▶ Disruptive Behavior Disorder



## The good news...

- ▶ Our brains grow and change all our lives. The brain can build new connections for feeling safe and avoid over-reacting. When we see the *search for safety* in behavior, how can we use it to promote healing?
- ▶ “no one ever got healed by a token economy”

# What does not help?

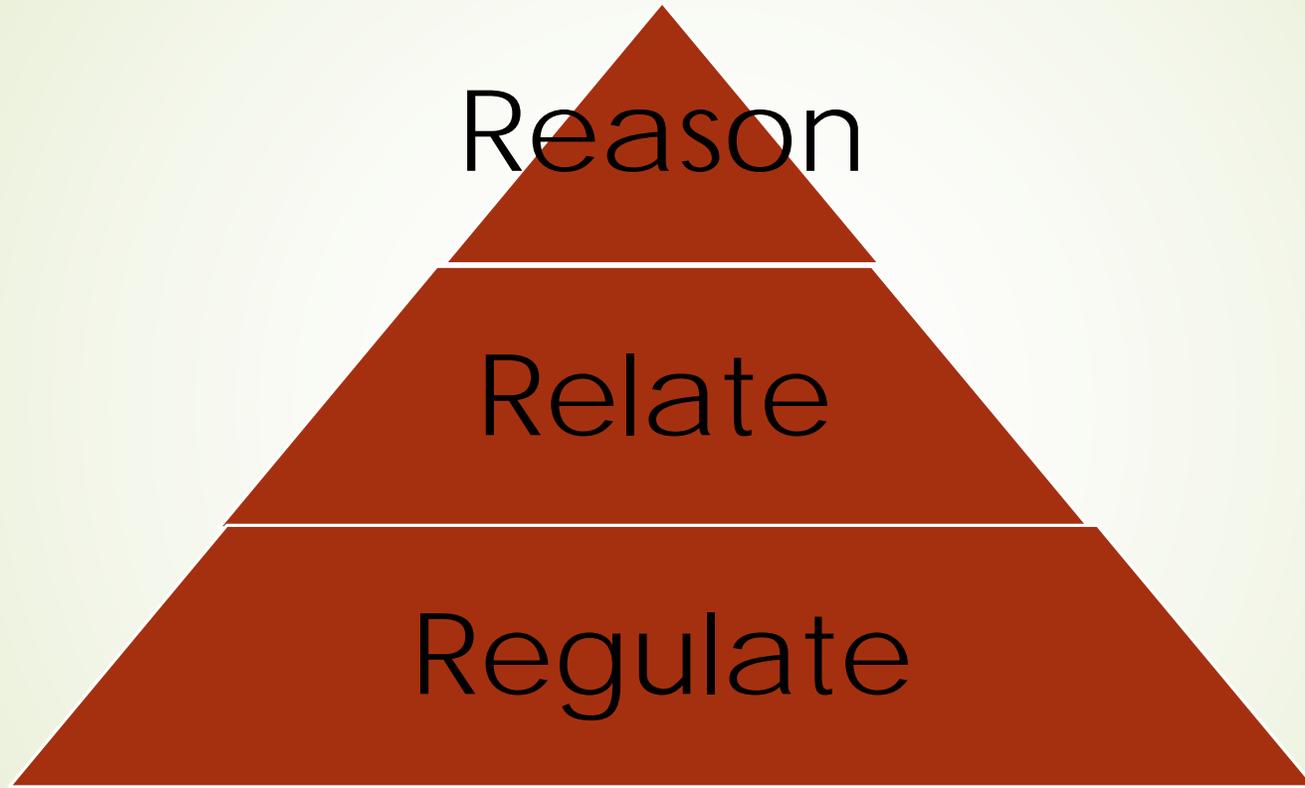
- ▶ Assuming behavior is an attempt to gain a specific outcome or manipulate
- ▶ Assuming the person has control over behavior in a crisis situation
- ▶ Oversimplified focus on contingencies
- ▶ Restriction or control (fuels feelings of powerlessness and may increase agitation)

# Positive Supports and Positive Psychology

- ▶ Focus on increasing happiness
  - ▶ Engagement and attachment
  - ▶ Developmentally appropriate expectation
  - ▶ Enhancing relationships
- ▶ Replacement skills
  - ▶ Functional communication
  - ▶ Ability to label feelings, calming skills
- ▶ Positive identity
  - ▶ Focus on strengths

# Increase Safety and Comfort

- Learn trauma triggers
- Planning to increase feelings of safety
- Real choices to reduce sense of powerlessness



Reason

Relate

Regulate



# Core Elements of Positive Therapeutic Experiences (6 R's)

- Relational – safe
  - Relevant – developmentally appropriate
  - Repetitive – patterned, predictable
  - Rewarding – pleasurable and positive
  - Rhythmic – resonant with neural patterns
  - Respectful – of individual, family, culture
- 



# Sensory Diets

- ▶ Sensory assessment can identify sensory problems and recommend a sensory diet:

Deep breathing

Foods to chomp

Full-spectrum lighting

Earplugs or headphones

Essential oils

Deep pressure

Yoga

Movement protocols



# Move the Activity of the Brain

- ▶ You want to move from brainstem, to limbic, to the cortex.
- ▶ Help them feel safe first
- ▶ Then try a thinking task like sorting cards (by color, by number, etc)
- ▶ The better the emotional associations with you or the materials, the quicker the task will help clear away the stress response



# What is calming?

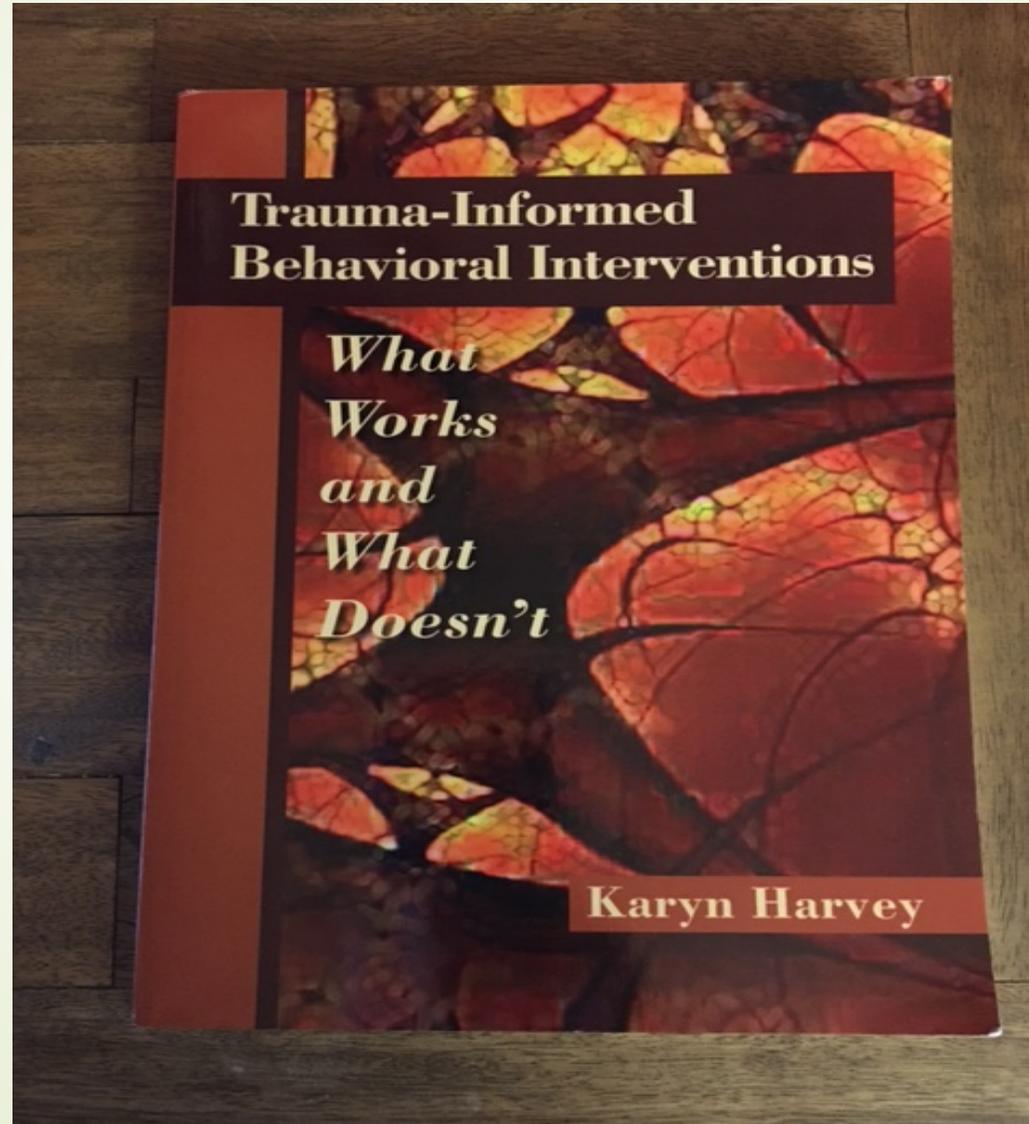
- Rhythmic moving (walking, drumming, rocking)
- Repetitive movement of hands (dribbling basketball, running hands through sand or beans)
- Sensation on hands (warm blanket, stuffed animal)
- Soothing smells
- Firm pressure
- Nature (walking barefoot on grass, smelling flowers)

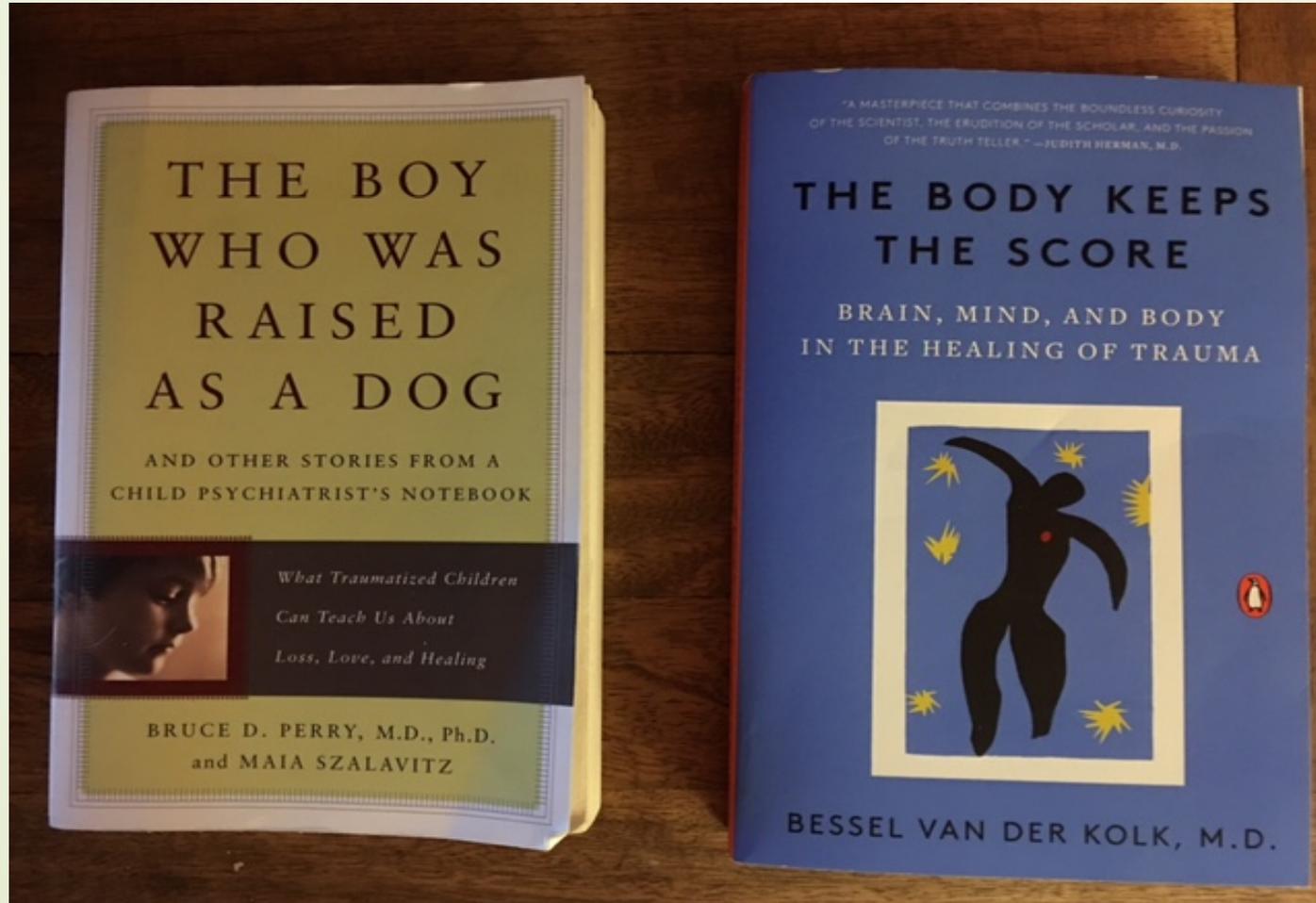


# Individual therapy?

Can be effective with people with IDD

- ▶ Emerging practices
  - ▶ EMDR
  - ▶ Brain-body intervention ( yoga, movement, dance, drumming, singing)
  - ▶ Modified DBT
  - ▶ Sensory diets







➤ Present

➤ Parallel

➤ Patient