

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

*A Training Toolkit*

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# Goal:

- ❖ Understand that children with intellectual/developmental disabilities (IDD) experience mental health conditions.
- ❖ Understand the various ways that children with IDD experience trauma.
- ❖ Understand the impact of trauma on children with IDD.
- ❖ Understand the importance of trauma-informed care for children with IDD.
- ❖ Understand how the toolkit can be used to improve provider/caregiver capacity for provision of trauma-informed care for children with IDD.

# Why is this important to children with IDD and those supporting them?

- ❖ High rates of abuse and neglect including physical, sexual and emotional
- ❖ High rates of bullying
- ❖ Victims of violent crimes
- ❖ Family stress can turn into family violence
- ❖ Institutionalization
- ❖ Abandonment and isolation
- ❖ Restraint and seclusion

# What mental health conditions do people with IDD experience?

The same mental health conditions as anyone else including depression, schizophrenia, bi-polar, anxiety, compulsive disorders, post-traumatic stress, and other serious emotional disturbances.

# What are we doing now?

- ❖ We typically attribute “challenging behaviors” to the disability.
- ❖ We try to manage behaviors often through some type of authority/control/compliance model.
- ❖ We focus on challenging behaviors and crisis intervention instead of the mental health and wellness of people with IDD.

***Why is it that when your IQ is over 75 you have a “mental health condition” that need assessment and treatment, but if your IQ is low you have “behaviors” that need managing?***

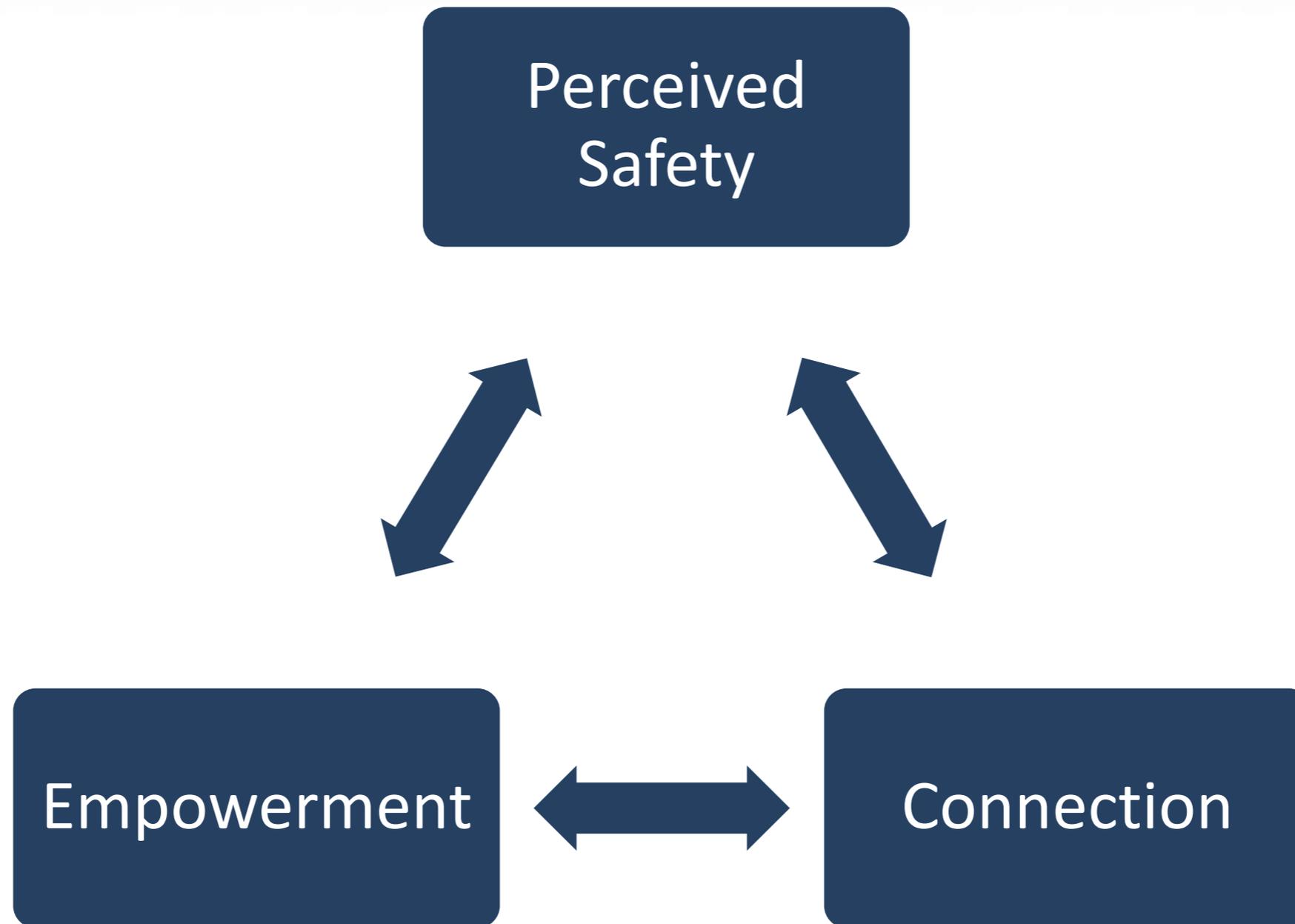
# Focus on recovery

- ❖ Develop a recovery focused approach to care for people with co-occurring IDD and mental health conditions. We know that people living with mental illness can recover.
- ❖ The Substance Abuse and Mental Health Services Administration (SAMSHA) defines recovery as “A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.”
- ❖ The mental health system in many states is recovery-based. However, the principles of recovery have not been incorporated into systems of care for people with IDD.

<http://www.samhsa.gov/newsroom/advisories/1112223420.aspx>

# Ingredients Necessary for Recovery

(K. Harvey)



75  
YEARS



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

NCTSN



The National Child  
Traumatic Stress Network

# Barriers to Recovery

- ❖ Historic behavior management models rarely offer the opportunity for a sense of safety, meaningful relationships, or empowerment.
- ❖ Instead, we focus on behaviors that we assume are the result of the disability (overshadowing).
- ❖ We try to alleviate the maladaptive behaviors instead of trying to treat underlying mental illness or trauma.
- ❖ We continue to focus on “what’s wrong” with the individual instead of asking “what happened to you” and, “how did what happened to you affect you?”

# What about trauma?

## What is a traumatic event?

- ❖ Trauma comes in many forms. Traumatic experiences can include: abuse and/or neglect, witnessing violence, abandonment or the loss of a loved one, traumatic grief, bullying, a traumatic event such as a natural disaster or car accident, painful medical treatment, school violence and more.
- ❖ Trauma can be cumulative with the impact building or can be episodic. Exposure to trauma often impacts development.
- ❖ Trauma can change an individual's sense of safety and how they perceive the actions of others – even those trying to help them.
- ❖ Trauma impacts development and mental wellness.

# Impact of trauma exposure on children (National Child Traumatic Stress Network)

- ❖ The world is uncertain and unpredictable; creates problems with boundaries and distrust; can cause social isolation.
- ❖ Increases stress hormones changing the brain chemistry. Can cause hypersensitivity to physical touch. May cause unexplained physical health problems.
- ❖ Causes difficulty in regulating emotions, difficulty in describing feelings, wishes and desires to others.
- ❖ Creates feelings of detachment, withdrawal, amnesia-like state.
- ❖ Causes poor impulse control, self-destructive behavior, aggression, sleep disorders and eating disorders.
- ❖ Causes problems with focusing and completing tasks, difficulty with planning, learning difficulties and language development.
- ❖ Low self-esteem, shame, and guilt.

# The science of trauma

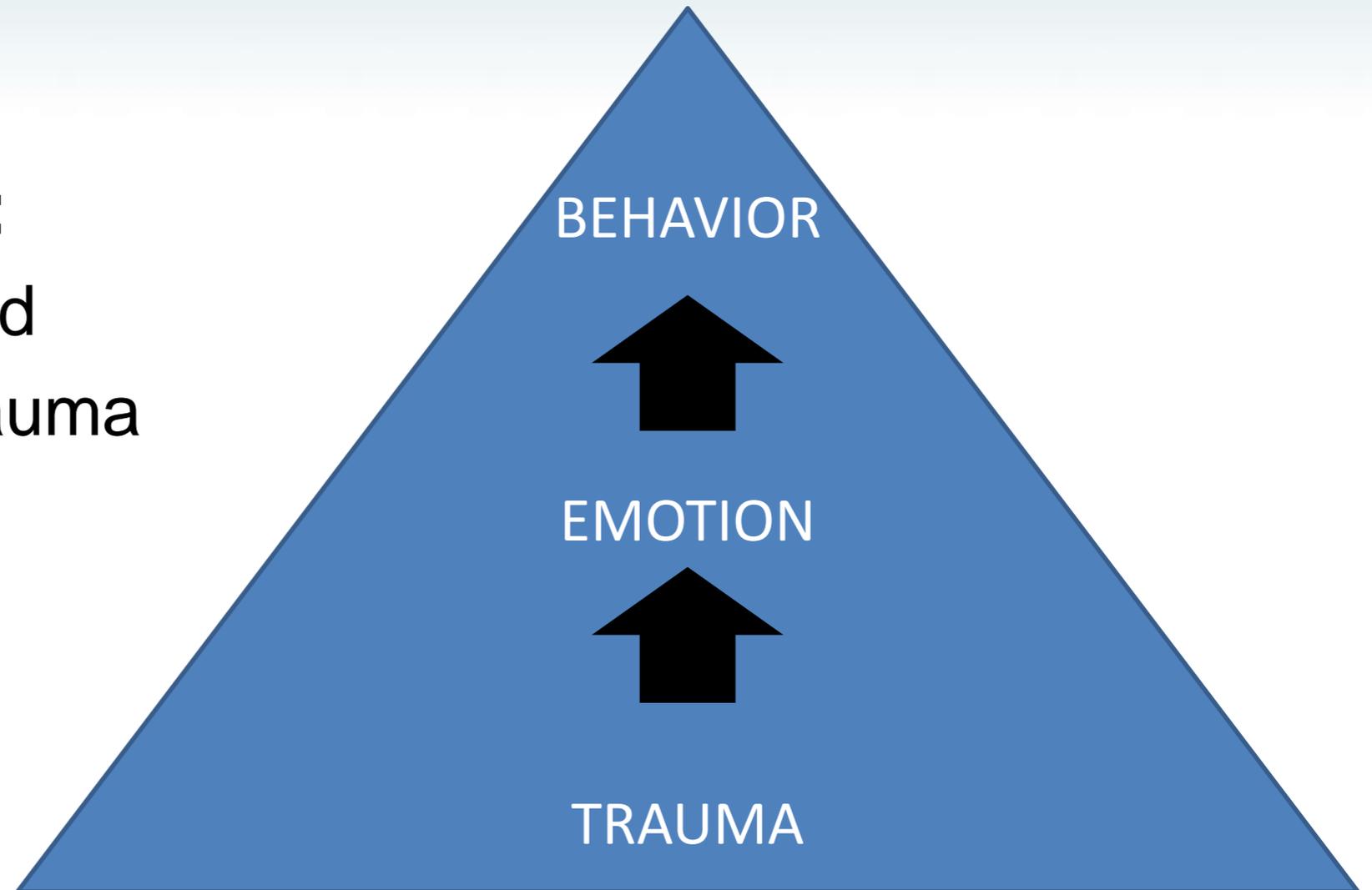
- ❖ When trauma occurs or past traumas are triggered, the brain reverts to its reptilian stage of survival.
  - ❖ Fight
  - ❖ Flight
  - ❖ Freeze
- ❖ Person perceives that he/she is in danger.
- ❖ Rational mind shuts down and reverts to survival mode.

***This is not a teachable moment!***

# The Behavioral Pyramid (K. Harvey)

## Behavioral Issues:

- Emotions Expressed
- Often Rooted in Trauma



When we only address the behavior, we miss the true cause and root of difficulties. (K. Harvey)

# Challenges in assessing, diagnosing and treating mental illness in people with IDD

- ❖ Overshadowing
- ❖ Communication challenges
- ❖ Lack of expertise in both the mental health field and in the IDD field
- ❖ Extended time it takes to assess (requires talking to more than just the patient; must interview critical caregivers, family, etc.)
- ❖ Professional biases – belief that evidence-based mental health treatments don't work on this population

# Challenges (continued)

- ❖ Mental health workforce shortage – especially expertise with people with IDD.
- ❖ Lack of cross-agency coordination
- ❖ Treating the behavior instead of the underlying mental health or medical condition; ease of using medication
- ❖ Failure to address the impact of past trauma
- ❖ Lack of consideration of people with IDD in state mental health policy

*People with IDD deserve the same state-of-the-art mental health treatment as everyone else.*

# What is trauma-informed care?

- ❖ Recognizes the impact of trauma on an individual's development, behavior, mental and physical well-being.
- ❖ Recognizes the need for people to feel safe.
- ❖ Recognizes the impact of trauma on the caregivers.
- ❖ Often requires a re-direction of our thinking.

***Now available! Training Toolkit for Trauma-Informed Care for Children with Intellectual/Developmental Disabilities developed by the National Child Traumatic Stress Network and the Hogg Foundation for Mental Health.***



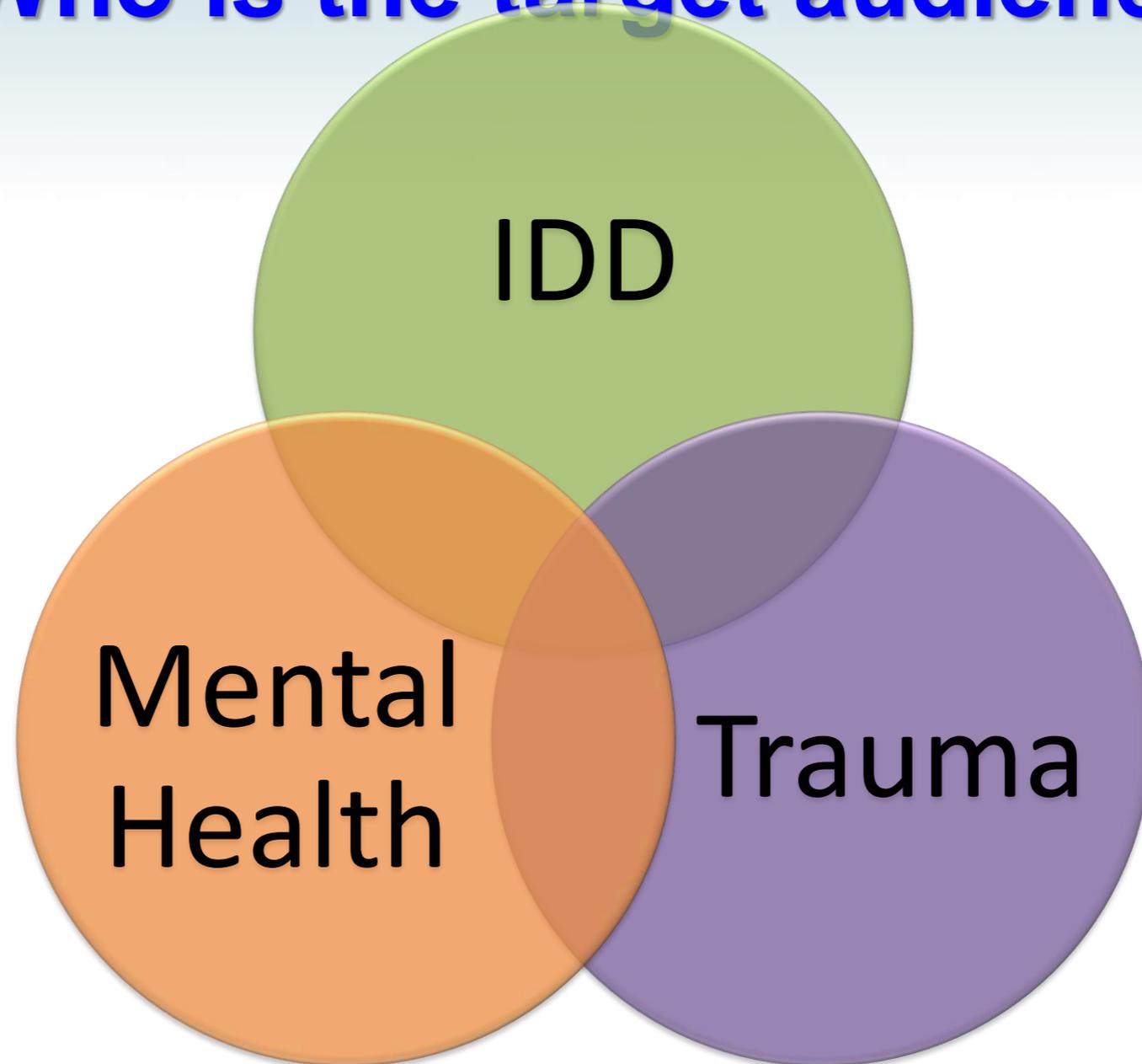
# The Road to Recovery: Supporting Children with IDD Who Have Experienced Trauma

# Components of the Toolkit



- ❖ About this Toolkit
- ❖ Facilitator Guide
  - ❖ Videos
- ❖ Participant Manual
  - ❖ Case Vignettes
  - ❖ Board Game/Activities
- ❖ Slide Kit
- ❖ Supplemental Materials

# Who is the target audience?



- ❖ Meridian Health Services in Muncie & Mishawaka, Indiana in June 2015
- ❖ Hogg Foundation for Mental Health in Austin, Texas in July 2015
- ❖ Depelchin Children's Services in Houston, Texas in July 2015
- ❖ Train-the-trainer in Redondo Beach, CA in August 2015

***Module One: Setting the Stage***

**Module Two: Development, IDD & Trauma**

**Module Three: Traumatic Stress Responses in Children with IDD**

**Module Four: Child & Family Well-Being & Resilience**

**Module Five: IDD- & Trauma-Informed Services & Treatment**

**Module Six: Provider Self-Care**



**75**  
YEARS



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

**NCTSN**

The National Child  
Traumatic Stress Network

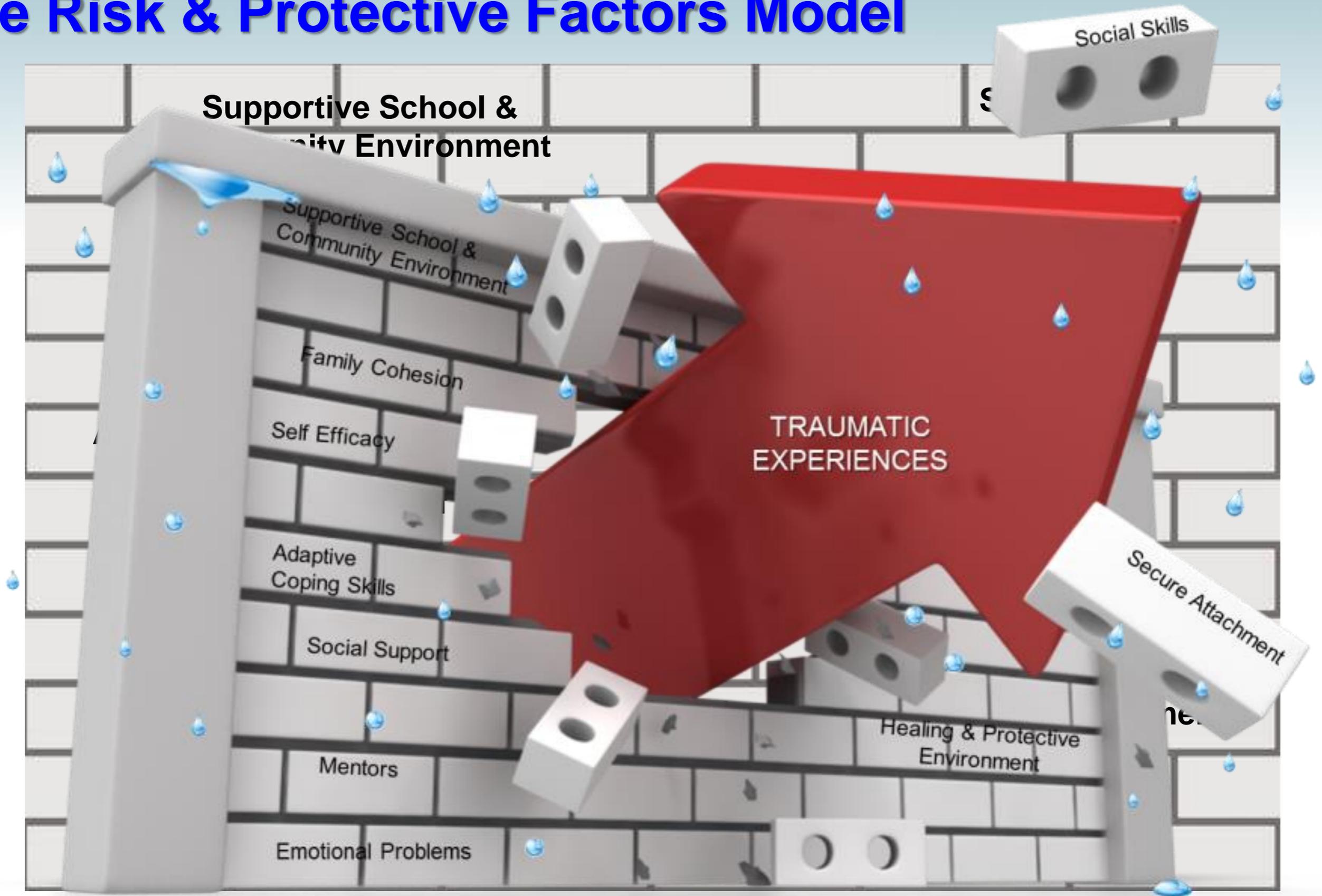
# Module One: Learning Objectives

## What Will I Learn Today?



1. Recognize that children with IDD are at-risk for traumatic experiences.
2. Articulate that recovery from traumatic experiences is possible.
3. Establish the important role of parents/caregivers and families on the road to recovery.
4. Describe frameworks that will be used to highlight key concepts throughout the training.

# The Risk & Protective Factors Model

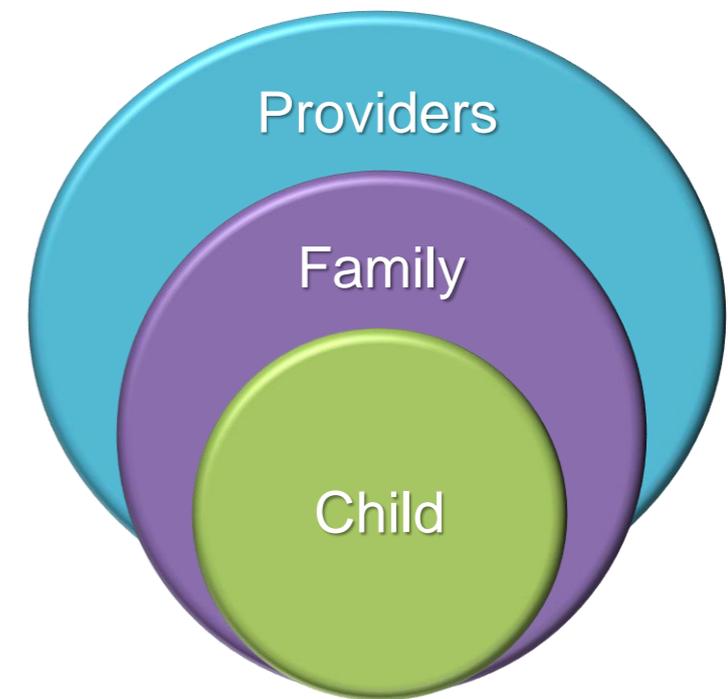


# Essential Messages of Working with Children with IDD who have Experienced Trauma

- ❖ Know that there's hope; recovery from traumatic experiences is possible.
- ❖ Recognize that a child with IDD may have had a traumatic experience(s), which can have profound effects.

# What Can a Provider Do?

- ❖ Create a learning climate/culture—honor the child's, parent's and provider's experience.
- ❖ Identify any fears or biases I have about working with children with IDD who have had traumatic experiences.
- ❖ Identify ways to increase my knowledge & skills.



Module One: Setting the Stage

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Module Six: Provider Self-Care



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# Module Two: Learning Objectives

## What Will I Learn Today?



1. Define IDD and various types of disabilities.
2. Discuss developmental tasks across typical development.
3. Describe how IDD and traumatic experiences may disrupt typical development.
4. Identify the areas in which children's functioning is affected by IDD & subsequent adaptations that must be made.

# Introducing...

- ❖ Ivana is an 18-month-old infant who was adopted at birth from Russia.
- ❖ Suzie is a 4-year-old living with her family in San Francisco.
- ❖ Joshua is a 6-year-old living with his family on the Upper West Side of Manhattan.
- ❖ Steven is a 10-year-old living with his family at Camp Pendleton in San Diego.
- ❖ Jacqueline is a 16-year-old who lives with her grandmother in Laredo, Texas.
- ❖ Justin is a 19-year-old living with his adoptive parents in Detroit.



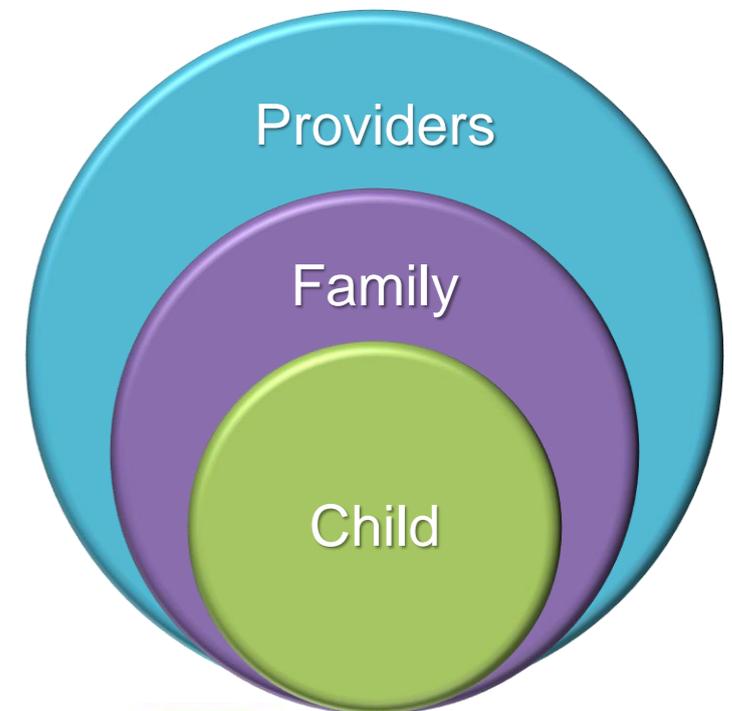


# Essential Messages

3. Recognize a child's developmental level and how IDD and traumatic experiences are affecting his/her functioning.
4. Utilize a developmental lens when making meaning of a child's traumatic experiences & responses.

# What Can a Provider Do?

- ❖ Ask questions and gather information (formally or informally) to understand the child's developmental age & how IDD is affecting his/her functioning.
- ❖ Identify IDD-related support needs of children & families.
- ❖ Identify how living with IDD is affecting the quality of the child's life.



Module One: Setting the Stage

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# Module Three: Learning Objectives

## What Will I Learn Today?



1. Define child traumatic stress and PTSD.
2. Describe the 12 Core Concepts for understanding traumatic stress responses in children and families.
3. Identify how traumatic experiences and their responses affect children with IDD.

# What is Child Traumatic Stress?

Personally experiencing or witnessing a real or perceived threat to emotional/physical well-being

Intensity & seriousness of the experience registers in child's body & mind

Reactions that persist and interfere with the ability to function even after the traumatic events have ended

Ongoing pattern of symptoms may be diagnosed as PTSD

*Not every child who experiences a traumatic event will develop symptoms of child traumatic stress.*

# Types of Traumatic Experiences

- ❖ Single traumatic experience (*e.g., serious car accident, disasters*)
- ❖ Experiences that occur together (*e.g., domestic violence & physical abuse*)
- ❖ Experiences that can extend over time (*e.g., sexual abuse*)
- ❖ Experiences that are a mixture of the above



# Core Concept 1: Complexity

*“There’s a lot going on in the child’s mind and body.”*



## For a family & child with IDD

Moment-to-moment reactions can be even more complex due to physical, cognitive or communicative limitations that impact the range of protective actions that were possible during the traumatic experience.

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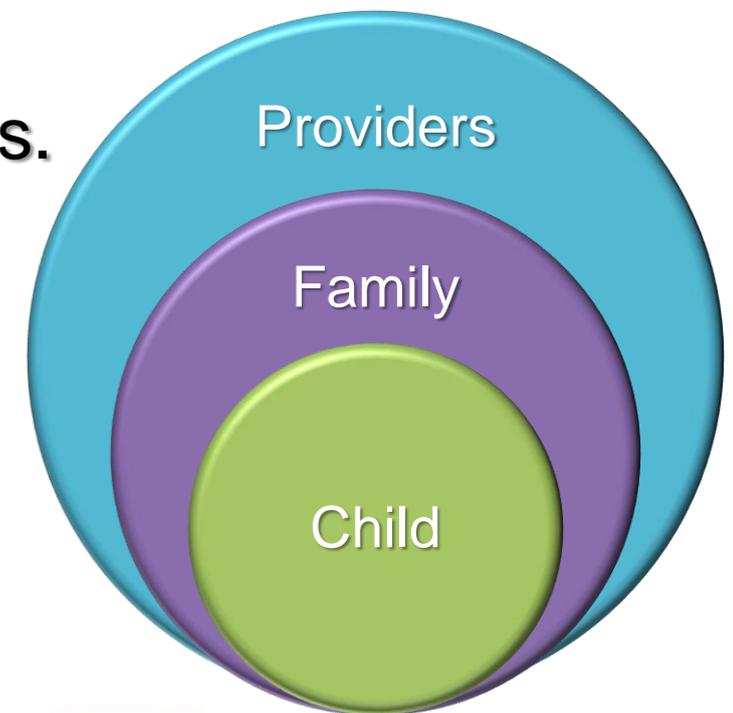


## Essential Message

5. Recognize that in the aftermath of trauma, understanding traumatic stress responses is the first step in helping children regain their sense of safety, value and quality of life.

# What Can a Provider Do?

- ❖ Learn about a child's moment-to-moment reactions during a traumatic event.
- ❖ Learn about the child-intrinsic and child-extrinsic factors that comprise the ecology within which the trauma occurred.
- ❖ Ask about trauma reminders.
- ❖ Ask children and parents how their perceptions of danger and safety may have changed following the traumatic experience.
- ❖ Explore how the cultural background of the child and family may be influencing responses to the traumatic experience.
- ❖ Ask if the child/family are involved with social institutions.



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# Module Four: Learning Objectives

## What Will I Learn Today?



1. Explore the impact on parents/caregivers of learning about their child's traumatic experience.
2. Explain strategies for strengthening protective factors to enhance child and family well-being, resilience and recovery.
3. Describe frameworks for promoting a healing and protective environment in order to create a safe and meaningful life for children.
4. Identify family-informed, child-centered planning techniques to help children realize their hopes and dreams.

# Putting It Into Practice



Adapted from: *The Life Course Game* that was created and developed by CityMatCH.

<http://www.citymatch.org:8080/lifecourse/toolbox/gameboard.php>



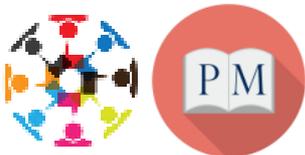
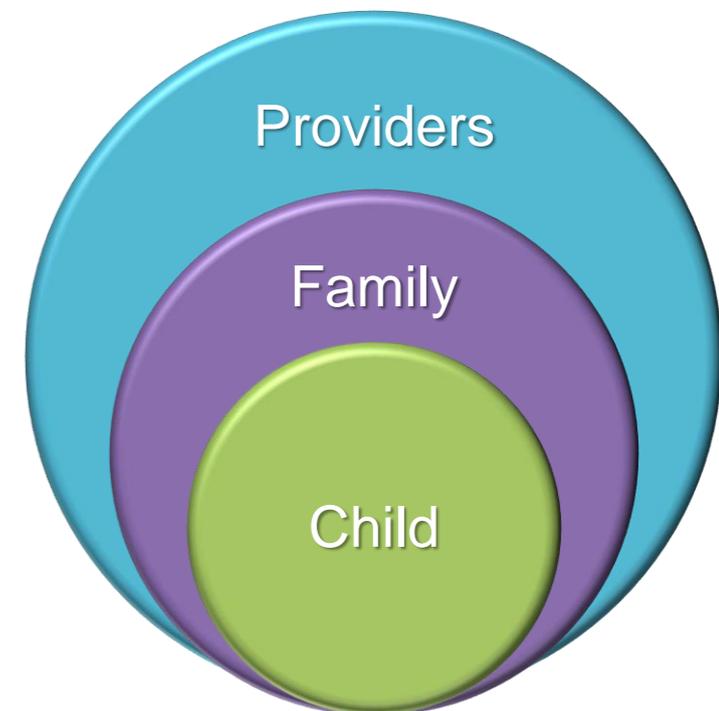


# Essential Messages

6. Utilize an IDD- & trauma-informed child-centered approach to support both the child & the family.
7. Help parents/caregivers, and other professionals in the child's life, strengthen protective factors.

# What Can a Provider Do?

- ❖ Identify and enhance family strengths and natural supports.
- ❖ Ask about siblings.
- ❖ Take the time to listen to parents/caregivers and ask them what about their questions, concerns & challenges.
- ❖ Provide practical tools for promoting a secure attachment and a healing & protective environment.
- ❖ Provide anticipatory guidance.
- ❖ Help parents/caregivers access support.
- ❖ Help parents find access to respite care.



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# Module Five: Learning Objectives

## What Will I Learn Today?



- 1. Explain how to enhance protective factors of children with IDD & families through appropriate trauma-informed services & treatment.
- 2. Discuss how to utilize adapted screening, assessment & planning tools to identify IDD- & trauma-informed needs of children & families.
- 3. Discuss strategies for adapting the core components of trauma-informed treatments for children with IDD.
- 4. Identify strategies for partnering with agencies & cross-system collaboration.

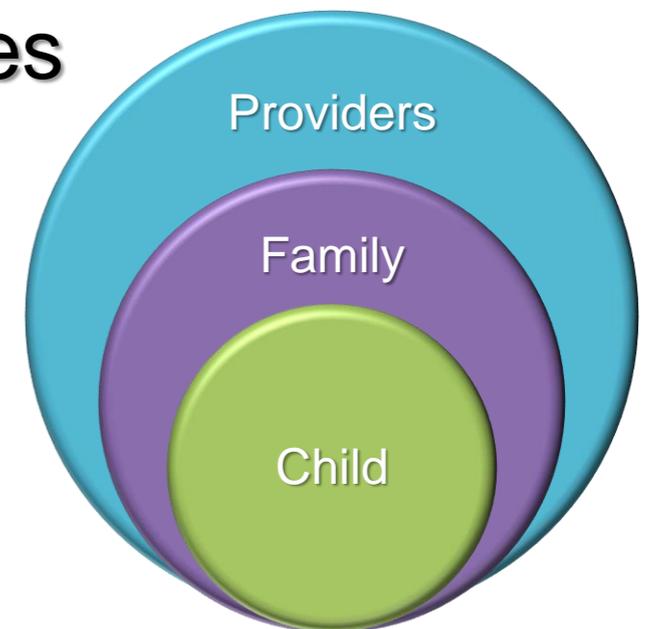


## Essential Messages

8. Partner with agencies and systems to ensure earlier and more sustained access to services.
9. Ensure that trauma-informed child-centered services, treatments and systems drive the recovery plan.

# What Can a Provider Do?

- ❖ Identify the developmental level of the child in order to guide appropriate selection of trauma screening/assessment tools, services & treatments.
- ❖ Coordinate continuous care through communication with therapists and other providers on a regular basis.
- ❖ Participate in cross-training with other agencies and systems on issues related to child trauma and trauma-informed care.
- ❖ Identify and interview local individuals/agencies



**Module One: Setting the Stage**

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*Module Six: Provider Self-Care*



# Module Six: Learning Objectives

## What Will I Learn Today?



1. Describe the difference between secondary traumatic stress, burnout and vicarious trauma.
2. Identify how burnout develops among providers.
3. Discuss potential sources, warning signs, and effects of secondary traumatic stress and organizational stress.
4. Implement steps to stress reduction and self-care.

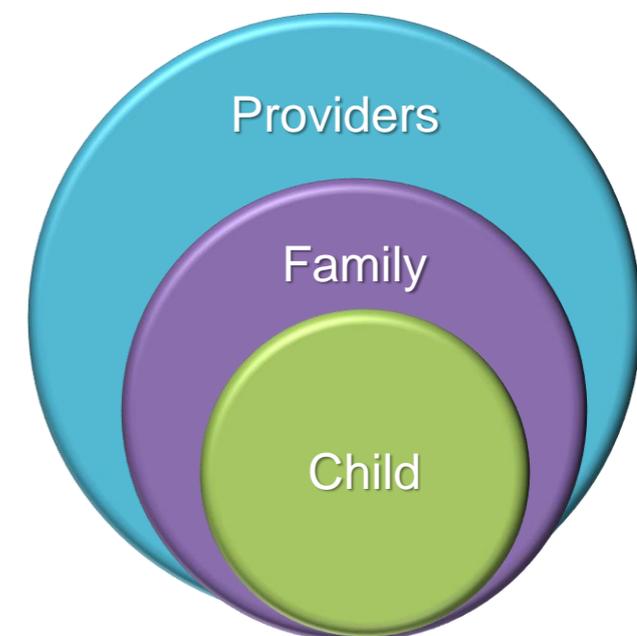


# Essential Message

10. Practice ongoing self-care in order to increase effectiveness in delivering high quality support, services and treatment.

# What Can a Provider Do?

- ❖ Identify potential sources, warning signs and effects of STS and organizational stress.
- ❖ Identify strategies for stress reduction.
- ❖ Practice the ABC's of self-care.
- ❖ Identify wellness activities that could be provided in your organization.
- ❖ Identify self-care resources that you'd like to explore further.



# The Road to Recovery Toolkit: Available on the NCTSN Learning Center

- ❖ Includes
  - ❖ Facilitator Guide
  - ❖ PPT Slides
  - ❖ NCTSN videos
  - ❖ Board Game files
  - ❖ Sample agenda
  - ❖ Pre-Training and Follow-Up Evaluations (PDF versions) & links to online Qualtrics versions
- ❖ Designed to promote communication between a community of facilitators where information & training events can be shared
- ❖ Identify strategies for stress reduction.
- ❖ Practice the ABC's of self-care.
- ❖ Identify wellness activities that could be provided in your organization.
- ❖ Identify self-care resources that you'd like to explore further.

# What's Next?

- ❖ Make trauma-informed care for children with IDD a national conversation
- ❖ Find ways in your state to get the training started.
- ❖ Change the culture of care for kids with IDD – it's not just about controlling behaviors.

# What do *WE* need to do?

- ❖ Question current behavior management practices.
- ❖ Ask more questions of professionals, i.e., “have you considered depression, anxiety or trauma?” Force providers and caregivers to consider the possibility of underlying mental health or medical conditions.
- ❖ Stop looking for “what’s wrong” with people and start asking “what has happened to them.”
- ❖ Move from a culture of control and compliance to one of respect and support.
- ❖ Look at current behavior management practices to determine if trauma is being exacerbated.

# What else?

- ❖ Demand trauma-informed care training for IDD and mental health professionals.
- ❖ Demand trauma-informed care and other evidence-based mental health treatment and practices including early identification and treatment.
- ❖ Start asking different questions – force others to think about the mental health of individuals with IDD.
- ❖ Don't settle for the status quo.
- ❖ Request better assessments.
- ❖ Demand better treatment.

# Additional Resources

- ❖ **National Child Traumatic Stress Network** – *The Road to Recovery: Supporting Children with Intellectual and Developmental Disabilities Who Have Experienced Trauma; Child Welfare Trauma Training Toolkit; Trauma Training Toolkit for Workers in the Juvenile Justice System*, and much, much more. [www.NCTSN.org](http://www.NCTSN.org)
- ❖ **Karyn Harvey, Ph.D.** -- *Positive Identity Development: An Alternative Treatment Approach for Individuals with Mild and Moderate Intellectual Disabilities; and, Trauma-Informed Behavioral Interventions: What Works and What Doesn't*
- ❖ **NADD** – National Association of People with Developmental Disabilities and Mental Health Challenges, [www.nadd.org](http://www.nadd.org)
- ❖ **Center for Disease Control and Prevention**  
*Adverse Childhood Experiences (ACE) Study*  
<http://www.cdc.gov/ace/index.htm>

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