

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 RESILIENCE IN TRAIL

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

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Self Care Alert!

- Step out and take a break.
- Talk to someone you trust.
- Do something relaxing.

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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.

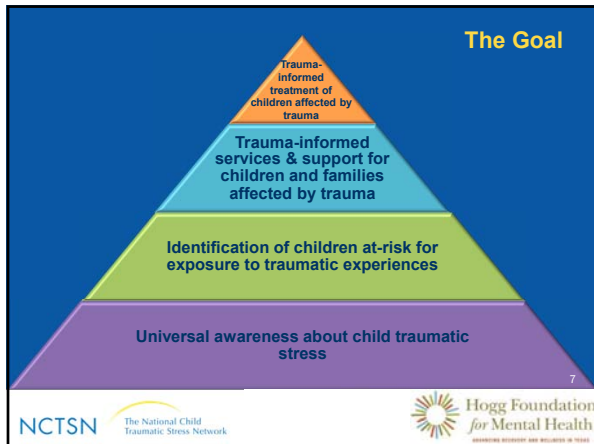
Interacting Influences



What are the frameworks you use in your work?


Changing the Course of Children's Lives By Changing Their Care





The Diagnostic Complexity of Trauma & IDD

- ❖ Situational stressors vs known developmental challenges
- ❖ Medical Issues
- ❖ Co-occurring conditions
- ❖ Traumatic experiences
- ❖ Communication challenges
- ❖ Challenges accessing supports & services



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*“We went to them and they had **no idea** how to help us.”*

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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



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Partnering with Families

Just as you are an expert in mental health or developmental disabilities, family members are experts in their children, family functioning, and sources of support.



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Trauma & IDD: Scope of the Problem

- ❖ Children with IDD:
 - ❖ At-risk for experiencing trauma
 - ❖ Experience high rates of out-of-home placements
- ❖ Providers often feel insufficiently equipped to support youth with IDD and trauma histories.
- ❖ Treatments for children with IDD often focus on behavioral compliance.
 - ❖ Co-occurring conditions make assessment & appropriate treatment identification more complex.
- ❖ Traumatic stress can lead to changes in learning, behavior & physiology—may place children at risk for further trauma.

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Trauma & IDD: Scope of the Problem

- ❖ Children with IDD are under-identified & under-served & often lack trauma-informed services when required.
 - ❖ Diagnostic overshadowing
 - ❖ Inadequate trauma screening & assessment tools
 - ❖ Assumptions made about (in)ability to engage in treatment.
- ❖ Quality integrated care and intensive case management needed for successful trauma treatment is resource intensive for this population.
 - ❖ Fragmented services
 - ❖ Low reimbursement rates

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At-Risk for Trauma



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



3x more likely to be in families with domestic violence



4x more likely to be victims of crime
2x more likely to be bullied

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At-Risk for Trauma



Subjected to traumatizing incidents of physical restraint & seclusion



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



Increased risk of psychological distress due to medical procedures

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Type & Timing Matters

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If a Trauma Occurs: Concerns & Challenges

- ❖ Parents may be at a loss to know how to respond, which may be compounded by the child's IDD
 - ❖ May feel grief at loss of idealized child (related to IDD/trauma)
- ❖ Finding the right type & high quality of care may be taxing
- ❖ Failure to provide a protective shield (from trauma) for a child may create feelings of guilt & other challenges for parents
- ❖ Parents may worry about how the traumatic experience might impact their child's ability to attain a meaningful life
- ❖ Trauma symptoms can exacerbate family life & adjustment
 - ❖ Impact on couples' relationship
 - ❖ Impact on siblings

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Parents Worry that Trauma Will Affect Children's Quality of Life

"We worked hard to get our child the services that we could. When Sarah lost her best friend in the car accident, we felt things were put in jeopardy. We were worried about how quickly she could lose the gains she has so painstakingly made over the last couple of years, which would then affect her chance at a happy life. We felt an urgency to respond."

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Parents' Desire for Safety & Protection



- ❖ Safety & protection are concerns for *all* parents
- ❖ Parents constantly adjust their lives to fit the needs of their children.
- ❖ Across the spectrum of disabilities, parents may have additional concerns related to safety & protection over time.
- ❖ Process of re-adjustment may be more challenging for parents of children with IDD.


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Recognize Parents' Hopes & Concerns

Parents of children with IDD want:



- ❖ To find & provide the best care for their child
- ❖ To sustain & maximize their child's maturity and independence across development & changing circumstances
- ❖ To help their child function at his/her best and attain a meaningful life

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All Behavior is Communication



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Recovery is Possible

Most importantly, provide HOPE that children with IDD can recover from trauma.



- ❖ Help (re-)establish a sense of safety
- ❖ Listen, hear & validate what happened to the child
- ❖ Support the child's caregiving system
- ❖ Provide trauma-informed support & services
- ❖ Provide trauma-informed treatment

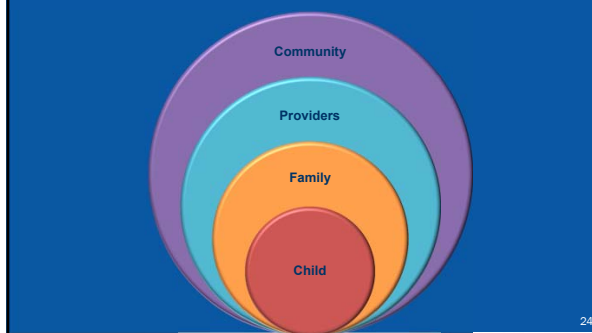
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What do we mean by "recovery"?



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The Ecological Model



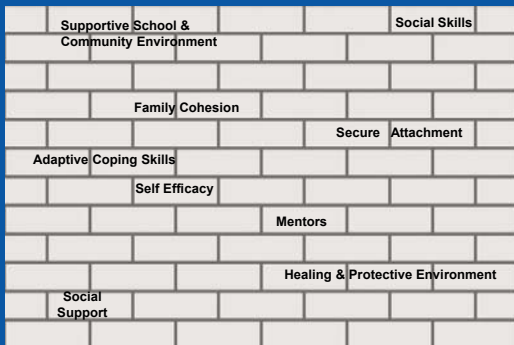
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Development Across the Lifespan

Stage	Task
Infancy	Being
Early Childhood	Doing
Middle Childhood	Mastery
Adolescence	Identity
Adulthood	Separation

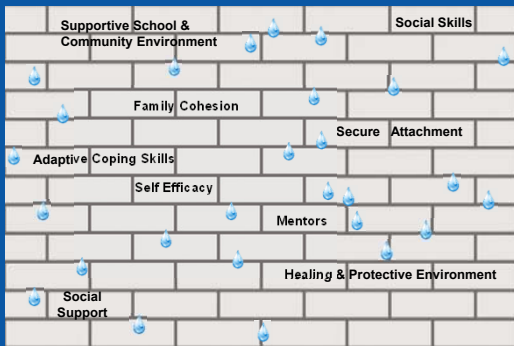
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The Risk & Protective Factors Model



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The Risk & Protective Factors Model



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Ask Yourself

A 15-year-old teenager with autism comes into your office. After speaking and interacting with him, it is evident that he verbally presents more like a 7-year-old, although some of his questions are about dating. You learn from his father that he recently disclosed that he was sexually abused by his mother's boyfriend when he was younger.

How would you recalibrate your therapeutic approach?

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You Can Do This Work

- ❖ Don't let fear and apprehension about IDD be a barrier for you.
- ❖ An effective provider:
 - ❖ Knows recovery is possible.
 - ❖ Uses language and a means of communication that is understandable and appropriate for each child & family.
 - ❖ Knows the child & family has just as much to teach you as you have to teach them.

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! **Essential Messages of Working with Children with IDD who have Experienced Trauma**

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


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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.



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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.

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What is Development?



Development is the process of change by which children become able to handle even more complex levels of moving, thinking, feeling and relating to others.

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Types of Development

- ❖ Biological development
- ❖ Temperament/personality development
- ❖ Cognitive development
- ❖ Psychosocial development
- ❖ Moral development

How does a child develop to his/her full potential?

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Development



Language development / Communication

- **Expressive language**
Communication using sounds, gestures, or words.
- **Receptive language development**
Recognition of sounds & understanding of spoken words & directions.
- **Pragmatic communication:**
Nonverbal & social communication

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Development



Motor development refers to the body increasing in skill and performance, and includes:

- **Gross motor development** refers to the development of large muscle groups (e.g., legs and arms)
- **Fine motor development** refers to the precise use of muscles, for example hands and fingers.

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Development



Cognitive development is learning the skills of understanding, memory and concentration, along with learning to communicate with family, friends, and community.

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Development



Social and emotional development

is the development of a child's identity, self-image, relationships, behavior patterns, accompanied with learning the skills to live in society as a member of the community.

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Development



Adaptive functioning

refers to the ability to adjust to various demands of normal daily living:

- **Self-Care:** activities such as eating, toileting, bathing
- **Community:** interest in activities outside the home
- **Home Living:** taking care of/assisting with household tasks & taking care of personal possessions
- **Health & Safety:** knowledge of basic health activities & physical dangers

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Traits vs. Skills

❖ Traits

- ❖ A distinguishing characteristic or quality, especially of one's personal nature.
- ❖ An inherited feature or characteristic.

❖ Skills

- ❖ Proficiency, facility, or dexterity that is acquired or developed through training or experience.
- ❖ A developed talent or ability.

Source: thefreedictionary.com

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Federal Definition of Intellectual and Development Disabilities

- ❖ Impacts available services for children & families
- ❖ Emphasizes functional limitations in adaptive behaviors:
 - ❖ Self-Care
 - ❖ Receptive & Expressive Language
 - ❖ Learning
 - ❖ Mobility
 - ❖ Self-Direction
 - ❖ Capacity for Independent Living
 - ❖ Economic Self-Sufficiency
- ❖ Impacts how or what parts of the system(s) families need to know how to navigate

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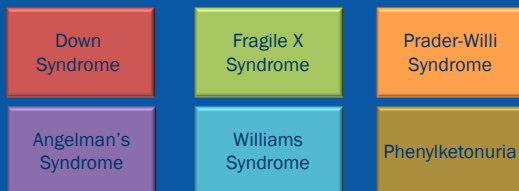
Types of Disability

- ❖ Genetic
 - ❖ Neuromotor
 - ❖ Mental health (e.g., ADHD, depression, anxiety)
 - ❖ Neurological (e.g., autism, epilepsy)
 - ❖ Intellectual
 - ❖ Sensory (e.g., vision, hearing, sensory-integration)
- ❖ Videos available on abnormalpsychology.org/videos

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Genetic Disabilities

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



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Neuromotor Disabilities

A disability caused by damage to the central nervous system (brain and/or spinal cord). The resulting neurological impairment limits muscular control and movement.

Cerebral Palsy

Spina Bifida

Traumatic Brain Injury

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Mental Health Disabilities

A disability caused by a mental health condition with a severe impact in functioning.

Depression
Anxiety

Emotional
Disturbance

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Neurological Disabilities

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

Autism
ADHD

Lead
Poisoning

Fetal
Alcohol
Syndrome

Epilepsy

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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

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Sensory Disabilities

A sensory disability is a disability that involves any of the five senses, as well as the brain's coordination of these senses.

Sensory
Integration

Vision
Impairment/
Blindness

Hearing
Impairment/
Deafness

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Traumatic Experiences & IDD Can Disrupt Development

- ❖ Development can still progress in children with IDD; however, it may occur at a different pace. There may also be different potential for skill development.
- ❖ Traumatic experiences at any age and stage of development can interfere with a child's developmental accomplishments.
- ❖ When children endure multiple traumatic events over long periods of time they are especially likely to have difficulty meeting developmental tasks.



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Development Across the Lifespan

Stage	Task
Infancy	Being
Early Childhood	Doing
Middle Childhood	Mastery
Adolescence	Identity
Adulthood	Separation

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IDD & Trauma in Early Childhood

Developmental Tasks

- ❖ Attachment to primary caregiver
- ❖ Development of visual & auditory perception
- ❖ Recognition of & response to emotional cues
- ❖ Develop greater independence & capacity to assess danger

Trauma's Impact

- ❖ Changes in eating & sleeping
- ❖ Become passive, quiet
- ❖ Heightened startle response
- ❖ Confusion about what's dangerous & who to go to for protection
- ❖ Fear of being separated from familiar people/places
- ❖ Engage in regressive behaviors

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IDD & Trauma in Early Childhood






A young child with IDD who has a traumatic experience, may have more difficulty calming down after being scared, and may even become aggressive; it may be harder to reassure him/her.


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IDD & Trauma in Middle Childhood




Developmental Tasks	Trauma's Impact
<ul style="list-style-type: none"> ❖ Manage fears, anxieties, & aggression ❖ Sustain attention for learning & problem solving ❖ Control impulses & manage physical responses to danger 	<ul style="list-style-type: none"> ❖ Unwanted & intrusive thoughts/images ❖ Preoccupation with moments from the traumatic experience ❖ Replay the traumatic event ❖ Develop intense, specific new fears linking to the original danger ❖ Oscillate between being avoidant & reckless ❖ Sleep or concentration challenges

IDD & Trauma in Middle Childhood






A school-aged child with IDD who has a traumatic experience, may have reduced receptive and expressive language skills that make it difficult to communicate about ongoing intrusive thoughts and images.

IDD & Trauma in Late Childhood & Young Adulthood

Developmental Tasks	Trauma's Impact
<ul style="list-style-type: none"> ❖ Think abstractly ❖ Anticipate & consider the consequences of behavior ❖ Accurately judge danger & safety ❖ Increased impulse control & ability to defer gratification by thinking through consequences 	<ul style="list-style-type: none"> ❖ May feel embarrassed or angry about bouts of fear & exaggerated physical responses ❖ Difficulty imagining or planning for the future; decreased motivation for learning ❖ Low self-esteem & helplessness ❖ Difficulties with trust ❖ Reckless &/or self-destructive behaviors (e.g., drugs, cutting)

IDD & Trauma in Late Childhood & Young Adulthood



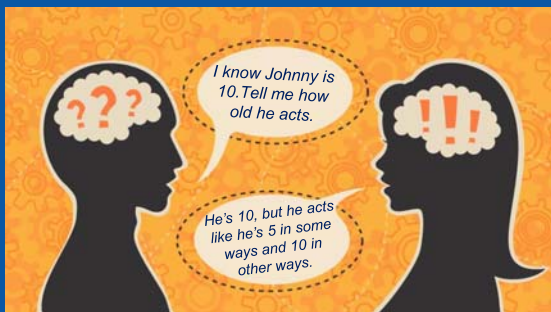
An adolescent with IDD who has a traumatic experience during late childhood or young adulthood may experience decreased motivation for learning.

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.





Developmental vs. Chronological Age





Living with IDD: A Child's Perspective

- ❖ Self-care
- ❖ Communication
- ❖ Mobility
- ❖ Interpersonal Dynamics & Relationships
- ❖ Home Living
- ❖ Community Use
- ❖ Health
- ❖ Safety
- ❖ Leisure
- ❖ Education/School



Living with IDD: A Family's Perspective

- ❖ Safety & health are ongoing concerns
- ❖ Children/youth with IDD may require extended parental and family involvement in care
- ❖ There may be increased stress in the home which leads to conflict between parents, siblings & other relationships
- ❖ Questions about the extent to engage in "disability culture"
- ❖ Concerns about how to help their child with IDD achieve a valued & happy life

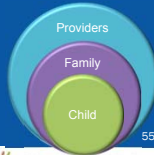
! Essential Messages

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.



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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.

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How would you define child traumatic stress?

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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

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What is Child Traumatic Stress?

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

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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



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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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Core Concept 2: Life Experience

"What the child brings to the experience from within and from the outside world effects the child's response."

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Core Concept 2: Life Experience

"What the child brings to the experience from within and from the outside world effects the child's response."

For a family & child with IDD
It is important to understand the traumatic experience within the context of how IDD affects the child's everyday life.

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Core Concept 2: Life Experience

"What the child brings to the experience from within and from the outside world effects the child's response."

Child-Intrinsic Factors	Child-Extrinsic Factors
IDD	Physical environment
Co-occurring conditions	Community & cultural responses to IDD
Prior exposure to trauma	Community & cultural responses to trauma

For a family & child with IDD
It is important to understand the traumatic experience within the context of how IDD affects the child's everyday life.

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Core Concept 3: Reminders & Adversities

"What's the world like that the child is living in afterwards?"

The diagram illustrates the flow from Trauma & Loss (a red circle on the left) to Ongoing Adjustment (a red circle on the right). In the center, four colored boxes represent intermediate stages: Secondary Adversities (green), Cascade of Changes (blue), Trauma Reminders (purple), and Loss Reminders (orange). Arrows point from Trauma & Loss to each of these four boxes, and from each box to Ongoing Adjustment.

For a family & child with IDD
 Trauma may add to significant secondary adversities related to IDD experienced by the child and family that existed prior to the traumatic experience.

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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."

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Core Concept 4: Wide-Ranging Reactions

"A child's reaction to a traumatic event varies greatly."

The collage consists of four vertical panels showing close-up faces of children. From left to right: a child with a closed mouth and a somber expression; a child with a wide-eyed, fearful expression; a child with a grimacing, pained expression; and a child with their mouth wide open in a scream or cry.

For a family & child with IDD
 Recognizing reactions to trauma in children with IDD can be complicated by the wide-ranging expressions of their disabilities.

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Who We Are

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Traumatic Stress & PTSD

- ❖ There are a common set of reactions frequently seen in children and adolescents—as well as parents—who have had a traumatic experience.
- ❖ When these post-traumatic stress reactions continue longer than one month—in a set pattern—they can meet criteria for PTSD.
- ❖ Although the presentation of these reactions may vary by age and developmental stage, children and adolescents can develop PTSD.

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Criteria for PTSD

Exposure	Re-experiencing	Avoidance
Negative Cognitions & Moods	Arousal & Reactivity	Impairment

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Traumatic Stress and Other Diagnoses

- ❖ Posttraumatic stress & grief reactions can develop into other mental health conditions & diagnoses over time (e.g., separation anxiety & depression)
- ❖ Exacerbate preexisting mental health problems
- ❖ Reactions to trauma reminders may sometimes result in misdiagnoses
- ❖ Competent assessment is critical for accurate diagnosis, and effective intervention

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Core Concept 5: Danger & Safety

"A child's ability to believe in and trust in a protective shield has been broken and must be restored."

For a family & child with IDD

Restoring trust requires both time and strategies which take the child's IDD into account.



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Core Concept 6: Caregiving Systems

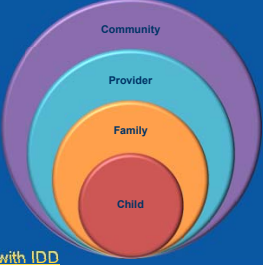
"Everyone is shaken up by what happened."



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Core Concept 6: Caregiving Systems

"Everyone is shaken up by what happened."




For a family & child with IDD
 Child, family & caregiving systems may feel devastated by what happened to their child and overwhelmed by their specific needs, which are over and above the needs they already had (related to the child's IDD).

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Core Concept 7: Protective Factors

"Promoting and restoring."



For a family & child with IDD
 Reassure parents/caregivers that strategies for addressing the effects of traumatic experiences can be adapted for children with IDD by enhancing protective factors.


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Core Concept 8: Development

"Don't just think symptoms—think development."


For a family & child with IDD
 Traumatic experiences may result in a significant setback in developmental progress, which was already challenged by IDD.



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Core Concept 9: Neurobiology
"How do you know what's dangerous?"




For a family & child with IDD
 IDD may affect how the child appraises and responds to danger.

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Core Concept 10: Culture
"Culture is layered in its meaning and layered in its effects."




For a family & child with IDD
 Children with IDD and their families are often part of many cultural identities and communities, including disability communities, which may impact the experience and expression and of trauma.

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Core Concept 11: Social Contract
"Protection has failed in some way."



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Core Concept 11: Social Contract

"Protection has failed in some way."




For a family & child with IDD
 Children with IDD and their families are impacted by societal attitudes about disability, which can affect their capacity to marital support and/or justice in the face of traumatic experiences.

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Core Concept 12: Provider Distress

"We are stewards not just of those who allow us into their lives, but of our own capacity to be helpful."




For a parent/caregiver of a child with IDD
 Traumatic experiences may (re-)evolve concerns about the vulnerability of their child and their own inability to protect the child from harm.

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Responses to Traumatic Experiences



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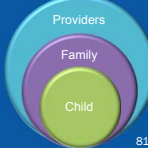
Essential Message

- 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.

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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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Evaluation of Learning: Day 1

- ❖ Questions?
- ❖ Post-Training Evaluation for Day 1
- ❖ Plan for Day 2

See you tomorrow morning!



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