THRIVING

Helping Adults with Intellectual and Developmental Disabilities Heal and Thrive Following Trauma

PARTICIPANT MANUAL

ACKNOWLEDGEMENTS

ACKNOWLEDGEMENTS

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INTRODUCTION

Welcome to Thriving: Helping Adults with Intellectual and Developmental Disabilities Heal and Thrive Following Trauma. This workshop is an introduction to trauma-informed concepts and resources. Trauma-informed services are those that focus on awareness of the impacts of trauma and practices designed to provide safety and empowerment to those who have experienced trauma.

Trauma-informed care is a universal intervention that benefits everyone – organizations, service providers, and people supported. Depending on your role, you may wish to further your training to be able to provide more trauma-sensitive or trauma-specific services. This training will provide some recommendations for resources to further your training.

This participant manual is part of the Thriving Toolkit, which also consists of a Facilitator's Guide, Slidekit, and Supplemental Materials. Together, they are designed to teach basic knowledge, skills and values about working with adults with intellectual and developmental disability (IDD) who have had traumatic experiences, and how to use this knowledge to support the person's safety, well-being, happiness, and recovery through trauma-informed practice.

These materials have been adapted with permission from "The Road to Recovery Toolkit: Supporting Children with IDD Who Have Experienced Trauma" developed by the National Center for Child Traumatic Stress and the National Child Traumatic Stress Network and a national selection of experts in trauma and IDD. The Thriving Toolkit provides up-to-date tools and resources that are developmentally appropriate for adults with IDD.

The toolkit was designed to support dissemination and implementation of trauma-informed care by providing complete easy-to-use materials so that anyone can provide the Thriving training in their own community and/or organization. The complete toolkit can be downloaded from the Thriving website. We hope that if you find the Thriving training valuable that you will consider hosting a Thriving workshop of your own.

The Thriving website also hosts the online course. The online course was designed to help those who are unable to attend a Thriving workshop due to time or distance. The online training does not contain the interactive activities which are a valuable part of the Thriving training. However, it still contains critical information and resources to support resilience and recovery of people with IDD who have experienced trauma. It is also a useful resource in preparing to provide the Thriving workshop yourself.

Organization of this course

This course contains six modules. Each module contains a set of learning objectives and are built around 10 Essential Messages. These Essential Messages are the key take-home messages of the training. Each module also includes a number of individual and group activities to help you apply what you are learning to your own role and context. If you are attending this course with others from your own or other organizations, we hope you take this opportunity to share your experience and learn from the experiences of others. At the end of each module you will complete and Action Planning activity where you will identify actionable steps you can take to apply the trauma-informed essential messages to your own work. At the end of the training, you will create a Personal Trauma-Informed Action Plan where you will identify the top 3 action steps that you can commit to implement in your work.

CONTENTS

ESSENTIAL MESSAGES

1. Know that there's hope; recovery from traumatic experiences is possible. (Module 1)

2. Recognize that an adult with IDD may have had a traumatic experience(s), which can have profound effects. (Module 1)

3. Recognize an adult's developmental level and how IDD and traumatic experiences are affecting his/her functioning. (Module 2)

4. Utilize a developmental lens when making meaning of an adult's traumatic experiences and responses. (Module 2)

5. Recognize that in the aftermath of trauma, understanding traumatic stress responses is the first step in helping an adult regain their sense of safety, value and quality of life. (Module 3)

6. Utilize an IDD- and trauma-informed adult-centered approach to support both the adult and the family. (Module 4)

7. Help parents/caregivers, and other professionals in the adult's life, strengthen protective factors. (Module 4)

8. Partner with agencies and systems to ensure earlier and more sustained access to services. (Module 5)

9. Ensure that trauma-informed adult-centered services, treatments and systems drive the recovery plan. (Module 5)

10. Practice ongoing self-care in order to increase effectiveness in delivering high quality support, services and treatment. (Module 6)

LEARNING OBJECTIVES

Module 1: Setting the Stage

- ☐ Define Trauma-Informed Care
- ☐ Realize that people with IDD are at-risk for traumatic experiences.
- ☐ Articulate that recover from traumatic experiences is possible.
- ☐ Establish the important role of parents/caregivers and the support network on the road to recovery.
- ☐ Describe frameworks that will be used to highlight key concepts throughout the training.

Module 2: Development, IDD & Trauma

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

Module 3: Traumatic Stress Responses in People with IDD

- ☐ Identify the types of events that can cause traumatic stress.
- ☐ Define traumatic stress and trauma-related disorders.
- ☐ Identify how traumatic experiences and their responses affect people with IDD.

LEARNING OBJECTIVES

Module 4: Well-Being & Resilience
- ❑ Explore the impact on caregivers of learning about the traumatic experience of the person with IDD they care for.
- ❑ Explain strategies for strengthening protective factors to enhance well-being, resilience, and recovery.
- ❑ Describe frameworks for promoting a healing and protective environment in order to create a safe and meaningful life for adults with IDD.
- ❑ Identify person-centered planning techniques to help adults with IDD realize their hopes and dreams.

Module 5: IDD- & Trauma-Informed Services & Treatment
- ❑ Explain how to enhance protective factors of people with IDD & caregivers through appropriate trauma-informed services & treatment.
- ❑ Discuss how to utilize adapted screening, assessment & planning tools to identify IDD- & trauma-informed needs of people with IDD.
- ❑ Discuss strategies for adapting the core components of trauma-informed treatments for people with IDD.
- ❑ Identify strategies for partnering with agencies & cross-system collaboration.

Module 6: Provider Self-Care
- ❑ Describe the difference between secondary traumatic stress, burnout and vicarious trauma.
- ❑ Identify how burnout develops among providers.
- ❑ Discuss potential sources, warning signs, and effects of secondary traumatic stress and organizational stress.
- ❑ Implement steps to stress reduction and self-care.

Module One

Setting the Stage

THRIVING

HELPING ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES HEAL AND THRIVE FOLLOWING TRAUMA

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Welcome!

Thank you for being here!

Acknowledgements

- Adapted from "The Road to Recovery Toolkit"

- Available for free on the **National Child Traumatic Stress Network** learning center

- https://www.nctsn.org/resources/road-recovery-supporting-children-intellectual-and-developmental-disabilities-who-have

The Road to Recovery

Hogg Foundation for Mental Health

NCTSN — The National Child Traumatic Stress Network

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Advisory Board

Ruth Brown, PhD, Ananda Amstadter, PhD, Michael Southam-Gerow, PhD • Virginia Commonwealth University	Patricia Hagood • Self-Advocate	Colleen Horton, MPAff • Hogg Foundation	Adam Kaul, MD • Regional Education Assessment Crisis Services and Habilitation
	Susan Ko, PhD • Science 37	Andrea Konig, PhD • Bon Secours St. Mary's Hospital	Michelle (Shell) Schwartz, MA • SafePlace, TX

What's new in this version?

- Focuses on the specific needs of adults with IDD, the contexts in which adults live, the impacts of trauma across the lifespan on adults, and assessment and treatments for adults with IDD
- Updated research findings on prevalence of trauma and stress-related disorders according to the most recent diagnostic manuals used by psychologists (DSM-5 and DM-ID 2)

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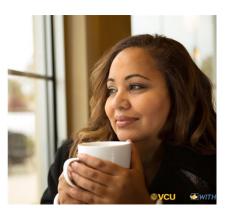
Terminology

- **Providers** – anyone who works with or provides services to people with IDD.
- **Intellectual and/or Developmental Disabilities (IDD)** – people who may have a broad array of conditions, beginning before adulthood and expected to last into adulthood, that result in significant impairment in adaptive functioning.
- **Person-first** – preferred by most professions. Puts the person first and the disability second (e.g., "a person with Down syndrome" versus "a Down's person"). Some self-advocates prefer identity-first language ("I am a disabled-person").
- **Behaviors** – a sometimes pejorative term describing the actions of a person with IDD when they are distressed, angry, frustrated, bored, etc.

Notes

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Self Care

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

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Modules

- *Module One: Setting the Stage*
- Module Two: Development, IDD & Trauma
- Module Three: Traumatic Stress Responses in People with IDD
- Module Four: Well-Being & Resilience
- Module Five: IDD- & Trauma-Informed Services & Treatment
- Module Six: Provider Self-Care

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Module one: Learning objectives

What Will I Learn Today?

- Define Trauma-Informed Care
- Realize that people with IDD are at-risk for traumatic experiences.
- Articulate that recover from traumatic experiences is possible.
- Establish the important role of parents/caregivers and the support network on the road to recovery.
- Describe frameworks that will be used to highlight key concepts throughout the training.

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What does it mean to be "Trauma Informed" ?

SAMHSA's Four R's of Trauma-Informed Care

- **Realizes** the widespread impact of trauma
- **Recognizes** the signs and symptoms of trauma
- **Responds** by changing behaviors, policies, and services to take trauma into account
- **Resists** re-traumatization of clients and staff with trauma histories

Source: store.samhsa.gov TIP 57: Trauma-Informed Care in Behavioral Health Services

Three Levels of Trauma Services

- **Trauma-Informed**
  - Universal intervention
  - Focuses on empowerment, safety, choice
- **Trauma-Sensitive**
  - Secondary intervention
  - Aims to address trauma through assessment and modification to services
- **Trauma-Specific**
  - Tertiary intervention
  - Use of evidence-based, or promising, trauma treatments

The Institute on Trauma and Trauma-Informed Care (2019). Trauma-Informed Organizational Change Manual. University of Buffalo School of Social Work. Retrieved from: www.socialwork.buffalo.edu/ittic

Realize

Trauma & IDD: Scope of the Problem

Trauma & IDD: Scope of the Problem

- 4x more likely to be victims of crime.
- 2x more likely to be bullied
- 3x more likely to be in families with domestic violence
- 2x as likely to experience emotional neglect, physical & sexual abuse

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Trauma & IDD: Scope of the Problem

- Have significant higher rates of serious injury
- Increased risk of psychological distress due to medical procedures
- Subjected to traumatizing incidents of physical restraint & seclusion

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NPR Special Series: Abused and Betrayed. The Sexual Assault Epidemic No One Talks About

"In Their Own Words: People With Intellectual Disabilities Talk About Rape"

https://www.npr.org/series/575502633/abused-and-betrayed

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Trauma & IDD: Scope of the Problem

- "... those numbers from household surveys don't include people living in institutions — where, Harrell said, research shows people are even more vulnerable to assault. Also not counted are the 373,000 people living in group homes."

The Sexual Assault Epidemic No One Talks About ; NPR. https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about

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History of Institutional Care

- Willowbrook State School and others
- Overcrowding
- Abuse
- Neglect
- Unethical medical experimentation

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Trauma & IDD: Scope of the Problem

- Study in the United Kingdom found that approximately 1,400 reports of sexual abuse committed against people with intellectual disability are reported annually
  - Only 6% reach the court
  - Only 1% result in conviction

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Trauma & IDD: Barriers to Recovery

- High rates of out-of-home placements
- Providers often feel insufficiently equipped to support people with IDD and trauma histories.
- Treatments for people with IDD often focus on behavioral compliance.
- Traumatic stress can lead to changes in learning, behavior & physiology—may place people at risk for further trauma.

"We went to them and they had no idea how to help us."
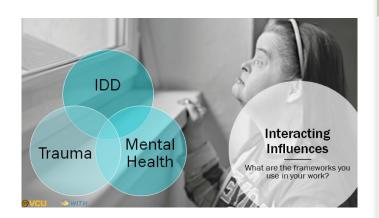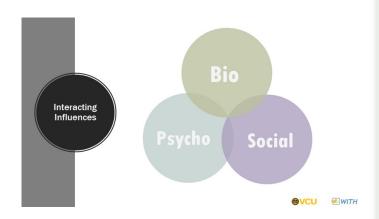
Myths about People with IDD

- People with I[DD] ... treatment
- Standar[d] ... ntal health treatment ... [e]ffective for peop[le] ... th IDD
- Be[ha]vior modification is the only option
- P[eo]ple with [intelle]ctual disab[ility] do not e[xpe]rience [tra]uma
- [Wo]rking with this p[opulation] requires signific[ant] [sp]ecialized training
- [C]hallenging b[ehavior] is [explai]ned by an int[elle]ctual [dis]ability
- P[eopl]e with I[DD] are protected fro[m] trauma [be]cause of the[ir me]ntal age (i.e., babies); they do n[ot] [re]member
- IQ sco[res te]ll you everything you nee[d to] know about a person
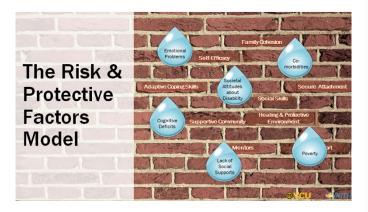
The Ecological Model

The Risk & Protective Factors Model

The Risk & Protective Factors Model

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 person.
  - Knows the person with IDD and their caregivers have just as much to teach you as you have to teach them.

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MAKING THE CONNECTION: WHY AM I DOING THIS WORK?

Think about what brought you to this training today. Is the reason professional? Personal? Is there a person with intellectual and developmental disability, in particular, whom you are thinking about?

- What is it that connects you to this work?

- What would you like to know?

Essential Messages of Working with People with IDD who have Experienced Trauma

1. Know that there's hope; recovery from traumatic experiences is possible.

2. Recognize that a person 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 person's, caregiver's and provider's experience.
- Identify any fears or biases I have about working with people with IDD who have had traumatic experiences.
- Identify ways to increase my knowledge & skills

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ACTION PLANNING
ESSENTIAL MESSAGES 1 & 2

Think about the person you identified at the end of Module 1 that connects you to this work. What can help that person and other adults with IDD who have experienced trauma? (Put an "X" in up to 3 boxes next to the ideas you think you would MOST like to emphasize in your daily practice.)

1

ESSENTIAL MESSAGE 1

Know that there's hope; recovery from traumatic experiences is possible.

❑ Over the next 3 months, I will identify my personal fears and/or biases of working with adults with IDD. I will begin to utilize the resources described in this Toolkit to help me to address those fears with knowledge and skills training.

❑ Over the next 3 months, I will read at least 2 articles online, or in peer-reviewed journals that describe the prevalence of trauma among adults with IDD.

❑ Over the next 3 months, I will articulate that recovery from traumatic experiences for adults with IDD is possible, to at least 3 adults with IDD and their caregivers.

2

ESSENTIAL MESSAGE 2

Recognize that adults with IDD may have traumatic experiences, which can have profound effects.

❑ Over the next 3 months, I will identify 3 ways in which traumatic experiences are impacting the **quality of life** for at least three adults with IDD. I will review these areas each time I meet with them.

❑ Over the next 3 months, I will identify **concerns and hopes**, of caregivers of 3 adults with IDD who have experienced trauma. I will review these areas each time I meet with them.

❑ (**Write my own**.) Over the next 3 months, I will…

Recovery is Possible

Most importantly, provide HOPE that people with IDD can recover from trauma.
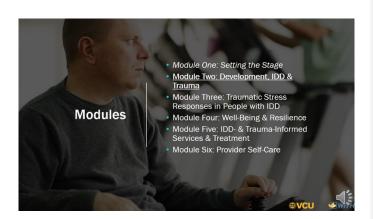
- Help (re-)establish a sense of safety
- Listen, hear & validate what happened to them
- Support the their caregiving system
- Provide trauma-informed support & services
- Provide trauma-informed treatment

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Module Two

Development, IDD, and Trauma

Modules

- *Module One: Setting the Stage*
- Module Two: Development, IDD & Trauma
- Module Three: Traumatic Stress Responses in People with IDD
- Module Four: Well-Being & Resilience
- Module Five: IDD- & Trauma-Informed Services & Treatment
- Module Six: Provider Self-Care

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 a person's functioning is affected by IDD & subsequent adaptations that must be made.

What is Development?

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

Types of Development

- Language
- Motor
- Cognitive
- Social/Emotional
- Adaptive

How does a person 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
Gross Motor

- Large muscle groups
- Walking, running

Fine motor development

- Precision movements
- Tying shoes, writing

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Development

Cognitive Development

- Attention
- Memory
- Spatial Ordering
- Sequential Ordering
- Problem Solving
- Social Thinking

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Development

Social/Emotional Development

- Self identity
- Relationships
- Social norms
- Sensory preferences and sensitivities
- Emotion regulation

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Development

Adaptive functioning
- 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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Federal Definition of Intellectual and Development Disabilities

- Impacts available services for people & 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

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.

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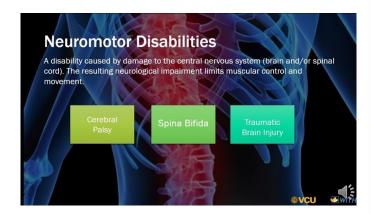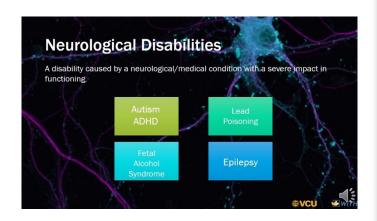
Types of Disability

- Genetic
- Neuromotor
- Mental health (e.g., ADHD, depression, anxiety)
- Neurological (e.g., autism, epilepsy)
- Intellectual
- Sensory (e.g., vision, hearing, sensory-integration)

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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

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

Mental Health Disabilities

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

- Depression
- Anxiety
- Bipolar
- Schizophrenia

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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

Autism

A. Deficits in social communication and interaction

B. Restricted, repetitive behavior and/or interests, sensory differences

May or may not have intellectual disability.

Intellectual Disability

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

Living with IDD

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

Living with IDD

If you are participating in an in-person workshop, you may complete this activity as a group. You can use this page to write down any insights that you want to keep in mind in your own work.

If you are completing this course independently, think about how living with IDD effects the quality of life for the person and the family. Imagine people with various disabilities. What are some ways their daily functioning is impacted in these areas? Think about the challenges that come with each of these areas and start to think about how you, as a provider, can help support people with IDD.

| Self Care | Communication
– Unable to ask for help | Mobility | Social and Romantic Relationships |
| Home Living | Community Use | Health | Safety |
| | Leisure | Education | |

Living with IDD: A Family's Perspective

- Safety & health are ongoing concerns
- Adults 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 person with IDD achieve a valued & happy life

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- Development can still progress in adults with IDD; however, it may occur at a different pace.

- Traumatic experiences at any age and stage of development can interfere with a person's developmental accomplishments.

- When people endure multiple traumatic events over long periods of time they are especially likely to have difficulty meeting developmental tasks.

Traumatic Experiences & IDD Can Disrupt Development

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Erikson's Theory of Development

Stage	Typical Age	Task	Existential Question
Infancy	0 – 18 m	Trust	Can I trust the world?
Early Childhood	2 – 4 yrs	Autonomy	Is it okay to be me?
Preschool Age	4 – 5 yrs	Initiative	Is it okay for me to do, move, and act?
School Age	5 – 12 yrs	Industry	Can I make it in the world?
Adolescence	13 – 19 yrs	Identity	Who am I? Who can I be?
Early Adulthood	20 – 39 yrs	Intimacy	Can I love?
Adulthood	40 – 64 yrs	Generativity	Can I make my life count?
Late adulthood	65 - death	Ego Integrity	Is it okay to have been me?

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IDD & Trauma in Early Childhood

Developmental Tasks	Trauma's Impact
▪ Attachment to primary caregiver	▪ Changes in eating & sleeping
▪ Development of visual & auditory perception	▪ Become passive, quiet
▪ Recognition of & response to emotional cues	▪ Heightened startle response
▪ Develop greater independence & capacity to assess danger	▪ 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 Middle Childhood

Developmental Tasks	Trauma's Impact
▪ Manage fears, anxieties, & aggression	▪ Unwanted & intrusive thoughts/images
▪ Sustain attention for learning & problem solving	▪ Preoccupation with moments from the traumatic experience
▪ Control impulses & manage physical responses to danger	▪ Replay the traumatic event
	▪ Develop intense, specific new fears linking to the original danger
	▪ Oscillate between being avoidant & reckless
	▪ Sleep or concentration challenges

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IDD & Trauma in Adolescence and Young Adulthood

Developmental Tasks	Trauma's Impact
▪ Think abstractly	▪ May feel embarrassed or angry about bouts of fear & exaggerated physical responses
▪ Anticipate & consider the consequences of behavior	▪ Difficulty imagining or planning for the future; decreased motivation for learning
▪ Accurately judge danger & safety	▪ Low self-esteem & helplessness
▪ Increased impulse control & ability to defer gratification by thinking through consequences	▪ Difficulties with trust
	▪ Reckless &/or self-destructive behaviors (e.g., drugs, cutting)

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IDD & Trauma in Adulthood

Developmental Tasks	Trauma's Impact
▪ Dialectical thought	▪ Difficulty imagining or planning for the future;
▪ Intimate Relationships and parenting	▪ Decreased motivation for learning or working
▪ Social Inclusion	▪ Difficulties with trust
▪ Work and career	▪ Isolation and social withdrawal
▪ Managing declining physical functioning/medical concerns	

IDD & Trauma in Older Age

Developmental Tasks	Trauma's Impact
▪ Continue living independently as long as possible	• Late-Onset Stress Symptomology (LOSS)
▪ Managing energy and physical changes	• Changes in cognition and memory
▪ Changes in health, cognition, and memory	• Symptoms of trauma may be mistaken for delirium or dementia
▪ Generativity	• Decreased independence
▪ Making sense of one's life	• Difficulty making meaning of trauma in context of life

IDD & Trauma in Older Age

"Adults with Developmental Disabilities" https://youtu.be/MGlEpswlE5w

Introducing…

- Jaqueline is a 34-year-old woman from El Paso, TX.
- Austin is a 22-year-old man from Cincinnati, OH .
- Joey is 30-year-old man from Wichita, KS
- Katie is a 35-year-old woman from Madison, WI
- Trevelyan is a 65-year-old man from Detroit, MI

CASE VIGNETTE
JACQUELINE

Jacqueline is a 34-year-old woman who grew up in the lower valley of El Paso, Texas. Jacqueline was diagnosed with Down's syndrome (trisomy 21) at birth and was identified with hearing impairment and a congenital heart defect early in her life. She was diagnosed with an intellectual disability in elementary school.

Jacqueline's parents divorced when she entered Kindergarten. She, her mother and two older sisters had no option but to move in and live with extended family members. They finally settled in and lived with Jacqueline's mother's sister. Jacqueline's mother was working two minimum wage jobs to save up for a place to live. She also contributed to her sister's household funds and her children's need. Jacqueline was often left in the care of her aunt, her older sister or an older cousin still living at home.

There were times during her childhood when occupational, speech therapy and doctor appointments were missed. Jacqueline's older cousin Robert, tended to play rough with her, sometimes leaving bruises and he frequently made fun of her speech. Jacqueline also cried a lot and had frequent tantrums at school and home. At those times, her aunt's boyfriend would send her to her room after yelling at her to stop crying and being such a bad girl.

Her mother eventually remarried and at the age of eighteen Jacqueline was placed in a group home.

In the group home where Jacqueline lives with 3 other women with disabilities, she began to experience waking in the middle of the night from nightmares. In response, sometimes evening staff would go into her room and just be with her until she was able to go back to sleep.

Jacqueline's sister visits every weekend and recently noticed that Jacqueline is very defensive to the touch and became physically aggressive when she tried to give her a hug. Jacqueline's sister also noticed that the sheets and bedding were soiled and had not been changed. Staff said that she has started wetting the bed again.

Jacqueline's sister is concerned with the aggressiveness and the care that Jacqueline may not be receiving by the staff in the group home.

CASE VIGNETTE
AUSTIN

Austin is a 22-year-old male who was a healthy baby and developed normally for the first year of his life. At 18 months of age, his mother started to notice that Austin didn't seem interested in or to have curiosity about other children. He began playing with only a few select toys. Shortly before the birth of his younger brother, Austin stopped making eye contact and by the time he was 21 months old, he had ceased speaking altogether (or making any sounds except when he cried). He seemed to be withdrawing more and more into his own world. Progressively, loud sounds were distressing and he began plugging his ears, eventually loud noises that never used to bother him—became unbearable. Along with his auditory hyper-sensitivity came sensory issues in all areas. When he was 2 1/2, he began showing signs of "visual stimming" (repetitive visual stimulation) and very pronounced obsessive compulsive behaviors. Austin was formally diagnosed with autism spectrum disorder by a pediatric neurologist.

Austin grew up in a bilingual household. His mother speaks English to him and his father speaks Hungarian. At the age of three, he was found to be farsighted and given glasses. At 3 1/2 years he was placed in a special education preschool. He was entirely nonverbal by that time. Over the summer he attended an Early Education Center. Austin received private speech therapy through Easter Seals in addition to public school and began speaking after the weekly speech therapy visits. His speech was limited to "no," "bye," and "hi." He would repeat words if asked and also use single words to request familiar things. Occupational therapy was provided intermittently throughout this time. These interventions became a regular part of his life throughout his early childhood and elementary years.

At the age of 12-years-old, Austin's parents stopped his therapies and interventions. They decided he needed a break and felt he had made great progress and was functioning well at school and home. His parents wanted Austin to be in general education for at least some of his classes. In middle school he began to run away from the school and school security would call his parents to come and pick him up once they had restrained and isolated him. Austin began to show more aggression as he entered high school at home and school.

In high school and through his transition age school years Austin began to see a psychotherapist on a weekly basis to help him with managing his emotions and interactions with peers. Austin was diagnosed with Bi-Polar disorder when he was evaluated by a psychiatrist his senior year of school. As Austin transitions out of high school at 22-years-old, his parents would like him to live on his own and are working towards a plan for him to live close to them in his own apartment. Austin has had difficulty making and keeping friends and his parents hope by living on his own it will help him achieve some social connections.

CASE VIGNETTE
JOEY

Joey, a 30-year-old with an intellectual disability from Wichita, KS was taken to have his blood drawn by his mother who typically accompanies him to medical visits a few years ago. The phlebotomist greeted Joey and his mother and escorted Joey to the chair for the blood draw. He then informed Joey's mother that she needed to wait in the waiting room. Joey's mother began to explain that she always accompanied Joey during his medical procedures, but the phlebotomist did not let her finish her explanation. He stated that all parents are required to wait in the waiting room and he shut the door as she stepped out.

Joey then got out of the chair and began to pace around the room. The phlebotomist asked him to sit down, but Joey said he wanted to leave. The phlebotomist said that they would leave as soon as he sat down and completed the procedure. Joey hesitantly sat down, but was squirming in his seat and fidgety with his hands. The phlebotomist insisted with an angry tone that he hold still. Frightened, Joey began to leave his seat. The phlebotomist blocked him and grabbed his arm and held it down. He said to Joey "if you don't hold still, you're not going to be able to leave." Joey became increasingly fearful and began to yell and cry for his mother. The phlebotomist proceeded to continue the blood draw restraining his arm and body.

Now, Joey becomes upset whenever he has to go to a doctor's appointment. He cries and tries to hide and sometimes becomes aggressive. As a result, he has been missing regular medical appointments and his mother is worried that his health is declining.

CASE VIGNETTE
KATIE

Katie is 35-year-old and has been working at her job in an office for almost a year. She has done well organizing supplies and keeping the conference rooms prepared for meetings. She gets along well with other employees and typically likes going to work each day. She is assisted by a job coach that supports her to stay focused on her tasks. While she sometimes gets distracted, she is congenial with all those supporting her.

Katie's job coach recently went on maternity leave for several months. The new job coach was a kind young man who was committed to helping Katie. Soon after he started the job, Katie became agitated on the job, wasn't relating well to other employees, and wasn't performing her tasks as was expected of her. Anytime the new job coach approached her to assist, Katie got angry and told him to go away.

Katie's employer noticed the changes and suggested that they consult with Katie's case manager to gain insight into what may have generated the change in Katie's work experience. It was discovered that in high school Katie had been sexually assaulted by a young man of similar size and build as the new job coach. Recognizing that Katie didn't feel safe (even though she was safe), enabled those supporting her to get her the support she needed to work through her fears.

CASE VIGNETTE
TREVELYAN

Trevelyan is a 65-year-old man from Detroit, MI. He has a bright smile and loves physical activity. Trevelyan has autism and lives in a residential center for people with developmental disabilities and has since he was 13 years old when his mother felt that she could no longer care for him at home due to his size and aggressive behaviors. Trevelyan does not use verbal communication. He knows a few words in sign language ("please," "thank you," and "sorry"). After bringing him to the residential center as a child, his mother and other family members have rarely visited him, stating that they couldn't afford to take time off work or travel the 1.5 hours to the center to visit him.
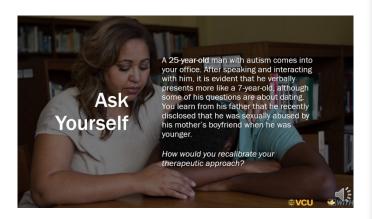
His case file indicates that he grew up in an impoverished area and that he likely had limited access to appropriate interventions, such as applied behavior analysis, speech and language therapy, or occupational therapy. Not much is known about his home life prior to coming to the center. Because he frequently exhibits aggressive behaviors towards staff and peers, he is often on one-to-one supervision. When he was younger, restraints and basket holds were frequently used in response to his aggressive behaviors.

A behavioral analysis indicated that Trevelyan is more likely to act aggressively when he isn't allowed to have a preferred snack (either it is unavailable or belongs to another resident), when another resident is doing something that he wants to do, or to escape demanding tasks at his day program. His behavior plan has focused on redirecting him to other tasks and minimizing task demands with limited success. However, there are other times when he will push staff, run out of the building, or start slamming into doors and walls with no apparent antecedent. It is assumed that he becomes "overstimulated" because of his autism. Staff are frequently injured and turnover has been high, and many staff report that the stress and injuries from working with Trevelyan is a major reason they quit.

PUTTING IT INTO PRACTICE
CASE VIGNETTES: TRAUMA, IDD & DEVELOPMENT

Read the case vignette your group has been assigned and identify the ways in which trauma and intellectual and developmental disability are/may disrupt development.

- Identify any behaviors and responses related to intellectual and developmental disability.

- Identify any behaviors and responses related to traumatic experiences.

- What are other ways that intellectual and developmental disability and traumatic experiences may disrupt typical development for the age range (e.g., emerging adult, adult, older adult) of the case you've been assigned?

Ask Yourself

A **25-year-old** man 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?

! Essential Messages

3. Recognize a person's developmental level and how IDD and traumatic experiences are affecting his/her functioning.

4. Utilize a developmental lens when making meaning of a person's traumatic experiences & responses.

What Can a Provider Do?

- Ask questions and gather information (formally or informally) to understand the person's developmental age & how IDD is affecting his/her functioning.

- Identify IDD-related support needs of the person & family.

- Identify how living with IDD is affecting the quality of the person's life.

Providers
Family
Person

ACTION PLANNING
ESSENTIAL MESSAGES 3 & 4

Think about the person you identified at the end of Module 1 that connects you to this work. What can help that person and other adults with IDD who have experienced trauma? (Put an "X" in up to 3 boxes next to the ideas you think you would MOST like to emphasize in your daily practice.)

3 ESSENTIAL MESSAGE 3

Recognize a person's developmental level and how IDD and traumatic experiences are affecting his/her functioning.

❑ Over the next 3 months, I will identify ways in which **trauma and IDD have disrupted development** for at least 3 adults with IDD. I will review these areas each time I meet with these them.

❑ Over the next 3 months, I will identify at least one **alternative way of communicating/teaching a therapeutic skill** (e.g. deep breathing, muscle relaxation) to use in place of, or in addition to, verbal communication for at least 3 adults with IDD. I will practice the chosen skill with them each time we meet.

❑ Over the next 3 months, I will review my **bibliotherapy resources** to determine if I have enough books to share with adults at different developmental levels about at least 3 different types of trauma.

4 ESSENTIAL MESSAGE 4

Utilize a developmental lens when making meaning of a person's traumatic experiences and responses.

❑ Over the next 3 months, I will identify how **living with IDD** is affecting the quality of life in specific areas (e.g., self-care, communication, etc) for at least 3 adults with IDD who have had traumatic experiences. For each of these people, I will develop a plan, with the person and caregivers that addresses these specific areas. I will review this plan each time I meet with them during this 3-month period.

❑ Over the next 3 months, I will learn a new method of assessing the person's **intellectual abilities** that may be better-suited to working with an adult with IDD who has had a traumatic experience (e.g., learn an IQ test that is normed on a more diverse population, non-verbal methods, etc.).

❑ (Write my own.) Over the next 3 months, I will…

Module Three

Traumatic Stress Responses in People with IDD

Modules

- Module One: Setting the Stage
- Module Two: Development, IDD & Trauma
- Module Three: Traumatic Stress Responses in People with IDD
- Module Four: Well-Being & Resilience
- Module Five: IDD- & Trauma-Informed Services & Treatment
- Module Six: Provider Self-Care

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Module Three: Learning Objectives

What Will I Learn Today?

1. Identify the types of events that can cause traumatic stress.

2. Define traumatic stress and trauma-related disorders.

3. Identify how traumatic experiences and their responses affect people with IDD.

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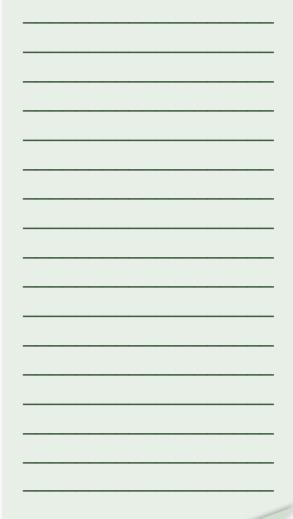
Recognize

the signs and symptoms of trauma

How would you define 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)
- Mass trauma (e.g., natural disaster, civil unrest, pandemic)
- Experiences that are a mixture of the above

Type & Timing Matters

Pre-trauma → Traumatic Experience → Post-Trauma

What is Traumatic Stress?

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

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

Ongoing **pattern of symptoms** may be diagnosed as PTSD or other mental health disorders

Trauma and Stressor-Related Disorders

Not Just PTSD

- Reactive Attachment Disorder
- Disinhibited Social Engagement Disorder
- Posttraumatic Stress Disorder
- Acute Stress Disorder
- Adjustment Disorders

Criteria for PTSD

Traumatic Event			
Intrusions	Avoidance	Negative Cognitions Mood	Arousal

PTSD with Dissociative Symptoms

Depersonalization
- Feeling detached or outside of body
- Feeling of time moving slowly

Derealization
- Unreality of surroundings World around individual is unreal, distorted, dreamlike

May manifest as acting-out of the trauma, self injury, agitation, aggression, or disorganized behavior in people unable to verbalize these unusual experiences

Acute Stress Disorder

- Similar symptoms and adapted criteria as PTSD
- Duration of at least 3 days, less than 1 month

Intrusion
Negative Mood
Dissociative Symptoms
Avoidance
Arousal

Reactive Attachment Disorder

Consistent pattern of withdrawn behavior toward caregivers

Persistent Social and Emotional Disturbance

Pattern of extreme neglect or unstable attachment

- Extreme rearing conditions believed to cause disturbed behavior
- Not due to autism spectrum
- Disturbance before age 5
- Developmental age at least 9 months

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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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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12 Core Concepts

- Complexity
- Development
- Social Contract
- Life experience
- Wide-ranging Reactions
- Protective Factors
- Reminders and Adversities
- Danger and Safety
- Provider Distress
- Culture
- Caregiving Systems
- Neurobiology

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Core Concept 1: Complexity

"There's a lot going on in the person's mind and body."

<u>For a person with IDD</u>

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

Intrinsic Factors
- Cognitive, social, and emotional development
- Co-occurring conditions
- Prior exposure to trauma

Trauma's Broad Context

Extrinsic Factors
- Physical environment
- Community & cultural responses to IDD
- Community & cultural responses to trauma

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Core Concept 2: Life Experience

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

<u>For a person with IDD</u>
It is important to understand the traumatic experience within the context of how IDD affects the person's everyday life.

Community

Providers

Family

Person

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Core Concept 3: Reminders & Adversities

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

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

Trauma Reminders

"For the longest time we couldn't understand why Billy would get so agitated for no apparent reason. We had no idea that the perfume his personal care attendant sometimes wore reminded him of his assault years ago."

Core Concept 4: Wide-Ranging Reactions

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

For a person with IDD
Recognizing reactions to trauma in adults with IDD can be complicated by the wide-ranging expressions of their disabilities.

Core Concept 5:
Danger & Safety

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

For a person with IDD

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

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Core Concept 6: Caregiving Systems

"Everyone is shaken up by what happened."

• Community
• Providers
• Family
• Individual

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

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Core Concept 7:
Protective Factors

"Promoting and restoring."

For a person with IDD

Reassure the person and parents/caregivers that strategies for addressing the effects of traumatic experiences *can* be adapted for adults with IDD by enhancing protective factors.

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Core Concept 8: Development
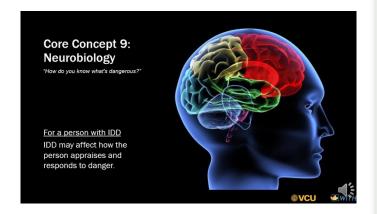
"Don't just think symptoms—think development."

For a person with IDD
Traumatic experiences may result in a significant setback in developmental progress, which was already challenged by IDD.
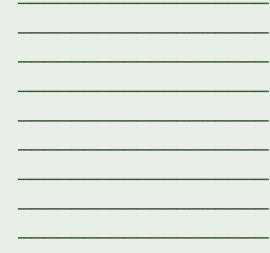
Core Concept 9: Neurobiology

"How do you know what's dangerous?"

For a person with IDD
IDD may affect how the person appraises and responds to danger.

Core Concept 10: Culture

"Culture is layered in its meaning and layered in its effects."

Exchange Support

Get Help

Experience & Express Distress

Disclose Personal Information

For a person with IDD
People 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.

Core Concept 11: Social Contract

"Protection has failed in some way."

For a person with IDD

People with IDD and their families are impacted by societal attitudes about disability, which can affect their capacity to obtain support and/or justice in the face of traumatic experiences.

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 or provider of an adult with IDD

Traumatic experiences may (re-)evoke concerns about the vulnerability of the person with IDD and their own inability to protect them from harm.

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PUTTING IT INTO PRACTICE
CASE VIGNETTES: RESPONSES TO TRAUMATIC EXPERIENCES

Read the case vignette your group has been assigned and identify details related to trauma and intellectual and developmental disability. Keep in mind that not every case will touch on all of the Core Concepts we've just discussed. Refer to the 12 Core Concepts handout to remind you of the main point for each Core Concept.

- Identify the traumatic experience(s) and any trauma/loss reminders.

- Identify the Core Concepts that are applicable to the case.

- Think about the person with intellectual and developmental disability that you identified in our first exercise on the Making the Connection handout—how do traumatic experiences impact this person? How would you apply the Core Concepts to this person?

12 Core Concepts

for Understanding Traumatic Stress in People with Intellectual and Developmental Disabilities

Core Concept 1: Complexity - "There's a lot going on in the person's mind and body."

Core Concept 2: Life Experience - "What the person brings to the experience from within and from the outside world effects their response."

Core Concept 3: Reminders & Adversities - "What's the world like that the person is living in afterwards?"

Core Concept 4: Wide-Ranging Reactions - "A person's reaction to traumatic events varies greatly."

Core Concept 5: Danger & Safety - "A person's ability to believe in and trust in a protective shield has been broken and must be restored."

Core Concept 6: Caregiving Systems - "Everyone is shaken up by what happened."

Core Concept 7: Protective Factors - "Promoting and restoring"

Core Concept 8: Development - "Don't just think symptoms—think development."

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

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

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

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."

Responses to Traumatic Experiences

! **Essential Messages**

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

What Can a Provider Do?

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

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ACTION PLANNING
ESSENTIAL MESSAGE 5

Think about the person you identified at the end of Module 1 that connects you to this work. What can help that person and other adults with IDD who have experienced trauma? (Put an "X" in up to 3 boxes next to the ideas you think you would MOST like to emphasize in your daily practice.)

5

ESSENTIAL MESSAGE 5

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

❑ Over the next 3 months, I will identify the **moment-to-moment reactions** people have during traumatic experiences with 3 adults with IDD.

❑ Over the next 3 months, I will explore **extrinsic factors** (e.g., physical environment, community & cultural responses to trauma & IDD) for 3 adults with IDD who have experienced trauma.

❑ Over the next 3 months, I will identify 2 **trauma reminders** for 3 adults with IDD who had experienced trauma. I will check in with them about their responses to these reminders each time I meet with them.

❑ Over the next 3 months, I will identify the impact of the traumatic experience on the **caregiving system** for 3 adults with IDD who have experienced trauma.

❑ Over the next 3 months, I will identify at least 3 **protective factors** that will help people to recover more quickly from the harmful effects of trauma or loss for 3 adults with IDD who had traumatic experiences. I will check in about these protective factors each time I meet with them.

❑ Over the next 3 months, I will ask 3 parents/caregivers about their feelings about the traumatic experience of the person with IDD they support to assess whether they need a referral to address **secondary traumatic stress**.

❑ (**Write my own**.) Over the next 3 months, I will…

Module Four

Well-Being and Resilience

THRIVING

HELPING ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES HEAL AND THRIVE FOLLOWING TRAUMA

WITH   VCU

Modules

- Module One: Setting the Stage
- Module Two: Development, IDD & Trauma
- Module Three: Traumatic Stress Responses in People with IDD
- **Module Four: Well-Being & Resilience**
- Module Five: IDD- & Trauma-Informed Services & Treatment
- Module Six: Provider Self-Care

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**Module Four:
Learning objectives**

What Will I Learn Today?

1. Explore the impact on caregivers of learning about the traumatic experience of the person with IDD they care for.
2. Explain strategies for strengthening protective factors to enhance 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 adults with IDD.
4. Identify person-centered planning techniques to help adults with IDD realize their hopes and dreams.

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

Protective Factors

Individual	Family	Community	Culture
• Cognitive Ability • Self-Efficacy • Internal Locus of Control • Temperament • Social Skills	• Family Cohesion • Secure Attachment • Interaction • Social Support (e.g. extended family support)	• Positive School Experiences • Community Resources • Supportive Peers / Mentors • Formal Support (e.g. Regional Center)	• Strong Sense of Cultural Identity • Spirituality • Connection to Cultural Community • Cultural Talents and Skills

Protective Factors

Community
Providers
Family
Individual

- Help Navigate Systems of Care, Including Systems Challenges
- Help Access IDD- & Trauma-Informed Support & Services
- Partner with Caregivers to Create a Recovery Team
- Address Trauma Experiences of Caregivers
- Promote Secure Attachment
- Promote a Healing & Protective Environment
- Promote Person-Centered Planning
- Provide Timely Information
- Ask & Answer Questions

Respond

Change behaviors, policies, and services to take trauma into account

Ask & Answer Questions

- Responses to Traumatic Experiences
- Cultural/Linguistic Factors
- Traumatic Experiences of Caregivers
- Family Dynamics
  - Current and historical dynamics
  - Needs of the Caregivers
- Existing Supports/Protective Factors

Provide Timely Support

- Prompt intervention, in response to traumatic experiences, can diminish the overall effects of traumatic stress in people with IDD using Psychological First Aid.
  - Stabilization
  - Information Gathering
  - Practical Assistance
  - Connection with Social Supports
  - Information on Coping
  - Linkage with Collaborative Services

Promote a Healing & Protective Environment

- Create or recreate a safe & secure interpersonal environment
  - "Micro-behaviors of relationships"
- Recognize behavior as the person's method for adapting to unwanted circumstances
- Use person-centered tools to:
  - Increase quality of life
  - Change the environment
  - Use alternative means of communication
  - Teaching skills (e.g., express needs & feelings in words, signs, pictures)

All Behavior is Communication

"If You Listen, You Will Hear Us" https://youtu.be/Hp4PW17U_h8

Enhance Well-Being and Resilience

- Families and caregivers are a critical part of both protecting people from harm and enhancing their well-being.
- Providing trauma-informed education and services to parents and other caregivers enhances their protective capacities.
- Providers should recognize that caregivers themselves may have trauma histories or experience secondary traumatic stress.

Recognize Caregivers' Hopes & Concerns

Caregivers of people with IDD want:

- To find & provide the best care for the person they support

- To sustain & maximize the person's maturity and independence across development & changing circumstances

- To help them function at his/her best and attain a meaningful life

The Challenge for Caregivers

- Feelings of Inadequacy/ Not Knowing What to Do

- Grief & Loss

- Strain on Relationships

- Anticipatory Anxiety

- Secondary Traumatic Stress

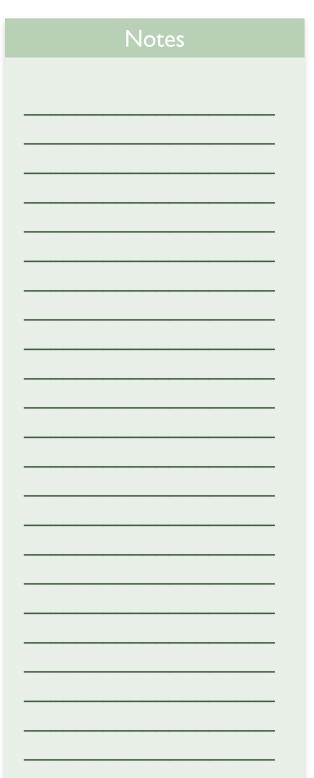- Stress due to ongoing needs of the person that has continued into adulthood

Address Traumatic Experiences of Caregivers

A personal history of trauma can:

- Compromise caregivers' decision-making
- Interfere with their ability to form and maintain secure & trusting relationships (with the person with IDD, partners, & service providers)
- Impair caregivers' ability to regulate their emotions
- Lead to less effective coping strategies, including substance abuse
- Cause caregivers to be reminded of their own traumatic experiences

Promote Secure Attachment

- A highly responsive caregiving style is associated with a variety of benefits across developmental stages – including into adulthood.
  - Imagine the inner life of the person
  - Create or re-create a nurturing/healing environment
  - Provide comfort to help a person regulate
  - Structure, routine & limit-setting
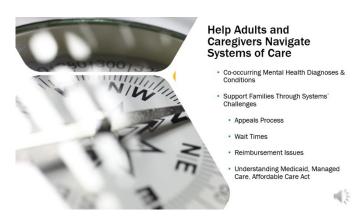- Facilitate healthy relationships with peers in the community.

Help People Access IDD & Trauma-Informed Support

LOCAL RESOURCES

Begin this exercise by identifying 5 local organizations that you frequently refer people and their caregivers to or find helpful. Once you've created your own list, walk around the room and ask others to share their list—find at least 5 new organizations to add to your list.

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

10. _____

Partner with Caregivers to Create a Recovery Team

Person with IDD

Additional Medical Specialists · Service Coordinator · Parents · Friends · Employers · Therapists (MH, PT, OT, Speech) · Medical Team · Respite Providers · Other Caregivers · Coach · Siblings & Other Family Members · Spiritual Leaders

—— Strong, positive connection   ····· Stressful connection

Help Adults and Caregivers Navigate Systems of Care

- Co-occurring Mental Health Diagnoses & Conditions
- Support Families Through Systems' Challenges
  - Appeals Process
  - Wait Times
  - Reimbursement Issues
  - Understanding Medicaid, Managed Care, Affordable Care Act

Putting It Into Practice

**Activity-
Putting It Into Practice**

Resist

Take steps to resist re-traumatization of clients and staff with trauma histories

**Promote Person-
Centered Planning**

- Develop a treatment and support plan using child-centered planning
  - Identify what is important to the person
  - Identify what others need to do to support what is important to the person
- Identify key individuals involved in person's life
- Foster collaborative relationships among those individuals

Positive Behavior Support

- Effectively used with individuals with IDD & mental health needs
- Different from behavior management
- Starts with the premise that individuals are coping in the most effective way they know
- Change the environment so that individuals can get what they want & teach skills so they have more effective tools to get what they want or cope when they can't

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Gentle Teaching

- Developed by John McGee to interact with people with IDD & challenging behavior.
- Basic premise is that challenging behavior is a reflection of life experience often characterized by absence of quality of life &/or trauma.
- Focuses on interacting in ways that improve quality of life for the person with IDD through meaningful & positive reciprocal relationships.
- Relationships are understood in GT as transacted in repetitive micro-behaviors using the tools of our hands, eyes, voice & presence.
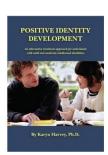
https://gentleteaching.com/

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Gentle Teaching

Positive Identity Development

- Developed by Karyn Harvey, PhD to assist individuals with IDD in revealing their true potential as human beings & experiencing the happiness in life that they so deserve
- Positive identity development for people with IDD focuses on discovering, defining & celebrating the self vs taking on the sole identity of "disabled"
- Basic premise is that an approach modeled on psychological well-being vs ineffective behaviors leads to human health & authentic happiness

POSITIVE IDENTITY DEVELOPMENT

An alternative treatment approach for individuals with mild and moderate intellectual disabilities

By Karyn Harvey, Ph.D.

VCU | WITH

Positive Identity Development

- **Pleasure**: things we enjoy in a predominantly happy state (e.g., eating, watching TV)
  - Passive
- **Engagement**: actively participating in something that is enjoyable (e.g., cooking, hiking)
  - Often leads to the development of skills & talents
- **Meaning**: the act of making a real difference in the world of others through use of one's own strengths

http://www.pursuit-of-happiness.org/teaching-resources/

Self-Actualizatio
Self-esteem
Love and belonging
Safety
Physiological

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Positive Identity Development

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

Available at pid.thenadd.org

My Book About Recovery!

This is the book about
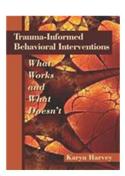
Traveling the Long Road to Recovery

By

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Trauma-Informed Behavioral Interventions

- Rich descriptions and case vignettes of effects of trauma on people with IDD.
- Strategies for trauma-informed crisis prevention and intervention.
- Examples of trauma-informed behavior support plans

https://www.aaidd.org/publications/bookstore-home/product-listing/trauma-informed-behavioral-interventions-what-works-and-what-doesnot

Essential Messages

6. Utilize an IDD- & trauma-informed person-centered approach to support both the adult with IDD & the caregivers.

7. Help caregivers, and other professionals in the person's life, strengthen protective factors.

What Can a Provider Do?

- Identify and enhance strengths and natural supports.
- Ask questions about what they need.
- Take the time to listen to 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 access support.
- Help find access to respite care.

ACTION PLANNING
ESSENTIAL MESSAGES 6 & 7

Think about the person you identified at the end of Module 1 that connects you to this work. What can help that person and other adults with IDD who have experienced trauma? (Put an "X" in up to 3 boxes next to the ideas you think you would MOST like to emphasize in your daily practice.)

6 ESSENTIAL MESSAGE 6

Utilize an IDD- & trauma-informed person-centered approach to support both the adult and the caregivers.

❑ Over the next 3 months, I will identify at least **3 activities** that adults with IDD who have had traumatic experiences find meaningful. I will check in with them about these activities each time we meet.

❑ Over the next 3 months, I will identify at least **3 life goals** (in their own words), that adults with IDD who have had traumatic experiences have for themselves. I will check in about these life goals each time we meet.

❑ Over the next 3 months, I will identify at least 3 adults with IDD who have **siblings**. I will work with the caregivers to identify needs of the siblings.

7 ESSENTIAL MESSAGE 7

Utilize a developmental lens when making meaning of a person's traumatic experiences and responses.

❑ Over the next 3 months, I will identify 3 **protective factors** to strengthen for 3 adults with IDD who had traumatic experiences. For each person, I will review these protective factors each time we meet during this 3-month period and develop strategies for enhancing them.

❑ Over the next 3 months, I will identify 3 adults with IDD, with whom I can work to **increase happiness** through activities that provide engagement and meaning. I will ask them about the activities each time we meet.

❑ Over the next 3 months, I will identify 3 adults with IDD to work with on building a **recovery team**. I will identify ways (in person, by phone, or by email) that I can help facilitate the participation of other providers on the recovery team.

❑ (Write my own.) Over the next 3 months, I will…

Module Five

IDD- and Trauma-Informed Services and Treatment

Modules

- Module One: Setting the Stage
- Module Two: Development, IDD & Trauma
- Module Three: Traumatic Stress Responses in People with IDD
- Module Four: Child & Family Well-Being & Resilience
- Module Five: IDD- & Trauma-Informed Services & Treatment
- Module Six: Provider Self-Care

Module Five: Learning objectives

What Will I Learn Today?

1. Explain how to enhance protective factors of people with IDD & caregivers through appropriate trauma-informed services & treatment.

2. Discuss how to utilize adapted screening, assessment & planning tools to identify IDD- & trauma-informed needs of people with IDD.

3. Discuss strategies for adapting the core components of trauma-informed treatments for people with IDD.

4. Identify strategies for partnering with agencies & cross-system collaboration.

Multiple Providers, Multiple Hats

Sometimes a provider has multiple roles. Most of the time, multiple providers each wear multiple hats.

Potential Pathways for Identifying IDD & Trauma

Natural Supports	Primary Care Provider	Referral to Adult Protective Services
Referral to Behavioral/Crisis Support Services	Referral to Trauma-Informed Services & Treatment	Referral to Informal Support Groups/Classes

Developing a Recovery Plan

Screening → Assessment → Recovery Plan

IDD-Related Needs

Trauma-Related Needs

Identify IDD-Related Support Needs

Screening → Assessment → Recovery Plan

- Developmental assessment & screening provide care providers with the opportunity to
  - Understand how the person is functioning
  - Understand how treatment may need to be modified to support the person
- Input from caregivers is invaluable in understanding the person's functioning in relation to his/her peers

Identify IDD-Related Support Needs

Screening

Assessment

Recovery Plan

- World Health Organization Disability Assessment Schedule 2.0
- Can be licensed for commercial or non-commercial use
- Available in many languages
- 3 versions
  - 36-items across 6 domains of functioning
    - Cognition
    - Mobility
    - Self-Care
    - Getting Along with Others
    - Life Activities
    - Participation in Community Activities
  - 12-item brief assessment of overall functioning
  - 12 + 24 version
- 3 Formats
  - Interviewer-administered
  - Self-report
  - Proxy-administered (e.g. parent/caregiver)

Source: http://www.who.int/classifications/icf/whodasii/en/

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Identify IDD-Related Support Needs

Screening

Assessment

Recovery Plan

- The Arc's Self-Determination Scale Adult Version
- Right of people to have control in their lives.
- Original Version
  - https://thearc.org/wp-content/uploads/forchapters/SD%20Scale%20Procedural%20Guidelines.pdf
- Adult Version
  - https://rtcom.umn.edu/database/instruments/asds

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Identify IDD-Related Support Needs

Screening

Assessment

Recovery Plan

Developmental Assessment

- A more in-depth exploration of the IDD and/or impact on development
- Venues for Assessment
  - Regional Center/Mental Health System
    - Neuropsychological / psychoeducational assessment
  - Medical System
  - Legal System

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Identify IDD-Related Support Needs

- Examples of Assessment Tools
  - Intelligence assessments
    - Wechsler Adult Intelligence Scales
    - Stanford-Binet Intelligence Scale
    - Woodcock-Johnson Tests of Cognitive Ability
  - Adaptive functioning assessments
    - Vineland
    - Adaptive Behavior Assessment Systems
    - Assessment of Functional Living Skills
    - Developmental Assessment for Individuals with Severe Disabilities
  - Non-verbal assessments
    - Wechsler Nonverbal Scale
    - Universal Nonverbal Intelligence Test
    - Leiter International Performance Scale
- Be aware of floor effects!
  - May not accurately portray the relative strengths and weaknesses

Screening — Assessment — Recovery Plan

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Identify IDD-Related Support Needs

- People with IDD may have more or less facility with communication
- Communication may be a struggle because a person may be nonverbal &/or use assistive communication devices
- Complex & chronic medical comorbidities (e.g., chronic lung disease, seizures & complex feeding problems) may require reliance on technologies (e.g., tracheostomies, home oxygen & gastrostomy tubes)
- Intensive coordination of services & therapies may detract from trauma-focused and related behavioral needs
- Disability Care Coordination Organizations

Screening — Assessment — Recovery Plan

VCU WITH

Identify Trauma-Related Support Needs

- Not everyone needs trauma-focused treatment.
- Trauma screening and assessment help identify the people who most need trauma-focused therapy.
- Consider the *type* of trauma experienced when making service referrals & service plans.
- Assess the functioning of the caregiving system, including the impact of caregiver trauma.

Screening — Assessment — Recovery Plan

VCU WITH

Identify Trauma-Related Support Needs

- Involve the person with IDD to the extent possible.
  - May need to make use of an intermediary (*e.g., sign language interpreter, professional familiar with assistive devices*)
- 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*)
- Involve a wide range of caregivers in the assessment process (e.g., parents, siblings, paid support staff, day program staff)

Screening → Assessment → Recovery Plan

VCU WITH

Identify Trauma-Related Support Needs Screening

- Does not necessarily have to be administered by a mental health professional
- Usually includes questions regarding exposure to trauma & related symptoms
- Assists providers in understanding the person's & family's history & potential trauma reminders
- Directs trauma-informed case planning; positive screen may result in referral for comprehensive trauma mental health assessment

Screening → Assessment → Recovery Plan

VCU WITH

Identify Trauma-Related Support Needs

Examples of trauma screening tools for adults with IDD include

Bangor Life Events Schedule for Intellectual Disabilities (BLESID)
- Self-report and caregiver-report versions available at http://www.leehw.com/blesid/
  - Hulbert-Williams, L., Hastings, R. P., Crowe, R., & Pemberton, J. (2011). Self-Reported Life Events, Social Support and Psychological Problems in Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities, 24*(5), 427–436. https://doi.org/10.1111/j.1468-3148.2011.00624.x

Lancaster and Northgate Trauma Scales (LANTS)
- Self-report and caregiver-report versions
  - Wigham, S., Hatton, C., & Taylor, J. L. (2011). The Lancaster and Northgate Trauma Scales (LANTS): The development and psychometric properties of a measure of trauma for people with mild to moderate intellectual disabilities. *Research in Developmental Disabilities, 32*(6), 2651–2659. https://doi.org/10.1016/j.ridd.2011.06.008

Screening → Assessment → Recovery Plan

VCU WITH

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Identify Trauma-Related Support Needs

Examples of trauma screening tools for adults with IDD include

Impact of Events Scale – Intellectual Disabilities

- Self-report version
  - Hall, J. C., Jobson, L., & Langdon, P. E. (2014). Measuring symptoms of post-traumatic stress disorder in people with intellectual disabilities: The development and psychometric properties of the Impact of Event Scale-Intellectual Disabilities (IES-IDs). *The British Journal of Clinical Psychology*, *53*(3), 315–332. https://doi.org/10.1111/bjc.12048

Screening
Assessment
Recovery Plan

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Identify Trauma-Related Support Needs

- Many caregivers have histories of trauma (in childhood & adulthood).
- Trauma can impact caregiving & protective capacities.
- Awareness of caregiver trauma history helps providers better understand caregivers and link them to appropriate services.
- Examples of screening tools for caregivers:
  - Parent Emotional Reaction Questionnaire
  - Life Events Checklist
  - Trauma Recovery Scale

Screening
Assessment
Recovery Plan

VCU WITH

Identify Trauma-Related Support Needs

Trauma Assessment

- A more in-depth exploration of the nature & severity of the traumatic events, the impact of those events, current trauma-related symptoms & functional impairment
- Includes a clinical interview, use of objective measures, behavioral observations of the person, and collateral contacts with family, caseworkers, etc
- Usually conducted by a mental health provider to drive treatment planning
- May occur over at least 2-3 sessions
- Should be used to determine the treatment plan

Screening
Assessment
Recovery Plan

VCU WITH

Identify Trauma-Related Support Needs

Screening → Assessment → Recovery Plan

- Domains covered include:
  - Basic demographics
  - Family history
  - Trauma history (comprehensive, including events experienced or witnessed)
  - Developmental history
  - Overview of person's problems/symptoms
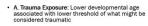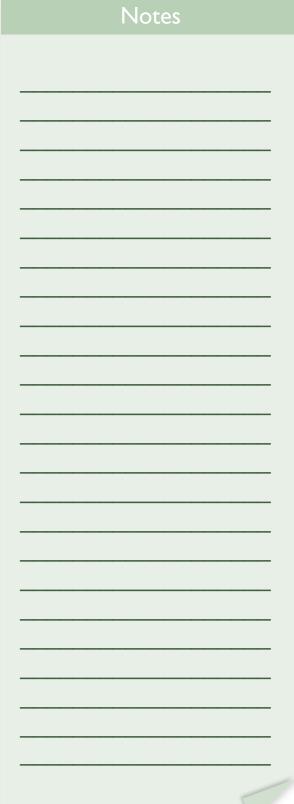
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Identify Trauma-Related Support Needs

Screening → Assessment → Recovery Plan

DSM-5 ICD 10-CM 2018 DM-ID 2

Classification Systems

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Adaptations to Diagnostic Criteria for PTSD

As recommended by DM-ID 2

- **A. Trauma Exposure:** Lower developmental age associated with lower threshold of what might be considered traumatic
- **B1. Distressing Memories:** Behavioral acting out and self-injury may be symptomatic for those with greater cognitive impairment
- **B2. Recurrent Dreams:** Distressing dreams without recognizable content may be more common in people with more severe cognitive impairment
- **B3. Dissociative Reactions:** Trauma-specific reenactments may be confused with symptoms of psychosis in adults with IDD
- **B4. Distress to Internal or External Cues:** May appear as disorganized or agitated behavior in people with greater cognitive impairments

Adaptations to Diagnostic Criteria for PTSD

As recommended by DM-ID 2

- **C. Avoidance of Trauma Cues:** Like trauma exposure threshold, the threshold for what may activate a trauma reaction may lower and broaden and result in a lowering and broadening of the avoidance
  - May be reported as "noncompliance" for individuals unable to verbalize reasons for avoidance
- **D1. Inability to Recall Details of Traumatic Event:** May be associated with cognitive impairment and requires careful assessment

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Identify Trauma-Related Support Needs

Screening
Assessment
Recovery Plan

DM-ID-2 Workbook

- Structured diagnostic method for mental health professionals.
- Incorporates structured caregiver interview for observable signs
- Guides clinicians in making more accurate diagnoses.

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Identify Trauma-Related Support Needs

Screening
Assessment
Recovery Plan

IDD- & Trauma-Informed Services & Treatment

- Trauma-Informed Services: refers to a broad array of support & care, including treatment
  - Advocacy
  - Case Coordination
- Trauma-Informed Treatment: refers to interventions that focus on addressing symptoms & responses to traumatic experiences
  - Continuous Assessment
  - Cross-System Partnerships

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Identify Trauma-Related Support Needs

Developing IDD- & Trauma-Informed Recovery Plans

- Identify what is important to the person.
  - Recognize the person's talents and strengths as well as needs.
  - Include the person's personal circle of significant relationships when developing a plan.
  - Identify the person's hopes and dreams, as well as fears and nightmares.
- Identify additional information that you need to gather.
  - Trauma assessment/screening
  - Protective factors to enhance
- Focus on concrete action to move toward the desired life.
  - Referrals to trauma-focused treatment
  - Referrals to other supportive services (e.g., respite, activities, parent trauma)

Screening → Assessment → Recovery Plan

VCU WITH

PUTTING IT INTO PRACTICE: FISH BOWL

In this activity, we will be using a role play to consider the perspective of people with IDD and/or their caregivers and providers when accessing services.

Let's put this into practice. Split up into groups of 4. Once you have your groups, please take your chairs and put them in a cross formation so a pair of them is facing one another and the other pair is facing on another. It will look like a +.

At your tables, assign a pair of chairs facing each other to be a provider and a person with IDD and/or their family member, and the other pair to be two observers.

Now take a seat and either choose a case vignette from your Participant Manual or think of a person with IDD your caseload to role play.

Once the activity starts the provider will begin asking the person with IDD and/or their family member questions to start the process of getting them closer to a IDD- & trauma-informed recovery plan. Think of everything we've already talked about.
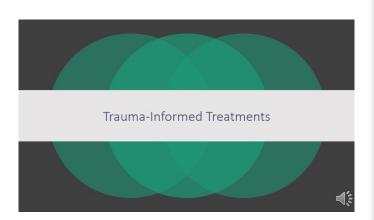
• Do you want to get information on the IDD diagnosis, or maybe the traumatic experience?

• Do you bring up screening and assessment?

• Identify risk or protective factors?

While the role play is occurring the two observers will watch and listen. At any point during the role play, the observers have the opportunity to pause the role play and give the provider helpful, supportive, or constructive feedback. When the feedback is done the role play can continue.

When I say stop, everyone will freeze, each group will stand and rotate clockwise, changing the roles of each group member. When I say continue, the group will carry on where the last one left off. Observers will then be able to pause the game as seen fit.

This will go on until everyone has a chance to be the provider, person with IDD and/or their family member, and the observer.

Once everyone has gone through all 3 roles, we will have a large group report out to talk about how that felt, what worked well, what you would chance next time you are confronted with the same situation, etc.

Trauma-Informed Treatments

Trauma-Informed Evidence-Based Treatments

There are many different evidence-based trauma-informed treatments. A trauma-informed mental health professional should be able to determine which treatment is most appropriate for a particular person and/or their caregivers.

- Cognitive Processing Therapy
- Cognitive Therapy
- Individual CBT with a Trauma Focus
- Prolonged Exposure
- Eye Movement Desensitization and Reprocessing (EMDR)
- *For fact sheets on treatments:*
- *http://www.istss.org/treating-trauma/new-istss-guidelines.aspx*

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How do trauma treatments work?

- Many effective trauma treatments rely on cognitive behavioral strategies:

  - Teach stress management & relaxation skills to cope with unpleasant feelings about the trauma

  - Utilize "exposure strategies" (i.e., talking about the traumatic experience at a speed that controls the level of distress for the person)

  - Create a trauma "narrative" or story of what happened in order to master painful feelings about the experience & resolve the impact of the experience

  - Explore potentially untrue ideas about what happened & why

  - Change unhealthy/incorrect views

  - May involve parents or other caregivers

Adaptations to Trauma-Focused Treatment

- Increased psychoeducation
  - Building an emotion vocabulary
  - Differentiating between thoughts, feelings, and behaviors
- Modify pace
- Frequent review of concepts
  - Practice skills multiple times in session
- Generalization Training
  - Increased opportunities to practice out of session
  - Practice in as many settings as possible
  - Enlist caregivers and support

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Trauma-Focused CBT
Adaptations for People with IDD

- Be creative in the ways in which the narrative is recorded
  - Dictate responses
  - Use a tape recorder, video or still camera
  - Role-play, sing or dance
  - Use play
- Slow down pace
  - Allow additional time to share thoughts & feelings about traumatic experience
- Recognize that repetition is helpful for learning
  - A person with IDD may return repeatedly to inaccurate or unhelpful cognitions

Source: Brian Tallant, LPC, Aurora Mental Health Center

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Trauma Services & Treatment Adaptations for People with IDD

- Be sure that all members of the caregiving team are using the same language to address the traumatic experience(s).
- Check for comprehension—don't assume that the material is too complex for the person to understand.
- Use multisensory interventions (e.g., non-verbal, play therapy) & tools to assist in learning.
- Allow more time for the client to learn the skills & use more repetition.
- Work explicitly on generalization of skills to other environments.

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Learning more about CBT strategies for People with Intellectual Disabilities

- Book: "**Cognitive Behaviour Therapy for People with Intellectual Disabilities: Thinking creatively**" by Andrew Jahoda, Biza Stenfert Kroese, and Carol Pert. Published by Palgrave Macmillan
- Book: "**The Emotion Regulation Skills System for Cognitively Challenged Clients: A DBT-Informed Approach**" by Julie Brown. Published by Guilford Press
- Online Course: "**Tailoring Trauma-Focused Cognitive Behavior Therapy for Children with IDD.**" The National Child Traumatic Stress Network's Learning Center https://learn.nctsn.org/enrol/index.php?id=566
- Online Course: "**Using Cognitive Behavioral Therapy with Persons with IDD.**" Relias Academy https://reliasacademy.com/rls/store/browse/productDetailSingleSku.jsp?&productId=c1110648

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IDD- & Trauma-Informed Services & Treatment: Questions to Ask

- Do you provide services to people with IDD who have had traumatic experiences?
- How do you approach therapy with people & their caregivers who have had traumatic experiences (regardless of whether they indicate or request trauma-informed treatment)?
- Do you provide trauma-specific or trauma-informed therapy? If so, how do you determine whether the person needs trauma-informed therapy (e.g., screening/assessment tools)?
- How familiar are you with evidence-based treatment models designed & tested for treatment of person trauma-related symptoms?
- Can you describe the core components of your treatment approach?

Other Services That Enhance Resilience & Recovery

- Mentoring programs
- Sports, arts, recreational activities
- Community service
- Wraparound programs

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Trauma & IDD: Create an Integrated System of Care

Healthcare Providers	Tribal, Community, and Faith-Based Organizations
Education/ Special Ed	Emergency Medicine
Public & Private Mental Health Agencies/Providers	Attorneys
Non-Profit Social Service Agencies	Legal System
Juvenile Justice	Foster Care & Adoption Agencies

Public & Private Health Departments
Law Enforcement
Specialty Programs (e.g., substance abuse/domestic violence)
Adult Welfare
Advocates

Advocacy Centers
Medicaid/ Managed Care/ Insurers
Courts
Disability Services Organizations
Federal Programs

Strategies for Cross-System Collaboration

- Cross-train on the intersection of trauma and IDD
- Jointly develop protocols regarding trauma and collaborative services that promote resiliency
- Create multi-disciplinary teams
- Schedule regular team meetings
- Co-locate staff in clinics & community "hubs"
- Identify & utilize cross-system assessment tools
- Share knowledge of local resources & trauma-informed treatment options
- Integrate information-sharing systems

PUTTING IT INTO PRACTICE:
CASE VIGNETTES: ACCESSING SERVICES

Read the case vignette your group has been assigned and answer the following questions. You may want to refer to the Protective Factors handout to give you some ideas.

- Are there protective factors that you want to keep in mind when identifying screening/assessment and/or treatment for this person and their caregivers? Are there protective factors that can be built upon in treatment? If you are unaware of any protective factors how would you cultivate some with this person and/or their caregivers?

- What challenges/barriers/risk factors do you anticipate coming up for this person and their caregivers? Do you think the challenges/risk factors will impact their ability to access services?

- What are three things you could do to advocate for this person and/or their caregivers to help them overcome these challenges?

PROTECTIVE FACTORS CHECKLIST

- ❑ Ask & answer questions of the person with IDD and their caregivers
- ❑ Provide timely information
- ❑ Address traumatic experiences of the person with IDD and their caregivers
- ❑ Promote secure attachment
- ❑ Promote a healing & protective environment
- ❑ Help access IDD- & trauma-informed support and services
- ❑ Partner with the person and caregivers to create a recovery team
- ❑ Help navigate systems of care, including systems challenges
- ❑ Offer community resources
- ❑ Connect people and families with supportive peers and mentors
- ❑ Refer for formal support if needed
- ❑ Encourage connection with any spiritual communities
- ❑ Connect the person and caregivers with cultural community
- ❑ Build & encourage family cohesion
- ❑ Promote supportive interactions between the person with IDD and their caregivers
- ❑ Build social skills
- ❑ Address cognitive functioning
- ❑ Promote self-efficacy skills

Remember These Faces?

Essential Messages

8. Partner with agencies and systems to ensure earlier and more sustained access to services.

9. Ensure that trauma-informed person-centered services, treatments and systems drive the recovery plan.

What Can a Provider Do?

- Identify the developmental level of the person in order to guide appropriate selection of trauma screening/assessment tools, services & treatments.

- Facilitate the person's self-determination

- 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 trauma and trauma-informed care.

- Identify and interview local individuals/agencies

ACTION PLANNING
ESSENTIAL MESSAGES 8 & 9

Think about the person you identified at the end of Module 1 that connects you to this work. What can help that person and other adults with IDD who have experienced trauma? (Put an "X" in up to 3 boxes next to the ideas you think you would MOST like to emphasize in your daily practice.)

8

ESSENTIAL MESSAGE 8

Partner with agencies and systems to ensure earlier and more sustained access to services.

❑ Over the next 3 months, I will identify 3 local agencies that provide **advocacy** for adults with IDD. I will attempt to make contact with at least 1 person in each agency.

❑ Over the next 3 months, I will identify 3 local organizations that provide **intensive case management or care coordination services** for adults with IDD. I will attempt to make contact with at least 1 person in each organization.

❑ Over the next 3 months, I will identify 3 local clinics/providers that provide **trauma-informed assessments** for adults. I will attempt to make contact with at least 1 person in each clinic.

❑ Over the next 3 months, I will identify 3 local clinics/providers that provide **trauma-informed treatment** for adults. I will attempt to make contact with at least 1 person in each clinic.

❑ (**Write my own**.) Over the next 3 months, I will…

ACTION PLANNING
ESSENTIAL MESSAGES 8 & 9

9	**ESSENTIAL MESSAGE 9** Ensure that trauma-informed person-centered services, treatments, and systems drive the recovery plan.

❑ Over the next 3 months, I will review the standardization, reliability, and validity information for 1 of the trauma screening or assessment tools I use to determine the appropriateness of use for adults with IDD.

❑ Over the next 3 months, I will identify a trauma screening tool and use it with 3 adults with IDD who have experienced trauma.

❑ Over the next 3 months, I will identify a tool to assess parent/caregiver trauma and use it with 3 caregivers of adults with IDD who have experienced trauma.

❑ Over the next 3 months, I will identify 3 adaptations I can make to my treatment of choice for 3 adults with IDD who have experienced trauma.

❑ (Write my own.) Over the next 3 months, I will…

Module Six

Provider Self-Care

Modules

- Module One: Setting the Stage
- Module Two: Development, IDD & Trauma
- Module Three: Traumatic Stress Responses in People with IDD
- Module Four: Child & Family Well-Being & Resilience
- Module Five: IDD- & Trauma-Informed Services & Treatment
- Module Six: Provider Self-Care

Module Five: 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.

Trauma Stewardship

- https://www.youtube.com/watch?v=tAKPgNZi_as

- <u>Secondary Traumatic Stress</u> (STS) refers to the development of post-traumatic stress symptoms caused by at least one indirect exposure to traumatic material.
- <u>Burnout</u> refers to emotional exhaustion, depersonalization, and a reduced feeling of personal accomplishment. Burnout develops as a result of general occupational stress.
- <u>Vicarious trauma</u> refers to changes in the inner experience of the therapist, resulting from empathetic engagement with a traumatized client. It focuses less on trauma symptoms and more on the changes that occur following cumulative exposure to another person's traumatic experience(s).

Provider Burnout

- Caseload that requires intensive case coordination
  - Need for Advocacy
  - Need for Collateral Engagement
- Longer therapeutic process & treatment times
- Working in a stressed system
- Identifying ways to adapt screening, assessment & interventions takes time

STS Warning Signs

Chronic Exhaustion	Disconnection/ Empathic Numbing	Social Withdrawal
Anger/ Cynicism	Avoidance	Issues with Boundaries
Diminished Self-Care	Illness	Survival Coping

STRESS WARNING SIGNS

Fill in the blanks below using the text in parentheses as your guide to learn more about your own stress warning signs.
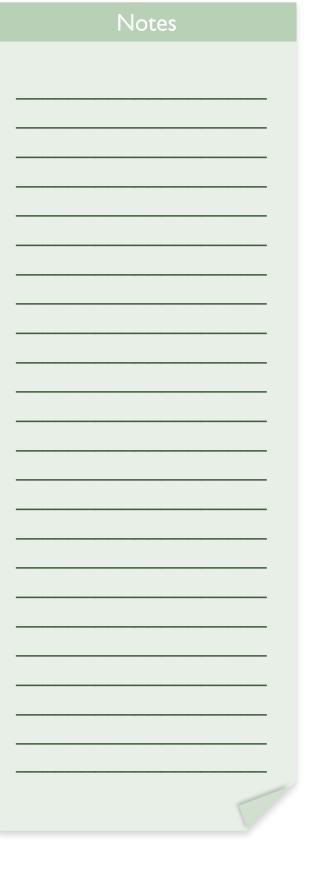
- I know that my stress level is beginning to affect my relationships when

  I _____, _____,
      (Identify a behavior or action verb)   (Identify a behavior or action verb)

  and _____.
      (Identify a behavior or action verb)

- Other people in my life can tell that I am stressed out when I look

  _____ or _____, or when I
  (Name an adjective that describes how you appear)   (Name an adjective that describes how you appear)

  sound like _____.
      (Name an unpleasant sound or noun)

- When I am feeling overwhelmed, staying connected is _____.
      (Write an adjective that says how you feel)

- The relationships in my life often _____ when my stress level is
      (Identify a verb)

  elevated.

What can we do?

Preventing and responding to burnout, secondary traumatic stress, or vicarious trauma

Self-care is the ability to engage in helping others without sacrificing other important parts of one's life.

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SELF-CARE OPTIONS

Below are some tips for using the time that you do have for self-care effectively. Carve out time each day to engage in self-care, even if you only have 2 minutes.

If you have…

2 minutes

- ❑ Breathe
- ❑ Stretch
- ❑ Daydream
- ❑ Take your stress temperature
- ❑ Laugh
- ❑ Doodle
- ❑ Acknowledge one of your accomplishments
- ❑ Say no to a new responsibility
- ❑ Complement yourself
- ❑ Look out the window
- ❑ Spend time with your pet
- ❑ Share a favorite joke

5 minutes

- ❑ Listen to music
- ❑ Have a cleansing cry
- ❑ Chat with a co-worker
- ❑ Sing out loud
- ❑ Jot down dreams
- ❑ Step outside for fresh air
- ❑ Enjoy a snack or make a cup of coffee/tea

10 minutes

- ❑ Evaluate your day
- ❑ Write in a journal
- ❑ Call a friend
- ❑ Meditate
- ❑ Tidy your work area
- ❑ Assess your self-care
- ❑ Draw a picture
- ❑ Dance
- ❑ Listen to soothing sounds
- ❑ Surf the web
- ❑ Read a magazine

30 minutes

- ❑ Get a massage
- ❑ Exercise
- ❑ Eat lunch with a co-worker
- ❑ Take a bubble bath
- ❑ Read non-work related literature
- ❑ Spend time in nature
- ❑ Go shopping
- ❑ Practice yoga
- ❑ Watch your favorite television show

The A-B-C's of Self-Care
- Awareness
- Balance
- Connection

Awareness

Body

Personal Life

Professional Life

Balance

Professional

Physical

Spiritual

Psychological

Emotional

Notes

_____

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BALANCING YOUR SELF-CARE

This assessment tool provides an overview of effective strategies to maintain self-care. Look through the list and see if there are one or two items you can start doing tomorrow.

Physical Self-Care
- [ ] Eat regularly (e.g. breakfast, lunch and dinner)
- [ ] Eat healthy
- [ ] Exercise
- [ ] Get regular medical care for prevention
- [ ] Get medical care when needed
- [ ] Take time off when needed
- [ ] Get massages
- [ ] Dance, swim, walk, run, play sports, sing, or do some other physical activity that is fun
- [ ] Take time to be sexual -- with yourself, with a partner
- [ ] Get enough sleep
- [ ] Wear clothes you like
- [ ] Take vacations, day trips, or mini-vacations
- [ ] Make time away from telephones
- [ ] Other:

Psychological Self-Care
- [ ] Make time for self-reflection
- [ ] Have your own personal psychotherapy
- [ ] Write in a journal
- [ ] Read literature that is unrelated to work
- [ ] Do something at which you are not expert or in charge
- [ ] Decrease stress in your life
- [ ] Let others know different aspects of you
- [ ] Notice your inner experience --listen to your thoughts, judgments, beliefs, and feelings
- [ ] Practice receiving from others
- [ ] Be curious
- [ ] Say "no" to extra responsibilities sometimes
- [ ] Other:

Emotional Self-Care
- [ ] Spend time with others whose company you enjoy
- [ ] Stay in contact with important people in your life
- [ ] Give yourself affirmations, praise yourself
- [ ] Re-read favorite books, watch favorite movies
- [ ] Identify comforting activities, objects, people, relationships, places and seek them out
- [ ] Allow yourself to cry
- [ ] Find things that make you laugh
- [ ] Express your outrage in social action, letters and donations, marches, protests
- [ ] Other:

Spiritual Self-Care
- [ ] Make time for reflection
- [ ] Spend time with nature
- [ ] Find a spiritual connection or community
- [ ] Be open to inspiration
- [ ] Cherish your optimism and hope
- [ ] Be aware of nonmaterial aspects of life
- [ ] Try at times not to be in charge or the expert
- [ ] Be open to not knowing
- [ ] Identify what is meaningful to you and notice its place in your life
- [ ] Meditate
- [ ] Pray
- [ ] Sing
- [ ] Spend time with children
- [ ] Have experiences of awe
- [ ] Contribute to causes in which you believe
- [ ] Read inspirational literature (talks, music, etc.)
- [ ] Other:

Workplace or Professional Self-Care
- [ ] Take a break during the workday (e.g. lunch)
- [ ] Take time to chat with co-workers
- [ ] Make quiet time to complete tasks
- [ ] Identify projects or tasks that are exciting and rewarding
- [ ] Set limits with your clients and colleagues
- [ ] Balance your case load so that no one day or part of a day is "too much"
- [ ] Arrange your work space so it is comfortable and comforting
- [ ] Get regular supervision or consultation
- [ ] Negotiate for your needs (benefits, pay raise)
- [ ] Have a peer support group
- [ ] Develop a non-trauma area of professional interest
- [ ] Other:

Balance
- [ ] Strive for balance within your work-life and workday
- [ ] Strive for balance among work, family, relationships, play and rest
- [ ] Other:

Connection

Organizational Stress

Organizations, like individuals, are living, complex, adaptive systems. They are vulnerable to stress, particularly chronic & repetitive stress.

Potential Sources of Organizational Stress

Budget Cuts
Lack of Peer Support
Layoffs
High Case Load
Organizational Stress
Media Attacks
Ineffectual Leadership
Change in Leadership
Lawsuits

Impact of Organizational Stress

- Poor Decision-Making
- Mission-less
- Crisis-Driven
- Punitive
- Unsafe

Impact of Organizational Stress on Providers

- Increased absenteeism
- Impaired judgment
- Unwillingness to accept extra work
- Low motivation
- Lower productivity
- Poorer quality of work
- Greater staff friction
- Higher staff turnover

Steps to Organizational Stress Reduction

- Practice principles of safety & empowerment
- Share successes & shortcomings
- Ensure regular & reflective supervision sessions
- Support open communication
- Hold multidisciplinary case conferences

Steps to Organizational Stress Reduction

- De-stigmatize providers' personal reactions to the work & prioritize self-care
- Provide mentoring to new professionals
- Support continuing education
- Encourage training on trauma-informed care at all levels
- Provide respite for providers

Wellness Activities

- Provide wellness activities
- Offer mindfulness exercises during lunch breaks
- Support staff celebrations

WELLNESS WHEEL

Intellectual · Social · Physical · Spiritual · Occupational · Emotional · Environmental

Self-Care Resources

- NCTSN Secondary Traumatic Stress Speaker Series
- What About You? A Workbook for Those Who Work with Others (Volk, Guarino, Grandin & Clervil, 2008)
- NCTSN Secondary Traumatic Stress: A Fact Sheet for Child-Serving Professionals
- Trauma Stewardship: An Everyday Guide to Caring for Self While Caring for Others (Van Demoot Lipsky & Burk, 2009)

Trauma-Informed Organizational Change

The Institute on Trauma and Trauma-Informed Care (ITTIC)

http://socialwork.buffalo.edu/social-research/institutes-centers/institute-on-trauma-and-trauma-informed-care/Trauma-Informed-Organizational-Change-Manual0.html

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Essential Messages

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.

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ACTION PLANNING
ESSENTIAL MESSAGE 10

Think about the person you identified at the end of Module 1 that connects you to this work. What can help that person and other adults with IDD who have experienced trauma? (Put an "X" in up to 3 boxes next to the ideas you think you would MOST like to emphasize in your daily practice.)

10 ESSENTIAL MESSAGE 10

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

❏ Over the next 3 months, I will designate a time to consider whether I am noticing the warning signs of stress in my relationships. I will utilize a self-care strategy when I notice that I am experiencing stress.

❏ Over the next 3 months, I will choose 3 tips for engaging in self-care from the Self-Care Options handout and practice 1 on a daily basis.

❏ Over the next 3 months, I will choose 3 strategies for maintaining self-care that I identified on the Balancing Your Self-Care handout and practice 1 on a weekly basis.

❏ (Write my own.) Over the next 3 months, I will…

Personal Trauma-Informed Practice Action Plan

Go back to the strategies you identified under the Essential Messages at the end of each module. Then, select three strategies that you want to commit to implementing as part of your Personal Action Plan. Write each of these strategies in the boxes provided below, and in the corresponding box in the left hand column, write in the Essential Message number associated with each strategy.

ESSENTIAL MESSAGES

1. Know that there's hope; recovery from traumatic experiences is possible, including for adults with IDD.
2. Recognize that a person with IDD may have had a traumatic experience(s), which can have profound effects.
3. Recognize a person's developmental level and how IDD and traumatic experiences are affecting his/her functioning.
4. Utilize a developmental lens when making meaning of a person's traumatic experiences & responses.
5. Recognize that in the aftermath of trauma, understanding traumatic stress responses is the first step in helping someone regain their sense of safety, value and quality of life.
6. Utilize an IDD- & trauma-informed person-centered approach to support both the person and their support network.
7. Help parents/caregivers, and other professionals in the person's life, strengthen protective factors.
8. Partner with agencies and systems to ensure earlier and more sustained access to services.
9. Ensure that trauma-informed person-centered services, treatments, and systems drive the recovery plan.
10. Practice ongoing self-care in order to increase effectiveness in delivering high quality support, services and treatment.

Personal Trauma-Informed Practice Action Plan

Essential Message	Strategies I will implement over the next 3 months… (refer to the strategies you identified under Essential Messages at the end of each module)
Example: 10	*Over the next 3 months, I will set aside time to meet with each of my supervisees to assess risks for burnout or vicarious trauma and support their self-care.*
	Strategy 1
	Strategy 2
	Strategy 3

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