

Trauma Informed Care: Applications for Individuals with Intellectual and Developmental Disabilities

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Objectives:

- 1) Participants will be able to list events that may contribute to a traumatic sequelae for individuals with I/DD.
- 2) Participants will be able to explain some of the ways that intellectual or developmental disabilities may mediate the symptoms of PTSD.
- 3) Participants will be able to describe at least two potential applications of trauma-informed care in their role with the intellectually/developmentally disabled adults


Introductions:

- A little bit about me...
- A little bit about you...



Trauma-Informed Care

Changing the question from "What is wrong with you?"
to "What happened to you?"




TRAUMA-INFORMED CARE & ALTERNATIVES TO SECLUSION AND RESTRAINT

- Realizes the widespread impact of trauma and understands potential paths for recovery
- Recognizes signs and symptoms of trauma in clients, staff, and others involved in the system
- Responds by fully integrating knowledge about trauma into policies, procedures, and practices
- Seeks to actively resist re-traumatization

Trauma Informed Care

“To understand the role that violence and victimization play in the lives of most of our consumers (of mental health and substance abuse services) and to use that understanding to design service systems that accommodate the vulnerabilities of trauma survivors and allow services to be delivered in a way that will facilitate consumer participation in treatment.”




“Healing Neen” Tonier Cain

(Harris & Fallot, 2001)

What is Trauma?

Trauma:

- “A disordered psychic or behavioral state resulting from mental or emotional stress or physical injury.”
Mirriam-Webster Dictionary
- “An extremely distressing experience that causes severe emotional shock and may have long-lasting psychological effects”
Encarta Dictionary



Trauma via DSM-5

PTSD related criteria:

- Exposure to actual or threatened death, serious injury, or sexual violence via...
 - Direct exposure
 - Witnessing the event as it occurred to others
 - Learning that the event occurred to a close family member or friend (if death, must have been violent or accidental)
 - Experiencing repeated or extreme exposure to aversive details of the traumatic event (not exposure through electronic media, TV, movies, pictures, unless work related)


Types of Trauma

- Acute Trauma = a single event that lasts for a limited time.
- Chronic Trauma = the experience of multiple traumatic events, often over a longer period of time.

Big "T" vs Little "t"


Examples of Trauma

- Domestic violence
- Sexual abuse and assault
- Physical abuse and assault
- Community violence
- Historical /Intergenerational
- Serious accidents
- Unexpected loss of a loved one
- Medical procedures or conditions
- War and/or terrorist attacks
- Institutional abuse
- Secondhand exposure



Examples of Trauma Specific to I/DD Population

- Violence at the hands of housemates and/or caregivers (including family, residential staff, friends, and/or teachers)
- Witnessing violence of those stated above
- Neglect or omission of adequate care
- Bullying/Verbal Abuse
- Accidents
- Hospitalizations/Restraints
- Destruction of medical equipment and communication devices
- Withholding, stealing, or overdosing of medications
- Financial Abuse
- Forced relocations
- Hate crimes
- Caregiver relationship transitions



Response to Trauma Varies

- Nature of the trauma
- How close the person was to the event
- Previous trauma experience(s)
- Relationship to the abuser or victim
- Perception of the person involved about the experience
- Chronicity and severity of the trauma itself
- Coping skills of the person prior to the experience
- Response of support system
- Level of life stressors at time of experience

I/DD May be More Vulnerable to Impacts of Trauma...

- Limited range of coping and adaptation skills as they are related to cognitive development and differ with age.
- Fewer previous experiences in managing negative life events.
- Early separation from parents or other stress on the family system may be present and reduce stress management abilities.
- More vulnerable to stress-related thoughts, feelings, and emotional/behavioral manifestations with decreased psychological flexibility.
- Limited capacity for gathering social support.
- Fewer of the protective factors that would limit the effects of trauma.

Impact of Trauma on People

- Neurological
- Biological
- Emotional
- Psychological
- Behavioral
- Social



Neurological Effects



- Some traumatic events have a direct impact on brain function and structure.
- Trauma activates stress hormones and neurochemicals
 - Acutely this results in flight, fight, or freeze.
 - Chronically this results in +/- changes to brain functioning and/or +/- changes to brain structure due to neuroendocrine system impacts.
 - Chronic trauma can cause over-activation of "HPA" axis in the brain, and constant production of stress hormone, cortisol.
 - The amygdala (emotion and fear response) and hippocampus (memory) are also impacted.
 - Brain changes can include: reduced cerebral volume, associated ventricular enlargement, alterations in pituitary and hippocampus.

Biological Effects

- Somatic complaints (i.e. chronic pain)
- Sleep disturbance
- Urological problems
- Headaches
- Stomach aches
- Fatigue
- Forgetfulness, confusion, and concentration difficulties
- Flashbacks (intrusive memories/sensations)
- Reduction in sensation (i.e. sexual numbing)
- Hypervigilance and exaggerated startle response



Emotional Effects

- Shock, numbness
- Disconnectedness
- Fear
- Anger, rage
- Worry, anxiety
- Sadness, grief
- Powerless, ineffective
- Overwhelm
- Depression
- Impatience
- Lack of trust
- Unsafe
- Inner turmoil and pain
- Restricted range of affect
- Self-blame, self-doubt
- Shame, secrecy

Psychological Effects

Cognitions are especially impacted by trauma:

- Distrust of others or expectations that they might be harmed by everyone
- Overestimation of and preoccupation with danger
- Low self-esteem and self-blame
- Helplessness and hopelessness about the future
- Shame and/or stigma
- Survivor guilt



"Experiences create expectations" –Potter, D.

Behavioral Effects

- Crying
- Agitation, irritability, rage
- Passiveness
- Diminished interest in activities
- Self-injurious behaviors
- Suicidality
- Reenactments
- Dissociation
- Risky, impulsive behaviors
- Compulsive behaviors
- Problems with eating
- Rigid behaviors
- Increased use of substances
- Panic, phobia

Social Effects

- Isolating, detaching from others
- Over working
- Relationship strains, dysfunction
- Neglect of responsibilities
- Poor parenting
- Feeling unlikeable or "strange" in social settings
- Assuming malevolence
- Avoidance of sexual activity or trauma related activity
- High rates of re-victimization

Post-Traumatic Growth



- After exposure to trauma most people will experience some of the effects noted above, but will not develop chronic symptoms or psychiatric illness.
- They will garner their resilience via internal strengths and external supports, and make constructive meaning of what has happened.
- People may reflect that trauma offered them opportunity to develop important coping strategies or other positive outcomes.

Recognize Resiliency!

- A large proportion of those exposed to trauma do NOT develop long-term negative effects....how??!!
 - Effective parenting/caregiving/support system
 - Connections to other competent and caring people
 - Problem solving skills
 - Self-regulation skills
 - Positive beliefs about the self
 - Beliefs that life has meaning
 - Spirituality, faith, and religious affiliation
 - Socioeconomic advantages
 - Pro-social peers and friends
 - Safe and effective communities

Adverse Childhood Experiences (ACE) Study

- Collaboration between the Centers for Disease Control and Prevention and Kaiser Permanente's Health Appraisal Clinic in San Diego.
- 1995-1997 enrolled 17,000 subjects via their HMO membership
- Surveys used to measure number of childhood trauma experiences and teen/adult risk behaviors and health.



Adverse Childhood Experiences

- 1) Emotional abuse (recurrent and severe)
- 2) Physical abuse (recurrent and severe)
- 3) Sexual abuse
- 4) Emotional neglect
- 5) Physical neglect
- 6) Mother treated violently
- 7) Household substance abuse
- 8) Household mental illness
- 9) Parental separation or divorce
- 10) Incarcerated household member

ACE Score =
Combined number
of individual
adverse experience

Zero (0) to Ten (10)

ACE Score → Health/Social Problems

- Alcoholism and alcohol abuse
- Chronic obstructive pulmonary disease (COPD)
- Depression
- Fetal death
- Health-related quality of life
- Illicit drug use
- Ischemic heart disease (IHD)
- Liver disease
- Risk for intimate partner violence
- Multiple sexual partners
- Sexually transmitted diseases (STDs)
- Smoking
- Suicide attempts
- Unintended pregnancies
- Early initiation of smoking
- Early initiation of sexual activity
- Adolescent pregnancy

Trauma- and Stressor-Related Disorders (DSM 5)

- Acute Stress Disorder (3 days to 1 month)
- PTSD (> 1 month)
- Other Specified trauma-related disorder
- Co-occurring SA/MH disorders are also common including MDD, GAD, OCD and other anxiety disorders, SUD, sleep disorders

PTSD Diagnosis via DSM-5

- Intrusion Symptoms (1 or more of following)
 - (1) Recurrent, involuntary, and intrusive distressing memories of the event(s)
 - (2) Recurrent distressing dreams in which the content or affect are related to the event(s)
 - (3) Dissociative reactions in which the individual feels or acts as if the traumatic event(s) were recurring
 - (4) Intense or prolonged psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event(s)
 - (5) Marked physiological reactions to internal or external cues that symbolize or resemble and aspect of the traumatic event(s)

PTSD Diagnosis via DSM-5

- Persistent Avoidance of Stimuli associated with the trauma (1 or both)
 - (1) Avoidance of or efforts to avoid distressing memories, thoughts, or feelings about or closely associated with the traumatic event(s)
 - (2) Avoidance of or efforts to avoid external reminders that arouse distressing memories, thoughts, or feelings about or closely associated with the traumatic event(s)

PTSD Diagnosis via DSM-5

- Negative Alterations in Cognitions and Mood associated with the event(s) (2 or more)
 - (1) Inability to remember an important aspect of the traumatic event(s)
 - (2) Persistent and exaggerated negative beliefs or expectations about oneself, others, or the world
 - (3) Persistent, distorted cognitions about the cause or consequences of the traumatic event(s) that lead the individual to blame himself/herself or others
 - (4) Persistent negative emotional state
 - (5) Markedly diminished interest or participation in significant activities
 - (6) Feelings of detachment or estrangement from others
 - (7) Persistent inability to experience positive emotions

PTSD Diagnosis via DSM-5

- Marked Alterations in Arousal and Reactivity (2 or more)
 - (1) Irritable behavior and angry outbursts typically expressed as verbal or physical aggression toward people or objects
 - (2) Reckless or self-destructive behavior
 - (3) Hypervigilance
 - (4) Exaggerated startle response
 - (5) Problems with concentration
 - (6) Sleep disturbance
 - Duration of disturbance is > 1 month, causes clinically significant distress or impairment, and is not attributable to the physiological effects of a substance or another medical condition.
 - Specify whether with dissociative symptoms (depersonalization or derealization)

PTSD and Other psychiatric illness in the I/DD Population

Diagnosing PTSD in the IDD population is complicated by a few factors:

- 1) DSM-5 criteria are not validated for this population
- 2) Symptoms are often expressed differently in this group
- 3) "Diagnostic overshadowing" attributes symptoms to the IDD
- 4) Assessment is difficult with impairments in receptive and expressive language
- 5) Studies specific to PTSD are few in number and strength of evidence is low, so much is extrapolated or based on clinical evidence

PTSD and Other psychiatric illness in the I/DD Population

Despite this, we know the following...

- 1) Point prevalence of "psychological problems" in the ID 40.9% with 2 year incidence of 16.3%.
- 2) Rate of psychiatric illness among ID is 2-4X greater than the general population, with affective disorders, anxiety disorders, behavior problems, and psychotic disorders most prevalent.
- 3) Studies show association between negative life events and psychological problems in the I/DD population. Subjective report of daily stressors as more impactful than non-ID.
- 4) Age and developmental level is important in the expression of PTSD, it can have a major impact on individuals' capacity to cope with traumatic events.

Effects Mediated by I/DD

- PTSD symptoms are more like those seen in children.
- Effects not seen in the general population literature – inappropriate or unusual statements, stereotypical behavioral, inappropriate speech, reduced self-care, reduced adaptive behavior.
- Reenactments:
 - Repetitive themes or aspects of the trauma expressed in interactions with others, may include onset of new behaviors or reemergence of such behaviors. Frightening dreams or fears surrounding the safety of family or the home environment.
 - Repetition of the trauma played out as either the victim or victimizer, effort to gain a sense of mastery or control over the traumatic experience. Can explain some of the aggression that is seen.

Effects Mediated by I/DD

- Interpersonal disruption:
 - Avoidant – worries about who is working, repeating statements about unrelated events, inability to assert or protect oneself, appear distant with preoccupied daydreaming. Phobic mannerisms to avoid cues or situations that trigger unpleasant sensations/memories, refusal to participate in day programs or work without obvious reasons. Decline in skill development after prior gains.
 - Aggressive – bold or secretive acting-out that can include aggression toward self, peers, caregivers, or pets. Testing and breaking rules, increased impulsivity, property destruction, self-injurious behavior including suicide attempts.
- Exacerbation of pre-existing psychiatric illness

DSM IV TR version of PTSD Adapted Criteria for individuals with ID (DM-ID)

Mevissen & de Jongh, 2010

Prevalence of Trauma

70% of us adults have experienced at least one traumatic event in their lifetime

20% of those go on to develop PTSD

About 7% lifetime rates in US population

Prevalence of Trauma

Among People with Intellectual and Developmental Disabilities

- Those with I/DD are more likely to experience traumatic events, especially sexual and physical abuse (also true for children). The range of types of abuse is also larger compared to those with a relatively high level of intellectual functioning.
- Rates of maltreatment in children with I/DD is 1.5 to 10X higher.
- Interpersonal violence and crime occur at greater rates than the general population, 4-10X higher risk. Some suggest nearly 30% known histories of abuse in the I/DD population.
- Reports are considered underreports – difficulty in communication, inability to make a report, and problems with the justice system. accepting credibility.
- Rates of PTSD in ID range from 2.5% to 60% in the literature. Lack prevalence data due to lack of diagnostic measure.

Why are people with I/DD more vulnerable?

- Trained to be compliant to authority
- Dependent on caregivers (long period of time, for a variety of needs, for a large number of caretakers)
- Less able to meet parental expectations
- Desirability of acceptance and fear of rejection
- Isolated from resources and fewer social
- Impairments in ability to communicate or mobility
- Cognitive or processing delays make understanding what happened difficult
- Less prone to critical thinking so may be easier to manipulate
- Often do not receive general sex education so may not recognize sexual abuse
- More comorbid conditions
- Discrimination and poverty

Higher rates of trauma exposure

+

Higher vulnerability to traumatic reactions

=

This is SO IMPORTANT

Core Principles of Trauma Informed Care for I/DD Setting?

Core Principles of T-I Care

- 1) **Safety:** Ensure physical and emotional safety
- 2) **Trustworthiness:** Maximize trustworthiness, making expectations clear, and maintaining appropriate boundaries
- 3) **Choice:** Prioritize consumer choice and control
- 4) **Collaboration:** Maximize collaboration and sharing of power with clients
- 5) **Empowerment:** Prioritize client empowerment and skill-building



“Systems that fail to understand trauma may inadvertently create invalidating and re-traumatizing environments...”

J. Keesler, page 39

Evidence for TIC (Keesler, 2014)

- Better subjective health and lower prevalence of chronic illness among women diagnosed with co-occurring disorders.
- Marked reductions in use of restraints and seclusion in psychiatric care for kids.
- Increased patient satisfaction, increased staff patience and consistency in approach, increased ability to deescalate, decreased counter-aggressive actions between clients and staff.
- Increased staff awareness of the impact of the communication on safety and increased leadership of youth in treatment.

Specifics for I/DD Providers



Universal Screening and Ongoing Assessment As Indicated

- Identifying trauma history early in the treatment process is an important aspect of TIC.
- Identifying trauma via screening and assessment can be complicated, but worth doing.
- Screening tools should be brief and with explanation of prevalence data as rationale.
- Trauma informed screening would not request details and would be able to contain responses.
- Can screen through caregivers, but remember they might not have all the information/understanding.

Assessment for PTSD in I/DD

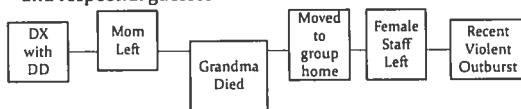
- Difficult due to issues mentioned above as well as no diagnostic instruments specifically available to assess PTSD in this population other than: *Diagnostic Manual-Intellectual Disability 2, Fletcher et al. 2017*
- Caregivers are not necessarily able to report as they don't possess the information or do not recognize events as traumatic.
- Significant differential diagnosis assessment is needed, as misdiagnosis is possible such as autism, intermittent explosive disorder, or schizophrenia.
- May need to rely on others to recognize significant departures from baseline behavior that may signal a traumatic response.
- Time delay between trauma and manifestation of symptoms can complicate diagnostic process. Temporal aspects are relevant.

Possible tools to measure the impact of traumatic events for people with I/DD:

- The Lancaster and Northgate Trauma Scales (LANTS)
- Bangor Life Events Schedule for Intellectual Disabilities (BLESID)
- Pediatric Emotional Distress Scale (PEDS)
- Behavior Problems Inventory (BPI-01)
- Adaptive Behavior Scale-residential and community (SABS)
- Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD)
- Ward Anger Rates Scale (WARS)
- The Brief Symptom Inventory (BSI) with checking for respondent understanding
- Impact of Events Scale (IES)

Biographical Timeline

- When behavioral modification is not useful in the here-and-now approach, developing a biographical timeline (Focht-New, et al. 2008) will help to provide insight into challenging behavior and in relation to ongoing triggers.
- Life events laid out chronologically, correlations are drawn and respectful guesses are made to link to current behavior.



Trauma Response vs. Behavioral Response

Trauma

- Triggered in an irrational manner
- Overreaction to small event
- Very emotion based
- Does not serve the person well
- Does not move them forward

Behavioral

- Has a purpose and intent
- Deliberate- acting on environment to get response
- Intent is important in identifying the response
- Goal is to get something they want, can move them forward
- You can typically identify the antecedent

*Slide used by permission from Karyn Harvey, PhD

For Treatment Teams...

- Service provider teams respond to behavior with consideration of trauma as potential cause.
- If trauma is identified, develop interventions that fill in the developmental or experiential gaps.
- Start with restoring a sense of safety and trust; eliminate frightening cues, develop *anchor for safety* and/or *safety valve* (Focht-New et. al 2008)
- Support patient's ability to recognize and handle stress via learning about their own triggers and common responses.
- Recognize that emotional experiences impact the learning process.
- Consider service providers' personal trauma history and risk of secondary trauma.



For Families...

- Provide trauma education to family members and other caregivers.
- Teach them signs/symptoms of trauma, and to differentiate these from everyday frustrations. Consider the pattern of crisis response and a few basic ways to alleviate the trauma based arousal.
- Teach basic communication skills to help them understand the problem, including opportunities for people with I/DD to express their needs and feelings.
- All must be aware of their own emotional needs and history of personal trauma, and the way these impact provision of care. Similarly, be aware of the traumatic exposures inherent in these family systems.
- Conflicts between caregivers and families in recognition of trauma and possible intervention need to be addressed directly.

For Patients...

- Treatment takes place in stages 1) Acknowledgement, 2) Establishing safety and a sense of competency, 3) Trauma processing, and 4) Transition back to normal life.
- Use concrete language and provide explanation of any traumatic event. Psychoeducation is valuable, correct distortions in knowledge.
- Help the I/DD person find a way to tell the story of the trauma, use of pictures and drawings may be helpful. Allow them to come in contact with the emotional content of the history.
- Remain patient in the repetition of linking experiences of past trauma to current functioning and emotional experiences.

For Patients...

- Allow for choice in group vs individual therapy. Groups with various levels of verbal expression may offer shared vicarious insight.
- Move towards creating a story that will support their sense of safety, well-being, and connection to the world. Review their interpretation of events.
- Continue to provide opportunities to develop skills and expertise to find status and a sense of mastery in their environment.
- Increase awareness of violence, promote safe living, foster crisis management, assertiveness, anger-management, self-determination, and stress management.
- Co-facilitation of treatment with a DD expert and a trauma expert would be indicated OR someone with cross training/practice experience.

Direct Care Staff

- Interpersonal trauma damages trust in people, thus relationships become the primary agent for recovery.
- Direct care staff are often the most prominent people in the lives of patients, and thus have great opportunity to influence outcomes.
- Staff level of stress related to perceived lack of training and/or increased responsibilities influences staff attitudes, behaviors, and practices.
- These aspects contribute to clients' discontinuity in care, poorer quality of care, and experience of vulnerability.
- Direct care staff will benefit from the efforts to ensure safety, trustworthiness, collaboration, empowerment, etc. in the facility

Trauma-informed Paradigm for Behavioral Interventions

Traditional Approaches

- Managing Behaviors
- Providing contingent rewards –shaming when not earned
- Power differentials –
- Forced Choice
- Restraints

Trauma- Informed Interventions

- Providing Emotional Safety
- Supporting choice
- Supporting relationships
- Facilitating Healing
- Empowering the individual
- Fostering a strong sense of self

*Slide used by permission from Karyn Harvey, PhD

Potential Barriers to Application?

- Staff attrition
- Democratic management style
- Lack of time to foster communication and team building
- Interdepartmental/Interdisciplinary differences in treatment approach
- Parameters set by state/federal policies
- Paternalism
- Staff actions motivated by fear of allegation



Trauma Informed Care
as a
Universal Precaution
for Everyone with a
Developmental
Disability.

Suggested by Lara Palay at The Center
for Systems Change

Thank You!

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