Trauma-Informed Peer Support for People Living with HIV

Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services

Developed by the National Center for Trauma-Informed Care and Alternatives to Seclusion and Restraint (NCTIC)
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Learning Objectives/Goals

• Define “peer support”
• Define “trauma” and its impact
• Define “culture” and its influence
• Discuss principles of trauma-informed practice and their application in peer support
• Explore strategies for applying this knowledge in peer-support relationships
Peer Support Basics
Peer Support Principles

- Voluntary
- Non-judgmental
- Respectful
- Reciprocal
- Empathetic
Peer Support Definition

• Peer support is a flexible approach to building healing relationships among equals, based on a core set of values and principles.

• Peers serve as role models for living and thriving with HIV, provide hope to clients living with HIV, and share strategies for overcoming the challenges of living with HIV (Boston University, 2009).
• In 1983, a group of people living with HIV came together to create a manifesto, called the Denver Principles.

• It was a call to action for the community, health care providers, and policymakers.

• "We condemn attempts to label us as 'victims,' which implies defeat, and we are only occasionally 'patients,' which implies passivity, helplessness, and dependence upon the care of others. We are 'people with AIDS.'"

- Denver Principles opening statement
What Peer Support is NOT

• A “program model”

• About “helping” in a top-down way

• Being a “counselor”

• Pressuring people to comply with adherence or treatment

• Monitoring people’s behavior
"Helping" in a top-down way may:

- Reinforce feelings of helplessness.
- Imply that one person is more “together” or “recovered” than the other.
- Send the message that people living with HIV are incapable of directing their own lives.
Peer Support Can Focus On . . .

- Educational pursuits
- Social activities
- Advocacy
- Harm reduction strategies
- Community connection
Co-optation occurs when a group tries to assimilate a weaker or smaller group, with the intention of neutralizing a perceived threat from the weaker group.
Co-optation can happen if people lose connection with peer support values and begin to take on views and beliefs that demean people who use services.

If the organization doesn’t support peer roles through policy and practice, peers can feel alienated or threatened.
To Avoid Co-optation

- Develop strong relationships with other peer support staff.
- Educate yourself about the history of the movement of people living with HIV.
- Reach out to local, state, and national organizations by and for people living with HIV.
- Talk about peer support values to non-peer staff.
• Educate people who use services about trauma and peer support.
• Educate staff about trauma and peer support.
• Have collaborative conversations by:
  – Exploring each others’ perspectives and experiences.
  – Using your story strategically.
  – Offering new solutions and ideas.
“In the thick of this work we often forget about our own needs . . .”

- Shery Mead, founder of Intentional Peer Support

Self-care is essential
Self-awareness (con.)

• Be aware of:
  – The impact of trauma on your own life.
  – Your own emotional “hot-spots”—words, sights, smells, sounds, behaviors, characteristics, and emotions.
  – How your own experiences may influence your feelings and responses to people you support.
Trauma & Its Impact
The 3 Es:

- “Individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual’s functioning and mental, physical, social, emotional, or spiritual well-being.”

(SAMHSA, Concept and Guidance for a Trauma-Informed Approach, 2014)
Some Potential Sources of Trauma

- Childhood sexual, physical, emotional abuse, neglect, abandonment
- Rape, sexual assault, trafficking
- Domestic violence, experiencing/witnessing other violent crime
- Catastrophic injury or illness, death, loss, grief
- Institutional abuse and neglect
- War/terrorism

- Community and school violence, bullying
- Cultural dislocation or sudden loss, historical/generational targeted violence
- Chronic stressors such as racism, homophobia, transphobia, misogyny, poverty, discrimination related to HIV diagnosis
- Natural disasters
- Invasive medical procedures
- Any misuse of power by one person over another
Tracing Trauma in Your Life
Talking about Trauma

• If, how, and when a person chooses to talk about experiences is personal.

• Some may not label what happened to them as “trauma.”

• Be aware of the words you use and be prepared that others’ words may be different.
Brain development is affected by early experiences, including traumatic experiences.

We develop ways to cope, survive, and defend ourselves against deep and enduring wounds.
The brain signals the body to respond to a perceived threat and the body prepares.

Ordinarily, when the threat is gone, the body returns to “baseline.”

If an ongoing threat is perceived, the body doesn’t return to baseline and remains prepared for threat, resulting in a “trauma response.”

The switch is stuck in the “on” position.
Symptoms of Un-Discharged Traumatic Stress

Source: Levine, 1997
### Trauma Linked to Health Challenges Over the Lifespan

<table>
<thead>
<tr>
<th>Adverse Childhood Experiences</th>
<th>Biological Impacts and Health Risks</th>
<th>Long-term Health and Social Problems</th>
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<tbody>
<tr>
<td>The more types of adverse childhood experiences…</td>
<td>The greater the biological impacts and health risks, and…</td>
<td>The more serious the lifelong consequences to health and well-being</td>
</tr>
</tbody>
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**Source:** Felitti, V.J., Anda, R. F., et. al., 1998
Factors That May Intensify Trauma

• The earlier in life trauma occurs, the more severe the likely long-term effects.
• Deliberate violence is particularly damaging, especially when inflicted by trusted caregivers.
• Violence, compounded by betrayal, silence, blame, or shame, impacts the ability to form intimate relationships.
• Sanctuary trauma occurs when a person or institution that is supposed to be safe, is not. The betrayal is deep and enduring.
Survivors may be responding to the present through the lenses of their past.

Things survivors do to cope may be misinterpreted by staff deliberately being uncooperative with a medical or medicine protocol; a term for this is “non-adherence.”

This can lead to punitive reactions by staff to people who are struggling with trauma responses.

Often, people are unaware that their challenges are related to trauma.
• Trauma can:
  – Leave people feeling powerless.
  – Have lasting effects on the ability to trust others and form intimate relationships.
  – Impact relationships with self, others, communities, and environment.
  – Create distance between people.
People living with HIV experience disproportionately high rates of trauma throughout the life span.

Traumatic experiences, including histories of childhood sexual and physical abuse, are far more common among people living with HIV than in the general U.S. population.

People living with HIV also are disproportionately affected by adult/ongoing trauma, including intimate partner violence (IPV).

Lifetime trauma impacts both HIV-risk behavior and the ability of people living with HIV to engage in HIV care.
• The vast majority of women living with HIV are dying not from HIV-related causes but from murder, suicide, addiction, and other causes associated with lifelong trauma (French et al., 2009).

• A 2018 California-wide study found that women living with HIV were >25 times more likely to die from an overdose or a mental health condition related to substance use than the general population of women in the state (Hessol et al., 2018).

• The same study found that men living with HIV were nearly three times as likely to die by suicide than the general population of men in California.

• HIV (like many other health conditions) is a symptom of a far larger problem: widespread, unaddressed trauma.
Impacts of Trauma on Health: Structural Violence

Living with HIV is traumatic.

Institutional Violence
Substance use and HIV criminalization laws, educational, vocational, housing and health care discrimination

Intimate Partner Violence
Disclosure, isolation, fear, depression, PTSD

Community-based Violence
Homophobia, transphobia, prejudice, discrimination

Health & Wellbeing

Source: Sonia Rastogi, 2012
Studies indicate that people living with HIV with past and/or recent trauma:

• Take longer to be linked to care after being diagnosed.
• Are less likely to stay engaged in care.
• Are less likely to adhere to antiretroviral therapy (ART).
• Taking antiretroviral therapy (ART) differently than prescribed is correlated with frequent childhood trauma, childhood sexual abuse, depression, and PTSD (Whetten et al., 2013; Meade et al., 2009).

• HIV-positive women with recent trauma are four times more likely to experience ART failure (Machtinger et al., 2012b).

• Sexual trauma is associated with greater likelihood of ART being unable to control HIV infection; a term for this is “treatment failure.”
Traumatic experiences over the life span are associated with faster development of an opportunistic infection or AIDS-related death (Leserman, 2007).
SAMHSA defines resilience as the ability of an individual, family, or community to cope with adversity and trauma and adapt to challenges or change.

Resilience is promoted in part by supportive relationships and social connectedness, as well as addressing sources of adversity.
“Our brains are ‘neuroplastic,’ meaning that they can change and adapt based on our environments and experiences.”

Source: Dr. Celeste Campbell. What is Neuroplasticity? https://www.brainline.org/author/celeste-campbell/qa/what-neuroplasticity
“Healing from trauma, like healing from a physical injury, is a natural human process.”

- Richard Mollica, 2008
Healing from Trauma

• Healing from trauma requires:
  – Regaining a sense of control over one’s life and environment;
  – Maintaining a sense of safety;
  – Developing the ability to trust self and others; and
  – Reconnecting with others.

• Healing happens in relationships.
Trauma-Informed Practices
Safety

Trustworthiness and Transparency

Peer Support

Collaboration and Mutuality

Empowerment, Voice, and Choice

Cultural, Historical, and Gender Issues
• Non-trauma-informed practices:
  – Recreate the fear and helplessness of the original trauma.
  – Cause distrust, sadness, anger, frustration, and confusion.
  – Can result in people disengaging from care.
  – Lead to survivor reactions being viewed as “symptoms,” which can increase the rationale for “management” and potential for coercion.
• Based on the universal expectation that trauma has occurred and/or may be ongoing.

• Focused on understanding “What happened to you?” not “What’s wrong with you?”

• Seek to understand the meaning people make of their experiences.
• Ensure all staff and people who use services are educated about trauma.
• Incorporate knowledge about trauma in all aspects of service delivery.
• Minimize revictimization—“do no more harm.”
• Take particular care to create a welcoming environment.
• Trauma-informed practices:
  – Strive to be culturally responsive.
  – Focus on resilience, self-healing, mutual support, and empowerment.
  – Ensure that trauma-informed principles (safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment, voice and choice; and cultural, historical, and gender issues) are specifically addressed.

• Trauma treatment is different: specific modalities or therapies to treat manifestations of trauma (works best in a trauma-informed setting).
“Radars”

Trauma survivors often have sensitive “radars” for detecting dishonesty and good reasons to be sensitive to any misuse of power and authority.
Those working with survivors “have a tendency to deal with their frustration by retaliating in ways that often uncannily repeat the earlier trauma.”

- Bessel van der Kolk, 2003, trauma expert
What does help look like?

• NOT Trauma Informed:
  – Needs are defined by staff
  – Safety is defined as risk management protocol
  – The helper decides what help looks like
  – Relationships based on problem-solving and accessing resources
  – Help is top-down and authoritarian

• Trauma Informed
  – Needs are identified by survivor
  – Safety defined by each survivor
  – Survivors choose the help they want
  – Relationships are based on autonomy and connection
  – Help is collaborative and responsive
Cultural Considerations
“We don’t see things as they are, we see things as we are.”

- Anais Nin, writer
Culture is defined as the shared values, traditions, arts, history, folklore, and institutions of a group of people that are unified by race, ethnicity, nationality, language, religious beliefs, spirituality, socioeconomic status, social class, sexual orientation, politics, gender, age, disability, or any other cohesive group variable.

- Singh, Williams, & Spears, 1997
Cultural Considerations

Self Identity
• Race
• Ethnicity
• Age
• Gender
• Sexual orientation
• Language
• Family
• Beliefs about capabilities
• History
• Country of birth

Belonging and Participating
• Spirituality
• Education
• Illness/wellness
• Literacy
• Incarceration
• Military
• Employment/Income
• Where you live
• Immigration status
• Parenting
My Cultural Pie
Cultural Considerations & Trauma

**Self Identity**
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**TRAUMA**
Culture Counts

• Culture influences:
  – The experience of trauma.
  – The meaning people make of what has happened.
  – How and whether people express their pain.
• One’s cultural experience affects beliefs, behaviors, and attitudes toward self and others.
• Assumptions made about others may become barriers to effective support.
No Assumptions

• Every conversation can be a cross-cultural conversation.
• We may not know the source of someone’s joy, pride, or pain.
• We do not know how oppression/trauma have impacted a person’s life.
• We do not know what self-protecting coping strategies people need to use.
BE CURIOUS,
BE EMPATHETIC,
BE FLEXIBLE
Trauma-Informed Peer Support
Effective Peer Support

- Validates personal reality
- Fosters trust and connection
- Leads to empowerment
- Breaks patterns of helplessness and hopelessness
- Encourages use of voice and choice
- Respects personal boundaries
- Creates a sense of safety in relationship
• Trauma-informed peer support:
  – Sees behaviors as strategies for coping with past and current trauma.
  – Helps survivors make sense of how they are coping and surviving.
  – Creates a safe space to consider new coping strategies.
Conflicting Definitions of “Safety”

- For people who use services, “safety” generally means maximizing control over their own lives.
- For providers, “safety” generally means maximizing control over the service environment and minimizing risk.
• If we’re not alert to the use of power, peer-support relationships may unintentionally recreate the power dynamics of the original trauma.

• Being mindful of peer-support principles can help address this issue.
There are no static roles of “helper” and “helpee” . . . reciprocity is the key to building natural connections.

- Shery Mead and Cheryl MacNeil, 2005
What gets in the way of sharing power?
What gets in the way of sharing power?

- Lack of role clarity
- Struggling to manage strong emotions
- Preconceived attitudes
- Desire to manage other’s behavior (particularly if viewed as harmful, self-inflicted violence)
- Fear, discomfort, misunderstanding
- How “safety” is defined and used
• Be transparent in your relationships.
• Let people you support know up front the limits of your relationship within the program and agency.
• Don’t assume the people you work with know what peer support is: teach them, and they can offer each other peer support.
Understanding Self-Injury and Other Coping Strategies
Understanding Self-Injury

• The intentional injuring of one’s body as a means of coping with severe emotional and/or psychic stressors

• The primary purpose is to provide a way of coping with what feels intolerable.

  - Ruta Mazelis, 2008
Self-Injury

• Evolves as a way to cope with trauma
• Is a response to distress, past and/or present
• Has meaning for each survivor, such as:
  – Regaining control
  – Asserting autonomy
  – Relief of emotional pain
Other Coping Strategies
• How does trauma impact our choices in relationships?
• How might trauma impact a person’s ability to protect him or herself in relationships?
• Can we understand what is called “risky sexual behavior” as the best coping strategy a person might have? How?
“The attempt to escape from pain, is what creates more pain. We should be asking not ‘why the addiction,’ but ‘why the pain?’”

— Gabor Maté, What is Addiction video
A Shift in Thinking

From
Seeing the person as engaging in meaningless, frustrating, and dangerous behavior

To
Understanding self-injury as an expression of profound pain that has meaning for the person

IT IS NOT YOUR JOB TO FIX ANYONE
Personal Narratives
Personal Narratives

• Personal narratives can:
  – Help organize one’s experience and help make sense of what has taken place.
  – Lay the groundwork for survivors to develop hope about the future.
  – Be told through talking, music, dance or movement, drumming, art, and writing.
• Trauma narratives may include:
  – All or part of the traumatic events.
  – The impact on one’s life.
  – The meaning one has made out of what happened.
  – Beliefs about who one is and who one is capable of becoming.
• Narratives that are difficult to listen to or hard to understand
• Telling the same narrative over and over again
• Competing trauma narratives
• Narratives told through the language of behavior (e.g., running out of a group, harm to self)
• Talking about the “taboo”
Is telling necessary for healing?

• People must be supported if they choose NOT to share their experience.
• Not everyone can or wants to share their experience.
• There may be cultural constraints on self-disclosure.
• It may be too painful.
• It may be currently unsafe.
Support Narrative Sharing

• Ask whether the person wants to share his/her/their experiences.
• Offer opportunities and materials to support different ways of expressing the narrative.
• Listen for meaning.
Reclaiming Power through Social Action
“All violence focuses on the unfair distribution of power and the abuse of this power by the powerful against the helpless. The solutions to these problems are not individual solutions; they require political solutions.”

- Tedeschi, Park, & Calhoun (Eds.) (1998)
 Trauma often leaves survivors feeling both powerless and full of rage.

Taking social action can be a:

– Positive act of healing.
– Productive way to channel anger.
– Way for survivors to reclaim a sense of purpose and personal power.
Social action can include:

– Organizing around a common goal.
– Giving witness testimony.
– Working to change harmful policies & practices.
– Challenging injustice.
– Creating supportive alternatives.
Self-care is a priority and a necessity – not a luxury – in our work.
WHAT WILL YOUR COMMITMENT BE?
References (1)


References (2)


References (3)


References (4)


References (5)


SAMHSA’s mission is to reduce the impact of substance abuse and mental illness on America’s communities.

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