REAFFIRMING MEANINGFUL COMMUNITY ENGAGEMENT

## HIV and Aging: Trauma Informed, Responsive Care and Resilience

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#### Professional Experience Influenced by Experiential Knowledge

- Or experiential knowledge influenced my professional trajectory
- Personal Trauma resolved
- Masters in Social Work
- Diagnosed with HEPC around 2009
- Experienced internal stigma and delayed treatment based on an initial medical enounter
- Interferon-based antiviral therapy (Ribavirin) 9 months-did not work
- HEP C Cured 2016, Harvoni, one of the first 1,000 in Baltimore City





# Today

- We will consider the three E's –Events, Experience and Effect as it relates to HIV, Aging in a Trauma Informed way.
- We will explore the impact of stigma associated with healing
- We will hear how Resilience can be a predictor of emotional wellbeing and psychological adjustment for people aging living and thriving with HIV.







## What is Trauma?

- Individual trauma results from an event, series of events, or set of circumstances 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.
- Trauma can impact our relationships.







## **Prevalence and Impact of Trauma**

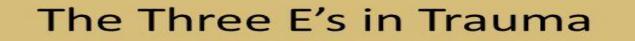
- Over the course of our lives, many elders have experienced one or more traumatic events, and the impact of that earlier trauma does not disappear with age.
- We are subjected to these events in the present as well as the past, and so may have more recent or current traumas of these kinds with which to contend.
- For the LGBTQ community these traumas are often compounded and rooted in stigma, rejection in addition to aging and HIV.

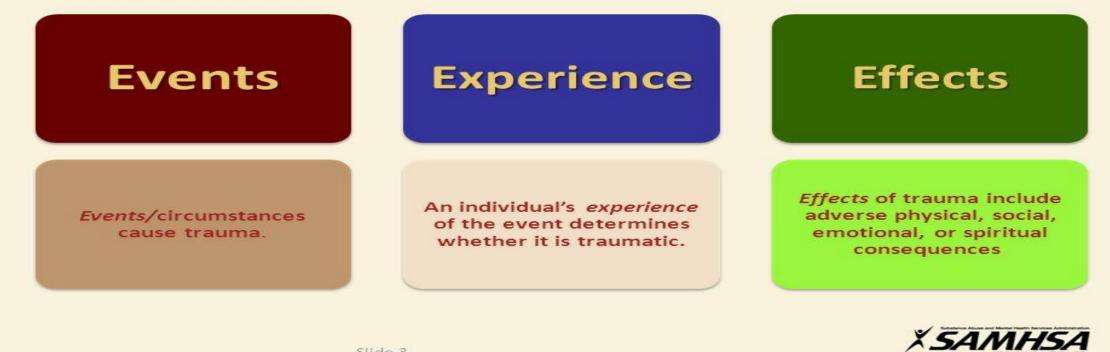
Karen Heller Key, Foundations of Trauma-Informed Care: (Baltimore, MD: LeadingAge Maryland/ Resilience for All Ages, 2018











Slide 3





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## Things to Keep in Mind

- Underlying question = "What happened to this person?"
- What are called behavioral health "symptoms" may be adaptations to traumatic events.
- Behaviors have meaning and purpose.
- Healing happens in relationships.







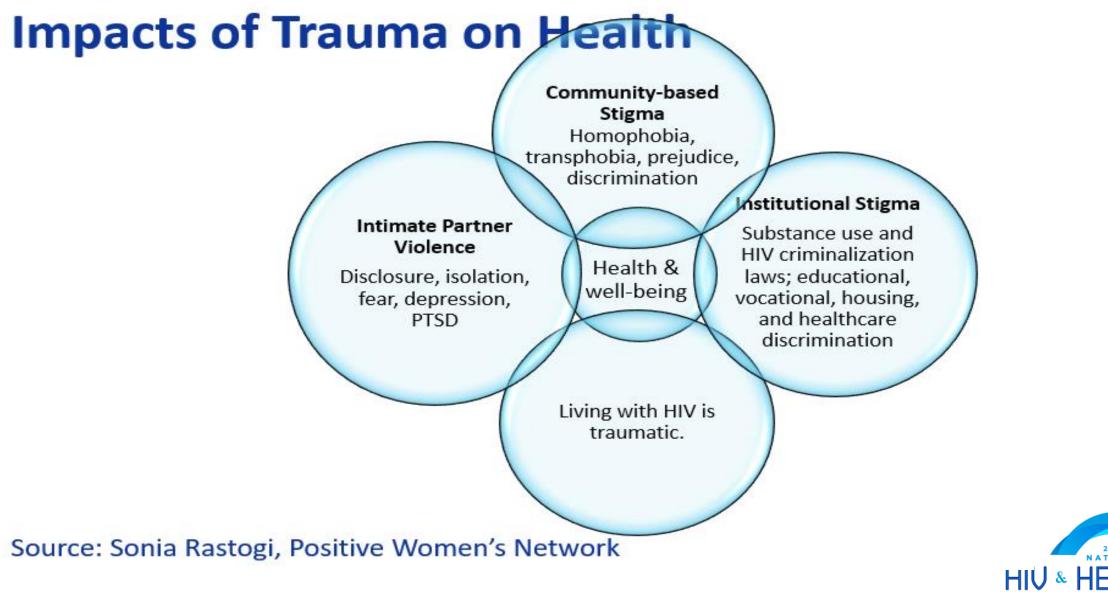
## **Promoting Healing and Well-being**

- People often use the terms "healing" or "wellness" instead of "recovery" when talking about trauma and HIV, but the basic message is the same:
- Everyone has the possibility of living a satisfying and meaningful life, regardless of what happened to them or what health challenges they are living with.
- Healing happens in relationships.













#### **Trauma Linked to Health Challenges Over the Lifespan**

Adverse	Biological	Long-term
Childhood	Impacts and	Health and
Experiences	Health Risks	Social Problems
The more types of adverse childhood experiences	The greater the biological impact and health risks, and	The more serious the life-long consequences to health and well- being.

Felitti et al., 1998





#### **Trauma Affects the Brain**



- Trauma at any age can affect the brain and result in changes in behavior and responses to life experiences.
- Our brains are "neuroplastic," meaning that they can change and adapt based on our environments and experiences.







#### "Providers recognize that patients may have past trauma, but what few realize is how prevalent it is and how much it affects patients' health."

-Michael Mugavero, researcher, Coping With HIV/AIDS in the Southeast (CHASE) Study









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## LTS, long-term survivors Thrivers

- Studies have found that older adults with HIV, particularly long-term survivors, have experienced deep psychological effects of the HIV/AIDS epidemic.
- The effects include higher rates of depression and anxiety, increased substance use, social isolation, and cognitive impairment.
- There has been a focus on post-traumatic stress disorders (PTSD) in long-term survivors (LTS).







### LTS, long-term survivors Thrivers

- PTSD in LTS often have their origins in the traumas associated with an HIV/AIDS diagnosis when there were no treatments, and a diagnosis was a "death-sentence". They woke up each day waiting for a treatment.
- LTS also faced losses of entire networks of friends. These stresses were compounded by the rejection of family, friends, and society as a whole that exhibited homophobia and fear of HIV/AIDS.







## What is stigma in aging?

- Ageism refers to the stereotypes (how we think), prejudice (how we feel) and discrimination (how we act) towards others or oneself based on age.
- Who does ageism affect? Ageism affects everyone
- Alongside intersectional stigmas, people ageing with HIV face specific challenges that are distinct from those faced by people with HIV at younger ages.
- Chronic comorbidities, which become more common as people age, can be more prevalent in people with HIV than those without, and are major determinants of poor HRQOL. (health related quality of life)
- Biomedical complications of ageing with HIV are beginning to be well described, the psychosocial stressors that older people with HIV have, and the consequences of these stressors on physical and mental health.







## What is resilience, why is it so important?

- Resilience refers to both the process and the outcome of successfully adapting to difficult or challenging life experiences, according to the definition from the American Psychological Association (APA).
- It's having the mental, emotional, and behavioral flexibility and ability to adjust to both internal and external demands, per APA.







## **Promote Resilience and Behavioral Health**

- Acknowledge the role of minority stress in creating or exacerbating behavioral health disorders
- Ask about sources of functional, social, and emotional support
- Promote positive self-perception of LGBTQ identity and LTS
- Recognize and validate unmarried partners and chosen families, regardless of legal or biological relationships
- Value the loss of a partner, friend, or pet; and provide support and referrals as needed







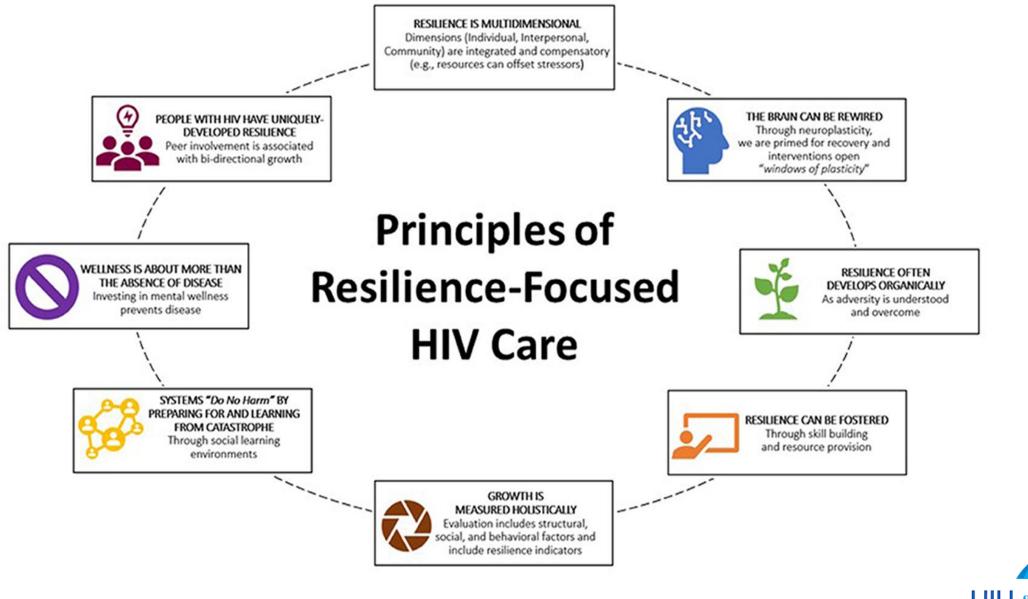
## Resilience

- Resilience is defined as "The ability of an individual, family, or community to cope with adversity and trauma and adapt to challenges or change."
- —The Substance Abuse and Mental Health Services Administration (SAMHSA)
- Resilience is promoted in part by supportive relationships and social connectedness, as well as addressing sources of adversity.











Citation: Brown LL, Martin EG, Knudsen HK, Gotham HJ and Garner BR (2021) Resilience-Focused HIV Care to Promote Psychological Well-Being During COVID-19 and Other Catastrophes. Front. Public Health 9:705573. doi: 10.3389/fpubh.2021.705573

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## Resilience

- Resilience requires a skill set that we can work on and grow over time.
- Building resilience takes time, strength, and help from people around us; we'll likely experience setbacks along the way.
- It depends on personal behaviors and skills (like self-esteem and communication skills), as well as external things (like social support and resources available to us).
- Being resilient does not mean that people don't experience stress, emotional upheaval, and suffering.
- Demonstrating resilience includes working through emotional pain and suffering.







#### Table 2.

Mental health promotion, services and support activities that can be implemented in the community and community health-care settings

Talking about mental health	Mental health promotion and prevention	Support for people with mental health conditions	Recovery and rehabilitation
Community education on mental health	Healthy lifestyle	Promoting human rights	Community follow-up
Reduction of stigma, discrimination and social exclusion	Life skills	Identifying mental health conditions	Vocational, educational and housing support
Involving people with mental health conditions and their families	Strengthening caregiving skills	Engaging and building relationships	Social recovery and connectedness
	Suicide prevention	Providing psychological interventions	Self-management and self- care, and peer support
	Prevention of drug use and substance use conditions	Referring for more care and services	
	Self-care for community providers	Supporting carers and families	

Source: reproduced from mhGAP community toolkit: field test version. Geneva: World Health Organization; 2019.





## Recommendations

- Engage at all levels in training that informs, promotes practical skills, interventions in trauma responsive care and healing for those that are aging re: HIV, HEPC to shift from a survivor to a thriver on a psycho, social, emotional, spiritual level.
- Holistic comprehensive care that recognize and understand the head is part of the body and the body is part of the head.
- Revisit and improve upon practices that work ie. The Buddy System"
- Build on qualitative care that incorporates intervention and care collaboratively.







#### **The Denver Principles**

- The Denver Principles were the foundation for the self-empowerment and selfdetermination for PWA (people with AIDS).
- In 1983, when the principles were written, HIV was a death sentence that was too often used as an excuse to deny housing, healthcare, even funeral services.

#### • **RECOMMENDATIONS FOR ALL PEOPLE**

- 1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.
- 2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.





#### **THE DENVER PRINCIPLES**

- (Statement from the advisory committee of the People with AIDS)
- We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others.
- We are "People With AIDS."





## **RIGHTS OF PEOPLE WITH AIDS**

1. To as full and satisfying sexual and emotional lives as anyone else.

2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.

3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.

4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.

5. To die--and to LIVE--in dignity

THE DENVER PRINCIPLES





#### Thank You !!!

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