

## SUBJECT MATTER EXPERTS (SME) = HIV Specific Care

### Lisa Johnson-Lett





Lisa Johnson-Lett, BPS, Human Services Living Well Peer Support Specialist

P.O. Box 55703 Birmingham, AL 35255

3529 7th Avenue South Birminaham, Al 35222

- D 205.918.8217 C 256.226.4987
- P 205.324.9822
- F 205.324.9311
- E lisa.johnson-lett@aidsalabama.org

W www.aidsalabama.org Follow us on Twitter, Facebook and YouTube @AIDSAlabama



## **OVERALL GOAL**

 Implementing Peer Support Specialists and their role to organization, community, and advocacy pertaining to HIV-specific Care.

## **LEARNING OBJECTIVES**

- Analyze Peer Support as the Subject Matter Expert
- Explain the vitality of the Peer Role especially in the south
- Describe Mental Health pertaining to HIV
- Discuss the overall impact of Peer Support services



## **HIV ADVOCACY**



Many People with HIV, (PWH) serve as peer advocates for the newly diagnosed with lived experience of HIV and/or work in the field of HIV who are providers of service.





## MENTAL HEALTH DIAGNOSES

47% of PWH reported a recent mental health diagnosis; among this group, the top two most common mental health diagnoses were depression (84%) and anxiety (62%).

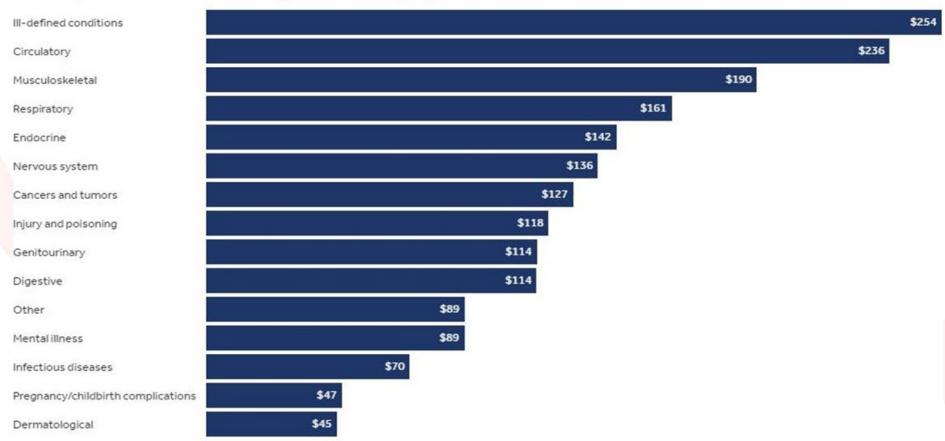
- Concerns about growing older with HIV. Top concerns were staying healthy and quality of life.
- Experiencing stigma for 11 of 12 stigma factors assessed. The most common stigma experiences were related to disclosure concerns.
- Living with one or more disabilities, an AIDS diagnosis, fair/poor health status, and a higher viral load.
- Experiencing problems with medication adherence.
- Having needed and used 7 of 19 HIV-related medical and support services assessed.
- That someone had talked with them about mental health issues and substance use in the prior six months.
- Living with Hepatitis C.





## ANNUAL SPENDING MENTAL HEALTH

Total expenditures in \$ billions by disease category, 2013





## **HIV AMIDST COVID-19**

Increased Mental Health Services especially in long-term survivors of HIV. "People are literally here today and gone tomorrow." The conditions of this world are triggers for people with HIV. Think about those who suffer from AIDS Survivor Syndrome: the toll it takes on a person with enormous amounts of deaths from both HIV and COVID-19 pandemics. There is increased internal stigma, afraid of a COVID-19 test diagnosis brings to surface vicarious and historical trauma of receiving a HIV diagnosis. L.J., NAPA-Al "People with HIV have fear and need support from another peer." - J.T., NAPA-WA.



## PEER SUPPORT & MENTAL HEALTH

Peer support alleviates the following:

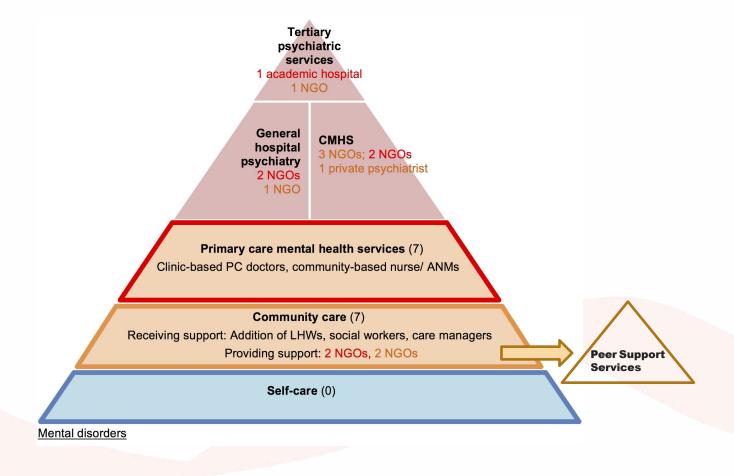
- Stress
- Anxiety
- Anger
- Depression
- Grief

"One can look up on Facebook and count anywhere from 5-600 HIV groups all over the world since COVID-19 and that alone should tell anyone the need for peer support."

-P.B., NAPA-NY



## **PYRAMID OF CARE**





# WHAT MAKES THE HIV COMMUNITY UNIQUE?

- 1) Mental Health & Stigma
- 2) General public perception
- 3) Criminalization
- 4) Intersectionality & Co-occurring diagnosis
- 5) Barriers to care in rural communities
- **-**6)



## 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, providing hope to clients living with HIV, and share strategies for overcoming the challenges of living with HIV.



## TYPES OF PEER SUPPORT

- Smart Recovery- D.R., NAPA-FL
  - 1. Identify the activating event (HIV diagnosis)
  - 2. Explain my belief system about HIV
  - 3. Evaluate the consequences behind beliefs
- Harm Reduction- P.B., NAPA-NY
   Caters specifically to populations with HIV &
   Substance use disorders
- Adapting the 12-step model -T.I.,NAPA-NY



### PEER AND MENTAL HEALTH

- Peer Support helps to reduce HIV/AIDS related emergency room visits
- Peers help Peers stay in care and introduce them to support groups as well as assist with treatment adherence. J.T., NAPA-WA
- Peer support is sustained by our own community
  - Many people who are HIV positive suffer from chronic pain and we are the only ones who can relate to our community. P.B., NAPA-NY
- Peer Support is an intervention and is an example of Upstream Suicide Prevention
  - Upstream Suicide Prevention supports the idea to provide services before crisis arise L.J., NAPA-AL
- Peer Support is a provider of services.
  - Often times Peer Support is intertwined with wraparound services and gets lost when provider of services are bill for psycho-education or Basic Living Skills filled under medicaid but offered and provided by HIV- near peers. We need Peers helping Peers who really are about our best interest and not utilize or mishandle HIV service just to cash-in on Insurance. D.R., NAPA-FL



## PEER SUPPORT = SME

- Specialize in skills providing perspective depending how many years since Sero-conversion/the onset of diagnosis.
- Specialists coming together from diverse backgrounds who share HIV experiences and support each other's healing and growth that is rooted in caregiving for oneself and others.
- The process of giving and receiving encouragement and assistance to achieve longevity and reach the goal of HIV-Universal Viral Suppression.
- Serve as coach and mentor on the journey to healing

"Whatever the unique needs are our specialized peer support covers it!."- NAPA



## Helpers; Peer Support; Peer Educators; Specialist: Subject Matter Expert (SME)

- Assist to reduce rates of HIV transmission through peer education
- Increase access to care and optimize health outcomes for People with HIV
- Reduce HIV-related health disparities and health inequities through advocacy efforts and health literacy
- Creates opportunities for People with HIV (PWH) to seek wellness and exercise power (autonomy) in their lives
- Providers of services for people with mental, physical, and emotional challenges with HIV-related stigma
- Assists to maintain independence and create inclusive safe spaces





## **TESTIMONIALS**

"If there were the implementation of Peer Support services across the nation and in every agency or organization that provides services for people with HIV then I would not have received a paper slid in front of my face and leaving me all alone at the age of 19 to decipher for myself If I am HIV+."
-T.I., NAPA-NY

"Peer Support offered a mental break for my anxiety and depression because my peer coached me into feeling better before I developed a crisis that would spiral out of control."

-J.T., NAPA-WA



## PEER SUPPORT

#### What is a Peer?

- Helpers who assists others experiencing similar situations
- Advocates for the client who maintains a professional helping relationship and empower while fostering cohesion, trustworthiness, and openness
- Student-leaders with personal lived-experience
- "Each one Teach One and soon the student becomes the teacher"
- Builds capacity enhancing community engagement
- Extends reach beyond clinical settings into the everyday environment
- Increases rates of adherence
- Promotes "Housing is Healthcare" model, P.B., NAPA-NY



## **HIV TREATMENT CASCADE**

Peers and/or Subject Matter Experts are additional services to existing professional roles. The function is designed to complement existing services. "*Upon diagnosis* there should always be a peer in the room, Pro-Peer."-P.B., NAPA-NY



- Serves as a role model of self-care
- Practice and effectively uses skills and non-therapeutically systems



## **TESTIMONIAL**

"I was told I had a million copies, I felt if my viral load had spiraled out of control and it was too high and too much for me to handle but I had a peer navigator to guide me to an understanding that through treatment it could be manageable and after 29 years I am still here today." - D.R., NAPA-FL



## TO BE PRECISE: A PEER IS...

- a public health professional >>...not a Clinician
- a supportive community member >> ...not a psychologist
- a patient >> ...not an epidemiologist



## PERSONAL CORE VALUES

- Awareness of self and others
- Root Cause Analysis and Intersectionality
- Mentorship
- Meaningful Involvement
- Leadership Development
- Accountability
- Healing & Resilience
- Interpersonal Communication
- Reflective Listening- (Motivational interviewing)



## **GUIDING PRINCIPLES**

- Embrace HIV- holding hope and empowers through services
- Voluntary- Participation consistent upon peer choice, the practice of autonomy is well encouraged.
- Optimistic- "to think of a glass half full" To be confident about the future.
- Open minded- willingness to consider new ideas; ability to consider other opinions and perspectives at the same time empathetic to other people, even when you disagree with them.
- Empathetic- showing the ability to understand and share feelings, emotions and livedexperiences.



## **GUIDING PRINCIPLES**

- Respectful- showing politeness, mannerism- feeling of admiration.
- Person-centered- with genuine interest "heart of the matter". Servicing the unique need under the human service umbrella.
- Non-judgmental.
- Relationship- the helping relationship-mutual, collaboration, respectful, trusts, and empathy
- Trauma Informed- utilizes a strength based framework emphasizing physical, psychological, and emotional, safety with bold use of HIV culture and empowerment expressing healing and resilience- offering Peer Support is one of the core principles of Trauma Informed Care.



## SUBJECT MATTER EXPERT

- Values and compliments peer support where they are one in the same (interchangeable);
- Peer workers who have lived-experience and can share inside knowledge;
- Heartbeat of every AIDS Servicing and Community Based Organization- Play a vital and pivotal role;
- "Nothing About Us without Us"
  - -"If you're not at the table then you on the menu"
- Meaningful Involvement of People with HIV/AIDS (MIPA)
- Greater Involvement of People with HIV/AIDS (GIPA)



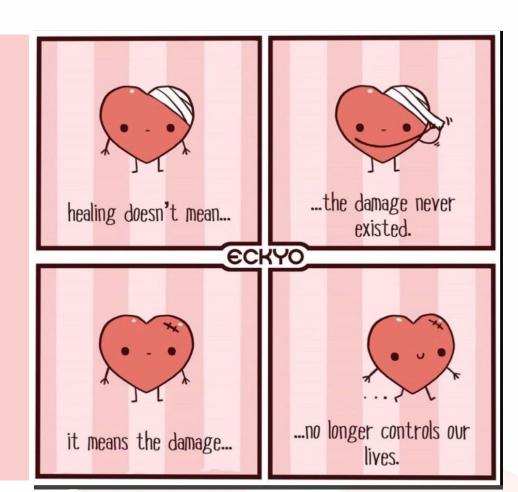
## DISADVANTAGES OF ADVOCACY

- Relived trauma experience
- Vicarious Trauma
- Advocacy Bullying
- Intergenerational Disconnect
- Misuse of MIPA
- Certification (HIV) Specific Standards
- Peer Support- undervalued
- Equality vs. Equity



At times as peers we come into advocacy out of anger and hurt.

We may have a broken mindset as the Subject Matter Expert as if we know it all and pull ourselves right back into the trauma--- If healing is not practiced then trauma will catapult you back into something you don't want to repeat.





## **ADVANTAGES OF ADVOCACY**

- Desirable Outcomes
- Art of Reciprocation
- Resilience & Healing
- Opportunities for personal growth
- Leadership Development
- Advocacy Advancement-local, regional, national, global
- Empowerment
- Provides REACH
- Family connections reinvented
- Finding mentorship



## **TESTIMONIALS**

"Peer Support taught me I will live again, I will have sex again!" P.B., NAPA-NY

"Peer Support taught me I can have a sex positively healthy relationship while being HIV+." D.J., NAPA-VA

"A woman only HIV support group help save my life. I came into the group lonely, lifeless, and afraid. Feeling I am worthless. Thinking I will never marry or be loved, or have sex, or have children but today I do have children and I can build relationships." J.T., NAPA-WA





## **INSURANCE COVERAGE**

Unfortunately there is no insurance for peer support (only RW), who are the payers of last resort and it is the lowest tier. Any state who has medicaid expansion, has a bill for wrap around services, which includes peer support, but the individual has to be in the highest tier. As advocates we have to fight for peer support services to be offered in every insurance tier. The HIV community needs to create a process to introduce universal billing codes our EMR systems for peer support.





## **BEST PRACTICES**

- Practice humility and remain teachable.
- Sit at the round table where no one is head.
- Learn from one another mentor/mentee approach.
- When engaged in a group, make sure the group dynamic is healthy, hopeful, and self-managing.



## **TAKE AWAYS**

- Everything you learn, you can to apply to yourself.
- Let go of your comfort zone and go to unfamiliar ground and for some may be unchartered territory.
- The Absence of disease does not adequate with good health.
- Complexity of multi-woven system.
- Understand Intersectionality & Root Cause Analysis.
- In the HEALTHCARE Delivery System- It is not a One Size Fits all Approach.
- Move away from questioning How did you get HIV or what did you do to get HIV to get them away from an identity crisis and encourage healing and resilience.
- Lack of Cultural Competency and People First Language and not being trauma informed leads to client dissatisfaction.
- Explore HIV-Culture- What are norms & best practices in HIV community.
- Explain the general public perception of HIV, political ramifications of HIV, and the community response to the epidemic.







## Lisa Johnson-Lett



Peer Support Specialist, SME
<a href="mailto:lisa.johnson-lett@aidsalabama.org">lisa.johnson-lett@aidsalabama.org</a>
256.226.4987

