

HEALTH **eBULLETIN**



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EDITOR'S NOTE

This issue of the Health E-Bulletin begins with two more articles that we solicited from presenters at Futures Without Violence's 2015 National Conference on Health and Domestic Violence. Both of these articles, one on trauma-informed care and the other describing how mindfulness is being used to help trauma survivors, reflect new opportunities and promising practices that are transforming the work we do.

In this issue, contributing authors also explore the ways in which trauma from violence is present in the lives of people living with HIV. You will hear from a national activist and policy advocate who describes not only the intersection of intimate partner/sexual violence and HIV, but also how both violence and HIV fuel each other and what can be done to address these issues.

There are innovative and trauma-informed programs that exist to support women living with HIV who have experienced trauma throughout their lives. One such program in San Diego, CA is working in partnership with women living with HIV to address their needs through a unique model of peer-based advocacy. We are grateful and proud to share

the story of one of the peer based advocates in this program; her account outlines the importance of supportive relationships in healing from trauma, a theme reflected throughout all of the articles in this edition.

Linda Chamberlain, PhD, MPH



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ADDRESSING LIFETIME TRAUMA IN PRIMARY CARE: CARING FOR OURSELVES WHILE CARING FOR OTHERS

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ADDRESSING LIFETIME TRAUMA WITH PATIENTS IN PRIMARY CARE PRACTICE CALLS FOR AN INTENTIONAL FOCUS ON HUMAN RESILIENCE AND CAPACITY TO GROW, CHANGE AND HEAL AFTER TRAUMATIC EXPERIENCES.

This healing environment is possible even in the context of brief encounters. Yet, the knowledge and skills necessary to help restore wholeness and integrity to someone who has been devastated or deeply affected by trauma are not traditionally taught as part of health professionals' education. For people who have experienced trauma, the ability to restore faith where it has been broken and personal integrity after violation involves the capacity to nurture inner peace and compassion during challenging moments and interactions. Each clinical encounter with a traumatized patient offers the opportunity to model and practice this type of nurturing relationship.

Our ability to care for ourselves while caring for others holds the key to being a nurturing healer.

Please, practice grounding yourself in a peacefulness that can provide healing to your patients and yourself simultaneously by following this brief guided meditation before reading the remainder of the article:

How would your medical practice change if you could remain grounded and peaceful while caring for patients who are suffering from traumatic experiences? What would it look like to care for ourselves while caring for others? We need to begin with an understanding about how adversity, especially childhood adversity, affects us. Because our biology and behaviors are constructed through our relationships, we can be harmed by relationships but also heal through relationships.¹

Guided Meditation

Let us sit together and open our hearts to the caring we bring to this journey. We are reading this article because we all share together in the desire to make this world a more loving place. Take a deep and cleansing breath. Feel your weight rest solidly on your chair. Let your body and feet relax and grow strong roots into the healing energy of the earth. Place your hands on your belly and take a deep breath in—breathe in healing energy. As you breathe out—let go and welcome a sense of peace. Breathe in rejuvenation.... breathe out... serenity.... Breathe in... healing energy, breathe out ... deep peace.



There is increasingly powerful evidence that optimal childhood development occurs through the experience of “positive stress”, the changes in our bodies and minds that result from brief periods of necessary stress that is buffered by the actions of a nurturing and attuned caregiver. For example, positive stress occurs when a toddler stumbles and is reassured by a caregiver or when a child is taken care of by a new babysitter who is loving and attentive. In contrast “toxic stress”, which is defined as the “strong, frequent, and/or prolonged activation of the body’s stress-response systems in the absence of the buffering protection of adult support”, results in a cascade of autonomic, neuroendocrine, immunological, epigenetic and behavioral changes that result in later adulthood disease.²

The largest study to have demonstrated an association between childhood adversity and adulthood disease and adverse behaviors, is called the “Adverse Childhood Experiences Study” or “ACE Study” and can be read about at: <http://www.cdc.gov/violenceprevention/acestudy/index.html>. This study demonstrates a dose-response relationship between ten types of highly traumatic childhood experiences of household/caregiver dysfunction including emotional, physical, and sexual abuse and neglect and, later, adulthood diseases and high risk behaviors.³ As the “ACE score” increases,

so does the risk of adulthood intimate partner violence; smoking, alcoholism, and intravenous drug use; increased number of sexual partners, early initiation of sexual activity, and sexually transmitted diseases; adolescent pregnancy, unintended pregnancy, abortion, and fetal death; depression and suicide attempt; ischemic heart disease, chronic obstructive pulmonary disorder (COPD), and liver disease. When compared to adults without any ACEs, those adults who had 4 or more ACEs had 14-times the risk of attempting suicide and double the risk of liver disease and COPD. Statistically, having a high ACE score is associated with premature mortality; people with six or more ACE’s died nearly 20 years earlier on average than those with zero ACEs.⁴

Please pause now to notice your reaction to what you just read about ACEs. As you read about the shattering effects of trauma on people’s lives, did your neck and jaw muscles tense? Did your heart rate increase? Take a moment to practice “re-grounding” yourself, just as you would do while you are caring for patients. You could also practice this re-grounding *with* a patient who is suffering from trauma or its sequelae.

How can we care for patients who have suffered a high burden of lifetime trauma, especially in the context of busy and not always well-designed or well-supported healthcare settings? First, we must acknowledge that

we are capable of changing our healthcare settings to become more ideally trauma-informed. Experts are beginning to provide guidance about how these new systems of care would be designed⁵⁻⁸ and how trauma-informed principles can be used to guide this systems-change work.⁹ Yet, what if we work in less than ideal circumstances? How can we provide trauma-informed care to an individual even if we are not working in a “trauma-informed” setting?

A framework that can be used to care for survivors of lifetime trauma is called the “FOUR C’s” which includes¹⁰:

- **Calm**—pay attention to how you are feeling while caring for the patient. Breathe and calm yourself to help model and promote calmness for the patient and care for yourself.
- **Contain**—ask the level of detail of trauma history that will allow the patient to maintain emotional and physical safety, respects the time frame of your interaction and will allow you to offer the patient further treatment.
- **Care**—remember to emphasize, for both the patient and yourself, good self-care and compassion.
- **Cope**—remember to emphasize, for

both the patient and yourself, coping skills to build upon strength, resiliency, and hope.

Guided Meditation

Remind yourself that you (and all of us together) are reading this article to make this world a more loving place. Take a deep and cleansing breath. Relax your muscles. Feel your weight rest solidly on your chair. Place your hands on your belly and take a deep breath in—breathe in healing energy. As you breathe out—let go and radiate compassion for yourself and others. Welcome a sense of peace. Breathe in rejuvenation.... breathe out... serenity....Breathe in... love. Breathe out ... peace.

For the remainder of this article, we will apply this framework to a fictional patient. Tonya Jones is a 44-year-old woman who comes to her first primary care visit complaining of pain and insomnia. She has poorly controlled diabetes and asthma. She is seen frequently in urgent care and the emergency department (ED) complaining of pain and shortness of breath. She has been noted to be intoxicated in the ED in the

past. She is upset that you are late for her appointment today.

CALM: Trauma can be conceptualized as “contagious” or easily transmissible. When we are exposed to trauma, we are at risk of vicarious traumatization.¹¹ As relational human beings we “co-regulate” with others around us; the more agitated the healthcare provider, the more agitated the patient will be (and vice versa), especially when the patient has a significant trauma history. We expect that Tonya may have a significant trauma history due to her poorly controlled medical problems, chronic pain, insomnia and adverse coping technique (the excessive use of alcohol). To transmit a sense of peace, one succeeds most effectively when one is internally peaceful. Ms. Jones’ provider says silently to herself, “I breathe in calmness, I breathe out peace. I feel my feet rooting deeply into the solid, peaceful earth” and then says aloud, “Ms. Jones, I am sorry that I am late. I am so happy that you waited to see me. Thank you.” One also remains calm by adjusting one’s expectations, goals and priorities. **A healthcare provider develops serenity by realizing that the formation of a healthy, respectful, trauma-informed relationship is the priority; that behavior change is slow; and that a focus on resiliency and empowerment rather than disease outcomes is often the most effective intervention.**



CONTAIN: There is abundant evidence that inquiry about adulthood experiences of intimate partner violence and sexual assault is acceptable to a majority of patients and can be done safely. However, there is a dearth of published evidence on addressing childhood trauma with adults during medical care. If Ms. Jones was abused by someone who was supposed to care for her, she has likely been taught—from a young age—inappropriate relationship boundaries and a betrayal of the safe, supportive, nurturing parental role. We must model respectful, compassionate and healthy boundaries rather than requesting that a patient share a degree of vulnerability inappropriate to a brief encounter with an unknown provider. If she has not already addressed her childhood trauma through a therapeutic process she may be may be “triggered” by a discussion of childhood abuse. We recommend that providers ask themselves the following questions:

- *Does the way I ask about or introduce trauma prioritize emotional and physical safety?*
- *Does it offer the patient choice and control?*
- *Does it allow me to offer the patient further treatment or assistance?*
- *Does it respect the time frame of the visit?*

So, for example, when Ms. Jones tells her provider on the very first visit that she first began drinking alcohol at age 10, her provider might say, “In my experience, when a patient tells me that she began drinking at age 10, it is often because she was experiencing very difficult things during childhood. We are just meeting each other for the first time today, so we don’t need to go into those details right now. I do want you to know that I am open to discussing your experiences or referring you to a counselor who specializes in trauma treatment if you think that would be helpful.”

CARE: Practicing compassion and good care for oneself and one’s patients allows for a healing connection to form. Because patients (and providers) who have experienced trauma may have turned to adverse coping techniques like substance use, demonstrating compassion and understanding can de-stigmatize behaviors that often feel shameful to people. When we learn (over many healthcare visits) that Ms. Jones’ father was incarcerated for intimate partner violence when she was 10 years old and that the uncle who moved in to “help out” sexually abused her for 3 years, we can say with great compassion, “No wonder you started drinking alcohol at age 10. You were coping with an impossibly painful situation. I am so sorry that happened to you.” Additionally, we can empathize with Ms. Jones’ inability to feel

like she can effectively cope with her diabetes and hypertension. We can gently postulate that, “It can be very hard to learn to take good care of yourself when you were hurt as a child.” We can also share this same compassion and understanding with ourselves.

COPE: Ultimately, addressing trauma ideally involves a recognition and celebration of resiliency. We recognize that Ms. Jones has displayed remarkable strength and utilized extraordinary coping skills to survive. Thus, everything we say in the visit is designed to draw Ms. Jones’ attention to her own inner strength and ability to cope. We offer partnership in enhancing her coping skills. Ms. Jones’ provider might say, “Look at how strong you are to have survived such difficult circumstances. I am so glad you had the strength to reach out for help today. I would like to partner with you to figure out how I can assist you.” In the course of talking with Ms. Jones, we learn that she had a favorite aunt who made her feel safe and loved. We remind her, repeatedly, of what this love felt like. “I hear how loved you felt by your favorite aunt. She understood that you deserved

to be treated with love and kindness.” And, as we are deeply affected by our own traumatic experiences and those of our patients, we maintain a focus on our own coping skills, resiliency and hopes for the healing power of trauma-informed care.

Trauma-informed care begins with each of us. By consciously nurturing a calm, compassionate, and hopeful presence we embody the trauma-informed approach. This, in itself, can have a healing impact on both patients and on the healthcare team. Embodying a trauma-informed approach individually is also an excellent way to inspire and advocate for clinic-wide or system-wide collaborative adoption of a trauma-informed culture and evidence-based trauma-informed services. Ultimately, together, we can greatly improve the experience and outcomes of our patients and the wellbeing of our healthcare teams by refocusing our healthcare systems to support resilience and positive growth.

To get started on learning about trauma-informed care we have listed some recommended resources that you can access by clicking [here](#).

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A MOMENT IN TIME, NOW: MINDFULNESS AND HEALING FROM TRAUMA

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FOUR YEARS AGO, I WENT TO HEAR A BUDDHIST CHAPLIN TALK ABOUT MINDFULNESS. DIRECTLY AFTER THE TALK, I APPROACHED HIM TO SEE IF HE MIGHT BE INTERESTED IN PROVIDING A GROUP FOR TRAUMA SURVIVORS. We discussed what types of experiences our patients have had in their lives—domestic violence, sexual violence and community violence—all forms of interpersonal violence are seen in our hospital-based program at the Center for Violence Prevention and Recovery at Beth Israel Deaconess Medical Center in Boston, Massachusetts.

There is a growing body of literature and practice that demonstrate the benefits of mindfulness practices for trauma survivors.^{1,2,3} In a recent study, mind-body practices including meditation, were found to be effective in reducing PTSD symptoms.⁴ The symptoms that so many trauma survivors readily describe and some of the benefits of mindfulness and meditation are shown in Table 1.

Mindfulness is a learnable set of skills, involving ongoing, moment-by-moment focused awareness and openness to the here-and-now, without judgment and with acceptance. It is, in some sense, the polar opposite of avoidance. “Increased acceptance of trauma memories by definition makes them less “negative”—thereby potentially requiring less avoidance and allowing more exposure and psychological processing,” says Dr. John Briere. Explaining the “pain paradox,” Dr. Briere states, “In the face of emotional pain, a common human response is to withdraw, numb, distract, deny, or to otherwise suppress awareness. Yet psychological avoidance may actually prolong or intensify psychological distress. Those who abuse drugs or alcohol, dissociate, externalize through dysfunctional behavior, or suppress upsetting thoughts and memories, for example, are more likely than others to develop intrusive and chronic problems and symptoms.”⁵

We started a mindfulness meditation group for trauma survivors at the Center for Violence

Prevention and Recovery in 2011. Our goal was to address some of the difficulties that trauma survivors have in enjoying their lives. Post-Traumatic Stress Disorder (PTSD) and other trauma symptoms can prevent people from living in the moment. Life is passing them by, without real connection to the people and activities that they are interacting with. Traumatic experiences keep many survivors worried about the future and very anxious in the present. Our groups are open to people of all genders with the majority of the participants identifying as female and there has been a significant representation of LGBT survivors.

With practice of meditation and exercises in mindfulness, those who have experienced trauma have the opportunity to be in 'the here and now'. With more moments in the here and now, there is the ability to connect to people and activities, opening up the possibility of enjoyment, calm mind and regulated mood. Generally, there can be an overall improvement in the quality of life. While only a few years ago, there was very little material on trauma and meditation as noted by Kathleen Kane in her paper on The phenomenology of Meditation for female Survivors of Intimate Partner Violence⁶, there are now numerous websites that discuss the potential benefits of meditation for survivors of interpersonal trauma including www.Meditation-PTSD.com and Trauma Recovery (<http://trauma-recovery.ca/>).

Meditating together as a group and sharing daily struggles and triumphs helps trauma survivors, who feel isolated in their pain and trauma, to feel like they are 'in the same boat,' and that slowly over time they can feel more connected and less alone. Given the devastating impact of being or feeling isolated from others, this aspect of the group is powerful and effective in addressing isolation.⁷ Sharing in aspects of their trauma can help survivors gain validation for their experiences that are often cloaked in shame.

Prior to the group starting, an initial meeting with individuals who want to participate in the group is conducted by the co-leaders. This meeting helps orient participants to the group and screens out those survivors who may need other types of intervention prior to engaging in a group. Our ten-week group, co-lead by one clinician and one meditation teacher, starts with a discussion of how the practice of meditation and mindfulness can help to address PTSD, other symptoms and struggles related to trauma. There is a brief time for check-in with participants.

"Our breathing is a stable solid ground that we can take refuge in. Regardless of our internal weather—our thoughts, emotions and perceptions—our breathing is always with us like a faithful friend. Whenever we feel carried away, or sunken in a deep emotion, or scattered in worries and projects, we return to our breathing to collect and anchor our mind."

—Tich Nhat Hanh

<http://plumvillage.org/mindfulness-practice/breathing>

While we gather background history about the individual participants during the initial meeting, the majority of time spent in the facilitated group focuses on how women are doing now and what they are doing to improve the quality of their lives. If a group member is intent on discussing their history, we gently encourage them back to ‘the here and now’. Various topics that are generated by participants for discussion are integrated into our agenda for the ten sessions as shown in Diagram 1. You can review an example of the handouts used in our group sessions at

<http://www.meditation-ptsd.com/concentration-meditation>

The structure of the group is the practice of meditation—everything else is fluid. We ensure that there are two times to meditate within the 75-minute sessions. Sometimes the meditation is short, particularly at the beginning. Instructions for how to meditate using the breath and/or visualization methods are demonstrated. After meditation, there is a

For more information on meditation methods go to the following link for Thich Nhat Hanh Guided Mindfulness Meditation:

https://www.youtube.com/watch?v=AW66B_aGuiA

time for participants to report on how they are doing. For some survivors, meditation can be triggering or overwhelming. We make certain to respond immediately if anyone is struggling and work together to find strategies and solutions to acknowledge and support that person. Our goal is to connect with group members and assure them that they are in a safe place with other survivors who can support them. While there is no one right way to practice mindfulness, instruction, structure and motivation

from the group helps participants to have a positive experience.

The group has been running for four years now and participants have informally shared feedback about what works and the impact of the group. Overall, people feel that it improves their life and provides them with a skill that they take with them everywhere—the ability to focus on their own breath—so simple, yet so precious. For survivors of domestic violence who have been told that many things about them are unacceptable, the mindfulness meditation approach of acceptance, self – compassion and self-worth can be invaluable.

Diagram 1



TABLE 1.

Trauma Symptoms and Benefits of Meditation/Mindfulness Practices

Trauma Symptoms and Struggles	Benefits of Meditation and Mindfulness Practices
Hypervigilance/Anxiety	Calm/stead state of mind and body
Fear and Anger	Confidence and decrease in negative emotions
Depression	Optimism
Feeling Numb	Being Present
Difficulty with Relationships	Increased Capacity for Relationships
Lack of Joy in Everyday Life	Contentment and Joy

Source: Yodsamapa & Hartwick, 2012; Handout developed for Center for Violence Prevention and Recovery

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Other resources

<http://plumvillage.org/mindfulness-practice/sitting-meditation>

www.meditation-ptsd.com/concentration-meditation

<http://www.meditation-ptsd.com/benefits-cautions/>

<http://trauma-recovery.ca/recovery/mindfulness/>

www.jimhopper.com

www.janinafisher.com

"Mindfulness - An introduction with Jon Kabat-Zinn" runs 1:34:03, and is produced by Mindfulness Academy Scandinavia: <http://mindfulnessacademy.com>

FOSTERING CHOICE, VOICE AND AGENCY TO IMPROVE THE HEALTH AND WELLNESS OF WOMEN LIVING WITH HIV: TRAUMA-INFORMED CARE AT CHRISTIE'S PLACE

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Despite wide-spread availability of effective HIV medications in the United States, the majority of women living with HIV are not accessing life-saving treatment. Women living with HIV are disproportionately impacted by trauma due to high rates of lifetime sexual and physical abuse, violence, and the ongoing effects of Post-Traumatic Stress Disorder (PTSD).¹ Women, particularly women of color, experience significant barriers to accessing high quality healthcare, and experiences of childhood and adulthood abuse are now recognized in the literature not only as risk factors for acquiring HIV but also as barriers to optimal engagement in and retention in HIV healthcare.² Further, trauma and PTSD are known to predict poorer HIV-related health outcomes including inferior health-related quality of life, lower rates of HIV medication adherence and higher mortality rates.¹

At Christie's Place, we recognize that trauma and PTSD impact every aspect of the HIV care continuum.³ In 2013, we expanded our existing gender-responsive and family-centered framework and embarked upon a timely and

Transforming lives since 1996, Christie's Place is a leading community-based nonprofit organization in San Diego, CA that provides comprehensive HIV/AIDS education, support, and advocacy to women, children and families impacted by HIV/AIDS. For over 19 years, Christie's Place has filled a critical need for gender-responsive, family-centered, culturally and linguistically competent behavioral health and social services closely linked to HIV healthcare which address the unique needs of these families; empowering them to take charge of their health and wellness. Our model includes: an early intervention services center with resource coordination, information and referral, medical case management, behavioral health, childcare, family case work, patient navigation, basic needs assistance, and community education and outreach. Further, our dedicated staff and volunteers have worked to cultivate a safe, welcoming and family-centered space which, for many women and their families, is a safe haven—a home away from home.

significant shift in our organizational culture by institutionalizing trauma-informed principles and practices. Over the past three years, we have developed a model of trauma-informed behavioral health and social service provision that has drawn heavily from our nearly twenty years of experience working with women, children and families impacted by HIV as well from leaders in the field of trauma-informed care including SAMHSA⁴ and the Office on Women's Health⁵. Further, central to our trauma-informed model of service provision is an understanding of how the effects of violence and abuse exist within the context of women's lives and the intersections of their identities across the lifespan. This is grounded in an understanding of structural issues such as poverty, housing and food insecurity and inadequate access to resources and how these issues can exacerbate gender related health disparities as well as make decisions about leaving violent situations more complex. This also involves recognition that women living with HIV live day to day with multiple experiences of marginalization along the intersections of their identities including their gender identity, race, ethnicity, immigration status and sexual orientation. While not exhaustive, the following will highlight a few key aspects

of our trauma-informed model which are both innovative and vital to our model's success.

As Christie's Place has always been a proponent of the meaningful inclusion of women living with HIV in all aspects of service design, delivery and evaluation, the voices and experiences of women living with HIV—inclusive of those providing and those receiving services—are integral to our trauma-informed model. Further, women living with HIV who also have histories with violence and abuse play an integral role within our agency as providers of peer-based patient navigation services. Christie's Place Peer Navigators develop relationships that foster hope via their common lived experiences, their expertise in navigating HIV medical care, and by demonstrating that one can not only live—but truly live well with HIV. Additionally, our peer-based patient navigation services include assessment for intimate partner violence and sexual assault as well as PTSD, depression, anxiety, and substance use in order to identify and provide additional supports necessary and facilitate referral to our strength-based medical case management and trauma-responsive behavioral health services.

We believe that trauma-responsive behavioral health services must be strength-based and

foster resiliency. We utilize an evidence-based, resiliency focused therapeutic model called Skills Training in Affective and Interpersonal Regulation⁶ as well as a social justice oriented approach called Narrative Therapy⁷. These

Trauma and PTSD are known to predict poorer HIV-related health outcomes including inferior health-related quality of life, lower rates of HIV medication adherence and higher mortality rates.



We are committed to addressing the power and hierarchy inherent to service settings... we consider our work as partnership between our staff and the women who access our services in which each bring knowledge and experience to the table.

services offered within the context of our trauma-informed agency environment foster an understanding of the effects of violence and abuse on a woman's lived experiences, inclusive of her resilience. As these insights develop, new and meaningful options become available for responding to trauma which are characterized by choice, voice, and agency. She gains a sense of control over life decisions which promotes physical, mental, emotional, social, spiritual, relational health and wellness and reconstructs safety in her life by reclaiming her identity, her hopes, her dreams, and her sense of purpose.

We also offer opportunities for women to be with one another informally in the context of our early intervention services drop in center

as well as through support groups, family events, educational opportunities and a yearly women's retreat. These forums allow women to share their stories and also learn that they are not alone in their experiences of violence and abuse—diminishing isolation and fostering the development of new support systems. This is illustrated by the sentiments of Jay Blount, Christie's Place Peer Navigator, who truly embodies our commitment to trauma-informed care. Diagnosed with AIDS in 1996, Jay is a survivor of multiple traumas both in childhood and adulthood including sexual abuse and intimate partner violence. She states: "I have now realized that my purpose is to continue to tell my story and to help women to become survivors not victims. You see, I am no longer a victim, I am victorious over my life's circumstances."

The development of our model required the commitment and dedication of all of our staff (inclusive of administrative staff) and our management team. As such, staff development is an integral component of our trauma-informed model. This has involved ongoing training on the effects of violence and abuse for all staff inclusive of training on secondary traumatization, regular supervision, and ongoing assessment of our training and resource needs by our Trauma Informed Service Provision Committee.

Additionally, our model has garnered the interest of and enhanced our relationships with local medical providers. A woman can truly take charge of her health and wellness in the context of collaboration between a trauma-informed community-based organization and medical providers.

Through our trauma-informed model of service provision, Christie's Place is supporting women living with HIV as they overcome fear, silence, stigma and isolation. We propose that this type of model should be considered an essential component of healthcare and social service provision. The development and maintenance of a trauma-informed model is an ongoing and dynamic endeavor—it necessitates the shared commitment of the stakeholders of our communities' health and wellness. Healing

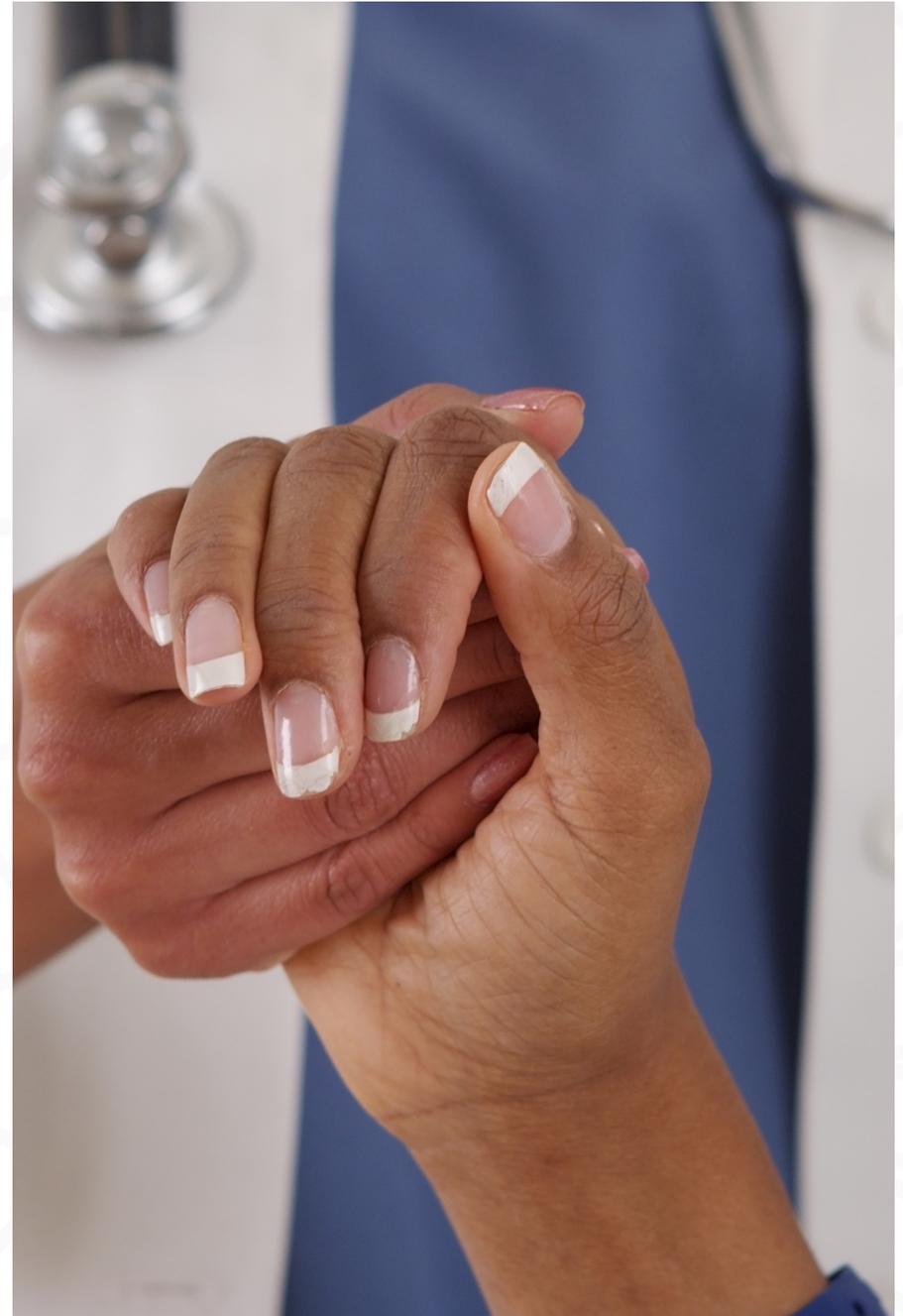
"I have now realized that my purpose is to continue to tell my story and to help women to become survivors not victim, I am victorious over my life's circumstances."

- Jay Blount, Peer Navigator

occurs in these relationships, and this affords an opportunity for all of us to make a transformative impact. Addressing the effects of violence and abuse in the lives of women living with HIV not only improves health outcomes, but fosters strength, resiliency and wellness throughout the lifespan.

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PRISCILLA'S STORY



Priscilla Mahannah
Peer Navigator and Survivor
Christie's Place, San Diego, CA

My name is Priscilla Mahannah and I am a woman living with HIV. I am 32 and I was born and raised in San Diego, CA. I am sharing my story because my life, like the lives of so many women living with HIV, has been significantly impacted by violence and abuse. It is my hope, that by sharing my story you can learn through my life experiences that trauma doesn't define us. Healing and recovery are possible for all.

My story begins as a little girl when I lived with my mother, younger sister and stepdad. I did not play much as I was really busy being my mother's protector. You see, violence was a regular occurrence in our household and my mother got beat almost every night for eight years. My sister and I were regularly awoken from our sleep due to screaming and once I remember that he even tried to drown her. That particular night, the only thing that stopped him from succeeding was that my sister and I woke up and started screaming and pleading for him to stop. Like I said, I was her protector and my mom always says to me that we saved her life in that relationship. My stepdad was also sexually abusive towards me. I was really afraid of him.

Drugs were a big factor for him and my mom as they both were heavy meth users. I remember one time when I was in first grade or so that I would walk around class with straws up my nose and I thought that was normal... until the school called my mom. I got in a lot of trouble at home for that incident. Other than that I don't remember much about school at all.

When I was nine years old my mom decided to finally leave my stepdad. We moved into our first new place together, just my mom, my sister and me. My mom became really depressed and tried to commit suicide. When I found her I called 911. As I was calling, I was also frantically cleaning the house because I knew I did not want Child Protective Services to come and take my sister and me away and separate our family. After that, I spent a lot of time with my grandparents.

They were my safety net and their home was the only place I could sleep soundly at night. However, my grandpa ended up passing away shortly after that and then my grandma died three days later. I remember feeling like I had lost everything. At nine I had already seen a lot, learned to keep my mouth shut and was already becoming a little adult.

The next few years were filled with chaos and instability. In an effort to get clean, my mom picked up and moved us to Oklahoma, but that didn't last long. Her then boyfriend up and left—never to be seen or heard from again—so we headed back to San Diego. Luckily, we had a neighbor that saw us as family and allowed us to stay with her and her family when we had nowhere to go.

At the age of eleven I started smoking pot and drinking. By twelve I was clubbing in Tijuana with a fake ID, drinking and smoking crystal meth. My sister found out I was using and I got her high because I did not want her to tell on me. I started to ditch school and get involved with gangs. By this time my mom had started using again too.

At this point I thought I was ready for a relationship, and, by the age of 13 I thought that I had met the man of my dreams. He was 27 years old. I lost my virginity to him and was in that relationship for two years. He later told me

he had AIDS and that he knew about it three years before he met me. In 1996, at the age of 14, I was diagnosed with HIV. I stayed in this relationship and I remember feeling like my life was over. My mom didn't know how old my boyfriend was—I had told her he was 18. I lied for him because I knew it would soften the blow about how old he was. I also told my mom I gave him HIV and she believed me. That relationship did not last much longer. He was emotionally abusive and we separated when I was 15. He and my family had started using together and he had moved in, so I moved out. I told my mom that I would never step foot back in her house as long as he was there. To this day, I have never lived with my mom again. I lived from place to place out of a backpack.

At the age of 16 I got into another relationship with a man that was 36 years old. At this point I was an IV drug user. In this relationship I got beat for a whole year to the point I was curled up in a ball in a corner and bleeding. Meanwhile, I was in and out of juvenile hall for drugs. I finally left him when I was almost 18 years old. However, the pattern of abuse didn't stop with this relationship. I got into another abusive relationship and had a daughter by this man when I was 19 years old. One night during one of our physical altercations my daughter woke up. I remember saying to myself this looks very similar to my life as a child. This marked

“I remember saying to myself this looks very similar to my life as a child. This marked the beginning of a turning point in my life.”

the beginning of a turning point in my life. Meanwhile, I found out that the man who gave me HIV had passed away two years previously. I went to where he was buried and at that point, for the first time in my life, I forgave him. That moment was truly healing for me.

Now let's talk about my health. I stopped taking my HIV meds when I left home at 15 years old. The only time my physician and case manager would see me would be in shackles. They always gave me hope and they were nice to me and that made me want to come to care and take care of myself. However, I was not on HIV meds or in care until I found out I was pregnant. After I had my daughter I stopped taking my meds, and sure enough, fell out of care.

Q+A with Priscilla

In conversation with Kate Vander Tuig (FUTURES)

If instead of doling out punishments, teachers had asked you more about what was going on, would that have had a different impact on your life?

It's funny that you ask that, just this morning I was talking with some San Diego police officers who work for the School District, and we were discussing, what if, there had been more information and education about where someone can go when they have experienced what I have? I might not ended up in the streets and been gang involved. I might've had a safer place to go to - but there is so much stigma. If someone asked about what I was going through and had connected me to an agency or services that could have supported me, it could have changed my life.

From your perspective, how is the Peer Navigator model unique? What is the most valuable aspect of this model?

Peer Navigators are unique. There is nothing like getting walked through the process by someone who has been there already. You can't be taught how to navigate personal experiences through books and in school, so if clients are working with people who have actually been there before, they are more likely to build that relationship. Peers are also often the reason that clients connect to therapy and other

services: a therapist can say "You should come see me" and I can say to myself "Yeah, maybe" but if someone I trust, someone who has had similar experiences to me, is telling me that going to therapy was really helpful for them, I am much more likely to do it. Lastly, in my role as a Peer Navigator, I am showing folks that they too can get to where I am at today. We are survivors.

You have been through many experiences in your life and are now helping people through their own experiences and are a leader in your community. Could you talk about your resiliency or what strengths you bring to your work as a Peer Navigator?

For myself, I am honest and straight forward. I am professional, but I can connect with clients. If my clients are in need of anything, and they're afraid to speak, I will speak for them. I love what I do, I believe in what I do to the fullest. I have had those few people in my life whose hearts were in it – because their hearts were in it, that brought me back. It was shown to me to have your heart in this work, so I bring that piece to the table. No matter what I have been through, I am still standing, and what I have been through is what makes be able to do this for others. I believe that everyone has a purpose everything happens for a reason. I have no regrets - it's been a great journey.

At 19 I started utilizing services at Christie's Place. I got a vision of hope there and started to learn about how my life could be different. Finally, a sense of normality! These people sparked something in me. I wanted help but was not quite done with the lifestyle I was used to yet. From 2003-2005, I was locked up and this afforded me a lot of time to think things through. While I was incarcerated I made the decision to leave the abusive relationship I was in with my daughter's dad. When I was released I went to a recovery program where I graduated and stayed clean with the help of aftercare and Narcotics Anonymous.

Next, I got into another relationship that was not healthy and had two more daughters. I got out of that relationship in 2013. Despite the abuse I was enduring, I knew I wanted to help others. I got my first job in a care giving agency in 2008 and worked there for five years. In 2012, I started working in HIV services as an intervention specialist. Unfortunately, my oldest daughter's father passed away due to alcoholism that year. This led to a year-long relapse on alcohol as I really struggled to cope with his death. Fortunately, my previous

sobriety program exposure had instilled a drive for life in me and I got clean for good on May 4th, 2013. I stayed out of a relationship for one year like suggested and worked on myself and my family. In 2014 I met the man of my dreams and am proud to say that I am now in a very healthy relationship; the type of relationship that my daughters and I deserve. In 2015 I landed the job of my dreams as a Peer Navigator at Christie's Place for our CHANGE for Women program. As a Peer Navigator I get to help women like me every day.

HIV has significantly shaped my life, but it does not define me. In many ways it has been a blessing and now I get to live my passion to help others who have walked in shoes like mine. My journey and everything I have been through was tough but I have no regrets. I am the person I am because of it and I am forever grateful for the life I am creating every day. My story is in dedication to those who have died due to complications of AIDS, to those living with the consequences of violence and abuse, to addicts who have succumbed due to drug use—and to the still-suffering addict. Stay strong. Thank you.

CHANGING POLICY TO ADDRESS VIOLENCE AND TRAUMA FOR WOMEN LIVING WITH HIV

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Over the past three decades, the proportion of deaths among women living with HIV (WLHIV) attributable to HIV-related causes has declined, from 85% in 1996¹ to approximately 25% in 2014.² In part, this may indicate that improved antiretroviral therapy (ART) has had a tremendous impact on controlling the progression of the virus and that fewer people are dying from HIV-related causes.

However, taking a closer look at causes of death among women living with HIV in recent years, we see that the percentage of deaths caused by overdose, suicide, violence, liver disease and heart disease is alarmingly high.³

Each of these conditions is known to be related to unaddressed childhood and adult trauma and to coping mechanisms often connected with post-traumatic stress disorder (PTSD).

Recent and past abuse are directly associated with poor outcomes at every stage of the HIV care continuum for both women and men, including lower rates of linkage to and retention in care, poor medication adherence and lower rates of viral suppression,^{4,5} as well as with other HIV-specific outcomes, including disease progression,^{6,7,8} hospitalizations,⁹ and risk of death.¹⁰ In fact, trauma has a larger impact on medication adherence than other conditions such as depression, substance use, stigma, financial constraints or pill burden.¹¹

A meta-analysis released in 2012 showed that women living with HIV are five times more likely to suffer from PTSD than the general population.¹² This is hardly surprising when you look at what's going on for women with HIV. Nearly two-thirds (61.1%) of women living with HIV in the United States (U.S.) have experienced sexual assault in their lifetime—five times the rate in the general population. Over half of women diagnosed with HIV have experienced intimate partner violence (IPV)—almost

twice the rate reported in a national sample of women.¹³ More than one-third (39.3%) of WLHIV have experienced childhood sexual abuse—more than twice the rate in the general population. The estimated rate of lifetime abuse among women living with HIV is 71.6%, compared with 39% in a national sample.¹⁴

While disturbing, these statistics reflect a tiny portion of the violence that may be faced by people living with HIV in the U.S., where the HIV epidemic is largely one of Black and Brown people, and people who are poor. Thus, people with HIV are likely to also be subject to structural and institutional violence – in the form of racism, discrimination based on socioeconomic status, displacement, housing and food insecurity, and policing practices that disproportionately target poor people, people of color, trans- and gender-non-conforming people, and people engaged in parallel economies*, including sex workers. By creating economic vulnerability, policies such as income eligibility caps on AIDS Drug Assistance Programs and the failure of some states to expand Medicaid are also responsible for perpetrating violence. Over half of U.S. states and territories currently have laws on the books criminalizing HIV exposure, non-disclosure and

transmission. Such laws enshrine and codify discrimination against people with HIV. HIV-related criminalization laws have been used to prosecute people with HIV in cases where no transmission occurred or was even possible. Policies promoting criminalization, which inscribe stigma into law, and discrimination in the workplace and health care settings create a hostile and traumatic environment for people living with HIV.

In recognition of the pervasive impact of trauma on health outcomes of women with HIV, the latest version of the **National HIV/AIDS Strategy**, released in July, identified the necessity of implementing trauma-informed care in health care settings for women with HIV. The Affordable Care Act coverage of IPV screening is a significant step forward. In addition, transforming the Ryan White system to a trauma-informed care system could have tremendous impact for the half-million

people with HIV who rely on the program to access care each year. For starters, Ryan White programs should collect and report data about rates of IPV and PTSD symptoms, using standardized measures, alongside existing quality of life indicators, as well as more accurate data around rates of substance use, depression, stigma and social isolation. The Health Resources and Services Administration's HIV/AIDS Bureau (HRSA HAB) can also encourage Ryan White programs to integrate evidence-based responses to PTSD into existing funded clinical services including therapy, psychiatry, medication adherence and substance abuse treatment. Clinics funded to deliver care to people living with HIV should be assessed on their commitment to and competence in delivering trauma-informed services, their community relationships to facilitate addressing trauma and violence, and their implementation of evidence-based interventions to reduce PTSD symptoms and promote healing.



*Parallel economy refers to income earned by activities not reported to authorities.

However, larger systemic change will also be necessary. Laws and policies that unfairly target people with HIV must be repealed. Service providers, law enforcement, health systems, etc. should be held accountable for practices that create a hostile environment for poor people, LGBTQ and trans/gender-non conforming communities, and people of color. Current laws and policies that criminalize substance use and sex work effectively impede harm-reduction strategies. Many of these laws are enforced primarily against people of color and sexual minorities, compounding the trauma these individuals and communities experience.

Only by seriously addressing these systemic inequities and policies that fuel trauma can we hope to improve the lives and health outcomes of those living with HIV, and support HIV prevention efforts.

Positive Women's Network-USA (PWN-USA) is a national membership body of women living with HIV and our allies that exists to strengthen the strategic power of all women living with HIV in the United States. We combat stigma, analyze policy, and promote the visible leadership of women living with HIV. In addition to national advocacy, we support leadership at a local and state level. PWN-USA believes in self-determination, sisterhood and solidarity. Every day we inspire, inform and mobilize women living with HIV to advocate for changes that improve our lives and uphold our rights. Learn more about PWN-USA at pwnusa.wordpress.com.

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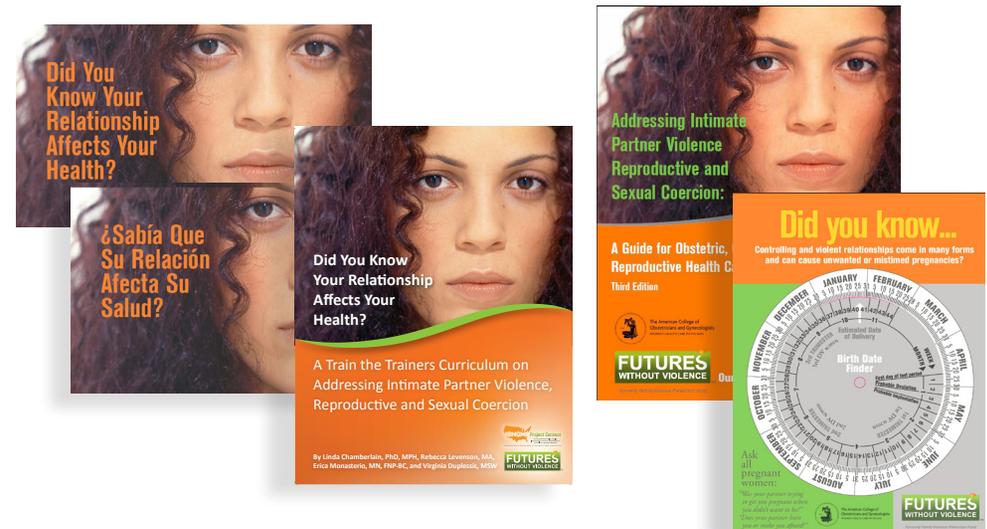


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Dr. Marylouise Kelley (Family Violence Prevention & Services Program Director, Administration for Children and Families, US DHHS) addresses the audience at the National Conference on Health and Domestic Violence in Washington, DC (March, 2015).

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