

World AIDS Day 2022

Centering Lived Experience: Lessons from the Community

Foreword

When I first met Alice Ferguson, I was working at the Central Area Health Education Center, Inc. in Hartford, CT - one of four AHEC sites in our state - and the only one with a focus on providing a full range of HIV/AIDS services across three counties. Alice was one of the CHWs and Peers working on the Ryan White Part A program, and was a natural leader, a tireless advocate and a compassionate and provider and generous colleague. Whether conducting street outreach, attending HIV consortium meetings, working with our city health department, acting in HIV-focused plays, or addressing statewide policy councils and planning meetings, Alice was always representing her community of diverse individuals living with HIV, ensuring that they were cared for and respected. Alice is among those CHWs who I consider an elder, mentor and friend, and I am honored to have her share from her storehouse of experience with the NACHW community in the article below.

- Denise O. Smith, CHW, PN, MBA, *NACHW Inaugural Executive Director.*



In my long journey as a Community Health Worker (CHW), I have held many positions. I have been a client, an advocate, an activist, and a peer navigator (PN). Most importantly, I have been a contributor with lived experience in the HIV/AIDS arena. I have lived 33 years with HIV/AIDS. That is 33 years that I have spent overcoming numerous related complications and mastering this chronic disease. Through my faith, I have transformed my mental, emotional, spiritual, and physical traumas into leadership skills and a journey of success. In this lived experience lies my passion for continued self-development, and a desire to use my voice for advocacy, empowerment, and creating spaces to raise the vibration and health of my community. I remain committed to overcoming stigmas in the health arena in all its shapes and various forms.

TALES FROM THE CASELOAD

I will give you a look inside the life I lived as an HIV/AIDS diagnosed CHW/Peer Navigator. A Google definition of a CHW is “one responsible for helping patients and their families to navigate and access community services, other resources, and adopt healthy behaviors. The CHW supports providers and the Case Managers through an integrated approach to care management and community outreach.” Whether titled as a CHW or PN, the core commonality is a commitment to meeting people where they are and serving them in the best way that serves their need. As I continue, you will see the acronyms used interchangeably.

As a CHW/PN working with HIV positive clients, I was assigned clients according to their viral detectability, length of time out of care and general difficulty producing favorable health results. Two

encounters that I remember distinctly include Nikki and Jonathan (not their real names). Nikki was a transgender transient female infected with AIDS. I started my encounters by establishing what I've found to be the most critical factors in client care; **trust and respect, partially gained by sharing my own HIV/AIDS experience**. Nikki was directed to my office shortly after walking into our organization one afternoon. Soon after, her case manager, our agency director and I went to work as her newly appointed care team. As our team worked to address her most immediate needs, Nikki went to sleep on my office floor. Nikki needed immediate housing, and management was able to secure a check for a 28 day stay in a motel. My part was to pick up the check from Home Office and deliver it and Nikki to that safe haven. It seemed to be a straightforward task but was anything else. By the time we finalized everything needed for payment it was after 4:00pm. Before picking up the check, I drove Nikki to two locations to recover her belongings and we discussed her care and future. Upon arrival at the motel, I learned Nikki had no identification. This required I use my ID to secure the room as my agency had closed. After checking into her room, Nikki asked, "Is there any way you could sit with me a few more minutes?" In that moment the humanness and frailty of my client was all too apparent.

My second client was Jonathan. Jonathan was actively addicted to heroin and had AIDS. He lived with his supportive but enabling family, who were unfortunately ill-informed about the reality of living with AIDS. Jonathan's family had decided to move him out of an HIV/AIDS residence due to disagreements over his belongings missing. As with every client, I had to establish trust not just with Jonathan, but also with his family. I accompanied him to several weekly appointments to make clear to him and his family, the significance of being in compliance with his medications.

What were the health outcomes for Nikki and Jonathan? Regrettably, after 3 months of working with them, both returned to not taking medication and had detectable viral loads. Nikki was even part of my client load a second time. I was serving ten other clients at the same time as I served Nikki and Jonathan, and all other ten clients were able to achieve undetectable viral loads and go on the monitor their own healthcare independently. Unfortunately, the demands and disruption caused by homelessness and addiction outweighed their commitments to managing their health. As a CHW/PN, these outcomes felt like defeats for me, but I understood the contributing factors. After five years, I terminated my employment with the agency.

The reason I choose to share those experiences was to put on display the vulnerabilities, successes, and failures one encounters serving as a PN/CHW. I was granted a limited time to learn the needs of clients as well as work to achieve, sometimes only a measure of the positive outcomes we hoped for. CHWs manage clients with limited time to access all the components involved with getting those who are "left behind" in our communities the things they need that most of society takes for granted. I had to learn how not to lose myself in trying to save the lives of my peers.

THE VALUE OF CHWs

CHWs are committed because of our spirit of care and compassion, and because we intimately understand the communities we serve. This shared lived experience elevates the overall health of the communities we serve. CHWs are keenly aware that genuine acceptance without judgement of an individual is the unspoken language we possess. In my experience, I was often the only advocate the client had in situations beyond their medical care. I was the voice of explanation about HIV/AIDS to

their families. Stigma and ostracism are REAL and present in the lives of my clients. While a lot has changed regarding stigma from the early days of the virus, we still need to pay attention to this aspect of living with the virus, and not only for people living with HIV/AIDS (PLWHA), but for their loved ones too. The advances in health, medication, and early-detection have significantly improved health outcomes for PLWHA. Addressing the conditions and comorbidities that increase the risk of transmission and decrease the chances of successful disease management are areas where the services of CHWs most shine.

Lived experience is an invaluable and untapped resource that allows CHWs and clients to establish deeper levels of trust that translate into better community education, disease management, and positive health outcomes. We who advocate for and serve communities as a CHW frequently receive lessons and wisdoms from our clients. The CHW builds on each encounter and consequently an entire community benefits. The unique position of CHWs is vital to client and community success but can also be leveraged to ensure program success. CHWs understand the nuances of a community, they understand the unseen challenges faced by those most in need of support, and when given space at the tables of public health leadership, are well-equipped to co-create and facilitate holistic approaches to the most complicated health challenges. **My lived experience has allowed me to engage with and understand my clients and their needs on a heightened level. It is this fulfilling work that makes keeps me committed to my endeavors as a CHW/PN.**

Alice Ferguson
Peer Navigator, HRA Wellness Resource Center