

September 28, 2018

HOPWA In Focus: Client Confidentiality

If you attended the Housing Opportunities for Persons With AIDS (HOPWA) Institute last year, you heard me speak about my past experiences working in a small HIV clinic. In the 1990s, I started my journey of work in the HIV field as a Prevention Education Specialist, taking the current prevention message to school kids, church groups, and businesses in a very rural 14-county area. By this time, tens of thousands of Americans were living with HIV, and new medications to treat the virus were on the fast track from development to production. As the epidemic neared the 15-year mark in the United States, we had a better understanding of the disease in the medical community...but outside of the medical setting, HIV stigma remained rampant. It was part of my job to help people understand that fear and stigma, or “otherism,” did not make them safe from HIV.

It was through this work that I became aware of the importance of protecting the confidentiality of our clients and their family members. Our organization had strong policies and procedures in place around confidentiality, and we upheld those high standards because our clients’ lives depended on it.

In 1998 I was in the parking lot of the local Winn Dixie grocery store where I happened to see a client, Ralphie. In accordance with the policy of the clinic, I did not smile, wave, or acknowledge Ralphie in any way. When I saw him again at the clinic the following week, I explained the policy of not acknowledging clients outside of the medical setting to maintain confidentiality. Ralphie laughed out loud. “Rita,” he said, “the next time you see me in public I want you to wave your arms and yell at me across the parking lot, ‘HEY, RALPHIE! It’s me, Rita, from the AIDS Clinic!’” Ralphie was an advocate for people living with HIV, and he was fortunate that he felt supported and safe in his small community. As much as I admired his spark, I would never break the agency policy even after he made that humorous comment. Ralphie would have to acknowledge me in public first, and from that day forward he always did.

In 2005 another client, Chuck, had moved into our HOPWA short-term housing facility while on the waiting list for a permanent unit. He got a job working in a restaurant and became friends with some of his coworkers. One of them gave Chuck a ride back to the HOPWA house after work, and later this coworker told their manager that Chuck lived in “AIDS Housing.” Chuck was called into the office, and the manager questioned him about HIV and food safety. Chuck was moved to tasks away from food and customer interaction, instead given cleaning and stocking jobs. Suddenly, his work was reduced to only a few hours a week and only late night after public transportation ended. Within days strangers were stopping Chuck in public and asking why he was risking the life of innocent people by working in a restaurant, handling food. After several instances of this, Chuck quit the job. He first wanted to fight the discrimination, but after a few weeks he decided it was safer for him to just move to a new city. Gossip spreads quickly in small communities, and people living with HIV, or even perceived to be living with HIV, suffer the consequences.

More than 10 years have passed since Chuck was forced out of his restaurant job, and yet HIV stigma still persists. Leading the Office of HIV/AIDS Housing allows me to stay connected to HOPWA grantees and providers and to get occasional glimpses into the small towns and cities served by the program. Although housing discrimination, stereotypes, and lack of HIV education is pervasive, more people living with HIV have chosen to disclose their status openly as Ralphie did years ago. Nevertheless, HUD insists

that all grantees and all project sponsors remain vigilant in protecting the health information for every client served by HOPWA, including family members and friends who may be perceived as HIV positive.

It's critical to develop good policies and procedures that are explained and implemented by all staff and volunteers. All policies of a HOPWA program should have provisions around confidentiality including accounting practices, records release, and electronic records management, so that a "Confidentiality Policy" does not stand alone. The physical address of HOPWA facilities must be protected, and the agency name and website should be carefully considered for potential breaches in confidentiality. HOPWA recipient information should only be shared on a "need to know" basis, including staff who are directly delivering services and HUD-required monitoring of records.

Our country has seen miraculous advances in HIV prevention, testing, and treatment since the 1990s including housing as a structural intervention; however, one thing has not changed – the health information of an individual belongs to the individual. A person living with HIV makes decisions about if, when, where, and to whom their HIV status is shared. We must all work to ensure the rights and the safety of people assisted by HOPWA. For more information on HUD's expectations on confidentiality, please review the [HOPWA Confidentiality Manual](#).

As always, thank you for your commitment to providing housing and services to people living with HIV as we all work toward the day when AIDS is no longer an epidemic.

Respectfully,

Rita

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