

# People with HIV As Community Health Workers (CHWs)

The HIV advocacy movement in the U.S. has transformed how public health efforts respond to and support marginalized and underserved populations. From the beginning, the HIV response has been set apart by the active role of community. People with HIV have been on the frontlines of shaping program and policy implementation around the communities most impacted.

While the U.S. has made progress in preventing HIV (See KFF, *The HIV/AIDS Epidemic in the United States: The Basics*, August 2024)) and increasing access to antiretroviral therapy (ART) and increasing viral suppression rates (HHS Press Release, *Latest Data from HRSA Ryan White HIV/AIDS Program Highlight Nine Out of Ten Clients with HIV Are Virally Suppressed*, December 1, 2023), there are still inequities across populations. While many may have access to good clinical care, some people are also socially isolated or report a poor quality of life. Our health care systems are also complex, and people who encounter barriers may give up and stop engaging in care. Policymakers and health care providers increasingly recognize the critical role that community health workers (CHWs) can play in bridging clinical care and addressing the social barriers to good care and a high quality of life. The American Public Health Association (APHA) defines a CHW as a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served, thus recognizing the role of community in affecting change (<https://www.apha.org/apha-communities/member-sections/community-health-workers>). This trusting relationship enables the worker to serve as a intermediary between health and social services and the target community to facilitate access to services and improve the quality and cultural competence of service delivery.

**One critical type of CHW is a peer, in this case, a person with HIV** who serves on a care team and relies, in part, on their own lived experience to help clients navigate our complex and often frustrating health care and social services systems.

## WHAT MAKES AN EFFECTIVE HIV PEER CHW?

The National Academy for State Health Policy, with funding from the Health Resources and Services Administration (HRSA) examined three state models (Florida, New York, and Wisconsin) of peer CHWs in their Ending the HIV Epidemic (EHE) Initiatives. (See chart to the right, based on <https://nashp.org/opportunities-for-states-to-improve-hiv-treatment-through-peer-delivered-services/>).

## WHY LIVED EXPERIENCE MATTERS

There are many people who come from community and serve as effective CHWs, but peers often bring special credibility and expertise that enables them to be effective. This is because of a few factors:

- **Trust:** In the provider-patient relationship, trust is built over time. Individuals who share an HIV diagnosis may also share a common journey from diagnosis to treatment which can create connection and trust within a medical care environment. For persons experiencing high levels of stigma and shame, engaging

## CRITICAL SKILLS FOR HIV PEER CHWs

CORE COMPETENCY THEMES	FL	NY	WI
Lived experience with HIV/AIDS, including effective disease management and self-care strategies	X	X	X
Relates to clients via shared lived experience, despite the differences that may exist between them; ability to strategically and comfortably share personal experience and HIV status		X	
Demonstrates strong and effective communication skills; communicates using a person-centered approach	X	X	X
Ability to self-advocate, advocate for others, and advocate for access to services	X		X
Understands their own personal and cultural identity and how these influence personal attitudes, reactions, and assumptions; develops awareness of and manages own personal biases and triggers	X	X	
Ability to address health literacy needs		X	
Ability to embrace and communicate a self-affirming empowering attitude	X		X
Trauma informed, person-centered approach		X	X
Upholds agency confidentiality policies and procedures		X	X
Recognizes their own vulnerabilities and emotional responses to work-related matters; employs self-care strategies to promote wellness and prevent burnout		X	
Recognizes knowledge limits and seeks supervisor assistance, opportunities to increase knowledge and peer support skills		X	

Source: National Academy for State Health Policy, 2022.

with a peer can enable them to overcome these experiences to form more effective relationships with different care providers.

- **Mutual Understanding:** A person working in health care and social services must be flexible and able to work effectively with clients and colleagues with different backgrounds and experiences. A client-peer relationship can foster an intuitive understanding of the client's situation based on shared experience. They also may have a similar cultural background that creates comfort in a way that enables more effective communication.
- **Community Networks and Connections:** Peers that have experienced and overcome similar obstacles to the client may be able to offer a community network and contacts that can be deployed to assist a client.

## COMMON TITLES FOR PEER CHWs

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There are not standard terms for peers and CHWs can play different roles. Common roles for peer CHWs can include:

- Patient or Peer Navigators
- Peer Educators
- Outreach Workers
- Peer Counselors
- Health System Navigators
- Linkage to Care Coordinators

## WHAT WILL IT TAKE TO EXPAND ACCESS TO HIV CHWs, INCLUDING PEERS AS CHWs?

In the U.S. health care system, the cost of an intervention can be a critical determinant of whether interventions are adopted. A growing body of research, however, shows how CHWs can be cost-effective and improve outcomes. This should facilitate even greater adoption of CHW programs across payors such as Medicaid, Medicare, and private insurance, as well as across public health programs.

From 2016-2019, HRSA supported a project in ten sites receiving funding from the Ryan White HIV/AIDS Program (RWHAP) to integrate CHWs (not exclusively peers) into HIV care to improve access to and retention in health care for people with HIV and to improve health outcomes through strengthening the health care workforce. HRSA supported a project in ten sites receiving funding from the Ryan White HIV/AIDS Program (RWHAP). An evaluation of the program (Drainoni, M. L. et al, *Journal of HIV/AIDS & Social Services*, 2020), found that CHWs interacted with clients on an average of 11 days over six months and they most commonly provided coaching and health education, emotional support, and appointment reminders. The study demonstrated improvements in all three clinical criteria (% increases): 1) clients with a primary care visit in the last six months, 2) clients with an active prescription for antiretroviral medication (ART), and 3) clients who achieved viral suppression. HRSA's technical assistance resource, <https://targethiv.org/chw>, offers a number of resources that came out of this project to assist with the adoption of CHW programs for HIV care.

In other therapeutic areas, research also documents the impact of CHW programs with strong results for underserved populations, indicating that CHW programs can improve health equity. A number of studies also show cost-savings associated with CHW interventions. See ASTHO/NACHW <https://www.astho.org/globalassets/pdf/community-health-workers-summary-evidence.pdf>.

Beyond the RWHAP, increasing the number of CHW programs in HIV care depends on sustainable financing. More than half of state Medicaid programs (the largest source of federal funding for HIV care) cover CHW services and this number is increasing (KFF, *State Policies for Expanding Medicaid Coverage of Community Health Worker (CHW) Services*, January 2023). Recently, Medicare (the second largest source of federal funding for HIV care) made changes to the physician fee schedule to permit billing for principal illness navigation (PIN) services for persons with serious conditions such as HIV (See <https://www.medicare.gov/coverage/community-health-integration-services>), as well as community health integration (CHI) services which can be provided by CHWs for services such as care coordination, health education, patient self-advocacy training, and social and emotional support. (See <https://www.medicare.gov/coverage/community-health-integration-services>).

CHWs enhance HIV care teams by working in partnership with case managers, medical providers, social workers and other care providers to address the whole person needs of people with HIV. CHWs can effectively serve as a bridge between a clinic or community-based organization (CBO) and the community they serve, however, only when they are recognized as a critical component of the health care team. In order for this to happen, organizations with CHWs must value the experience of and contribution to care that people with HIV have to clinical services by ensuring that they are fully integrated as respected as part of the care team. It also requires ensuring that CHWs are adequately compensated, receive training and career advancement opportunities, and receive supports necessary to help manage the stress and trauma associated with assisting clients who have difficult experiences and complex needs.

## TO LEARN MORE

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For additional background information, the link below for our forthcoming brief, *Leveraging Community Health Workers (CHWs) to Improve HIV Patient Navigation*. See also:

The National Association of Community Health Workers (NACHW) provides a broad range of resources for entities seeking to deploy CHWs, they can be found here: <https://nachw.org/generalresources/>.

Boston University developed *A Guide to Implementing a Community Health Worker (CHW) Program in the Context of HIV Care*, updated October 2023, [https://targethiv.org/sites/default/files/file-upload/resources/CHW\\_ImplementationGuide\\_508.pdf](https://targethiv.org/sites/default/files/file-upload/resources/CHW_ImplementationGuide_508.pdf).