



Sustaining CHW Programs in the HIV Response: Lessons Learned from the United States

Community health workers (CHWs) have an important role in the HIV response globally, especially to increase coverage, uptake, and retention of HIV services at the community level, to reach the 90-90-90 targets. In HIV-burdened countries, PEPFAR has recognized the need to strengthen CHW program functions to increase the impact and sustainability of HIV services. These key functions include training, supervision, mentorship, role definition, recognition, linkages, incentives, and career advancement.

The rich experience with CHWs in the United States offers lessons for PEPFAR-supported countries about building, growing, and sustaining strong CHW associations; providing training, mentorship, and advocacy; and engaging CHWs with the formal health system. CHWs in the United States are culturally diverse and work in underserved areas, much like communities served by CHWs globally. To explore lessons from the US experience for CHW programs in the HIV response, USAID, the USAID ASSIST Project, and CHW Central organized a webinar on November 30, 2016 that brought together CHW leaders and organizers from California, Florida, Massachusetts, and Wisconsin. This short report summarizes key themes and takeaways from the webinar.

Getting the CHW organization started

Issues in forming sustainable CHW organizations include the type of organization, defining its mission, recruiting members, organization governance, and obtaining financial or other support to help establish the organization. Ideas for starting CHW organizations include:



WEBINAR:
Sustaining CHW Programs in the HIV Response:
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The recording of the webinar, questions and answers for the panel, and recommended resources are available at: <https://www.usaidassist.org/content/webinar-sustaining-chw-programs-hiv-response-lessons-learned-united-states>.

- Organize meetings of CHWs working with communities to decide the strategic direction for the group.
- Convene forums of CHWs, public health professionals, and civic leaders to discuss issues facing CHWs and raise awareness.
- Use social media, including digital stories, to raise awareness of the organization.
- Local government health departments and civic organizations can be tapped to support start-up activities.
- Informal and even volunteer groups of CHWs with common interests who have established relationships can be a good basis for forming an organization.
- Consider uniting the efforts of cross-sectoral community workers and not limit the focus to health. This may help generate broader support for the organization.
- Existing task groups of CHWs can be leveraged to take on new issues.
- Frequent, organized meetings of CHWs and other stakeholders in early stages of formation of a CHW organization are important to sustain interest.
- Annual meetings of the CHW organization with partner organizations, local government agencies, and other community development agencies help ensure engagement and coordination.

Growing and sustaining the CHW organization

Once started, sustaining a CHW organization requires deliberate strategies to maintain membership engagement as well as to finance the operations of the organization. Strategies and lessons from the panelists include:

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- Consider both financial sustainability and the vibrancy of the movement; a well-financed movement without a spirit and purpose is not likely to thrive.
- Engagement of stakeholders, cultivating CHW leadership, and conducting advocacy to sustain government and civil society support for the organization have all been important sustainability strategies in the US.
- Creating an identity for the organization and promoting that identity through meetings, and social media helps to raise its profile.
- Concrete action plans that are developed by CHWs and respond to locally identified priorities have been important for sustaining the engagement of CHWs.
- Providing leadership training to CHWs has been valuable to develop leadership roles in the organization and to strengthen the advocacy role of the organization.
- Incorporating the CHW organization as a not-for-profit organization may provide avenues for fundraising to support training and meeting expenses.
- Ensuring the voice of the CHW is at the table, deciding on priorities, and engaging with partners has been important for sustainability.

Theme 3: Support to strengthen CHW effectiveness

Strengthening the role of CHWs requires sufficient support functions, including training, supervision and mentorship, incentives, and career advancement. Certification of CHWs is being pursued in several states, including Florida. Insights from the panelists:

- Certification can be linked to pay, benefits, supervision, and career pathways. Certification has controversy too. Some worry that it over-medicalizes CHWs and creates different classes of CHWs.
- If establishing CHW certification, consider introducing a “grandfathering” scheme which provides a path to certification for long-serving CHWs by requiring documentation of a certain number of hours worked or minimum hours of training without having to take an exam.
- A continuous professional development model is another approach pursued by some CHW programs in the US, providing skills training based on needs identified by CHWs across a spectrum of care.
- The experience that CHWs in the US have gained from leading workshops, developing and executing plans, making presentations,

and participating on projects often help to create a pathway for obtaining paid employment if the CHW so chooses.

- In programs that link CHWs to facilities, it is important to look at facilities’ institutional readiness to absorb CHWs into their activities. Providing training and tools to supervisors on how to work with and empower CHWs have been important for effective CHW utilization.
- Close mentorship and supervision are important so that CHWs feel supported and are able to connect community members with other resources.
- Peer-to-peer support among CHWs and self-care (stress reduction and mental health) have been emphasized by several US programs.
- Organizing visits of CHWs to speak with legislators and policymakers helps to make CHWs’ voices heard and advocate for community-level concerns.

Theme 4: Connecting CHWs with the formal health system

CHWs are often expected to represent both the community and the formal health system, yet they can get caught in the middle between meeting the needs of the community versus the needs of the health system. It’s important that CHWs have both a voice in the health system and active participation in community governance. Insights from the experiences of CHWs in the US:

- There is a need for recognition and clarification in roles. In the community, CHWs are at the frontline in improving access to care, but should also be considered as a member of the health team. The links to the health system should be clear. This includes reliable referral pathways to facilities and facility counterparts for supportive supervision.
- It’s important to work with the hospitals first to make sure the institution has the necessary level of readiness to work effectively with CHWs. By partnering with local community organizations health facilities can better draw on all the resources available in the community to support the continuum of care—not just in prevention, but through treatment and even to end of life, with hospice care.
- Embedding the CHW in the health care facility has the advantage of facilitating access to medical records and team consultation and sometimes gives more credibility to the CHW. At the same time, CHWs based in

the community seem to do a better job with home visits than CHWs who spend most of their time in the hospital.

Theme 5: Role of CHWs in HIV programs

There is increasing dependence on CHWs performing more medically oriented tasks, often associated with home-based care. Key advice from panelists about supporting and sustaining the role of CHWs in HIV programs:

- Gather data to show the impact of community-based interventions; this can be important to maintain funding. In the US, an organization was able to show that clients receiving CHW home-based care services had higher pharmacy claims because the CHWs were improving treatment adherence but lowering overall costs due to lower rates of hospitalization among clients receiving home-based care from CHWs.
- Provide training for CHWs who provide home-based care on medications for HIV as well as other conditions often experienced by PLHIV, to expand their role in helping people who need support adhering to HIV treatment.
- Consider the role that CHWs can play in helping PLHIV navigate the health system by teaching clients when to seek care and what conditions can be managed by the patient. In Uganda, tools for patient self-management and action planning have been used successfully by CHWs and expert patients to help PLHIV improve adherence and wellness.
- To address stigma and confidentiality issues, ensure that CHWs are not presented as HIV workers so as not to arouse suspicion from neighbors about the purpose of the home visit.

Conclusion

Overall, the diverse experiences shared on the webinar suggest the value of diversity as a strategy in and of itself. Often in developing country contexts, we talk of transformation through one approach—for example, making CHWs salaried and part of government. The panelists showed the value of having diverse approaches and community-driven models and organizations. Panelists also emphasized the critical value of CHW involvement and CHW leadership, from forming the organizations to policy and advocacy, to determining how credentialing is to be done. In linking CHWs to the health system, programs must strike a balance between the needs of institutions and the needs of communities.