



# Impact of Community-Based Organizations for People Living with HIV

## Question

What is the impact of community-based organizations (CBOs) in supporting individuals living with HIV?

## Key Take-Home Messages

- Since the beginning of the epidemic, CBOs have displayed cultural competency and have gained the trust of community members, allowing them to target their services to people living with HIV who are less likely to use mainstream health care services (1;2).
- CBOs are able to help “hard-to-reach” populations (2;3), ethnic minority youth (4) and men who have sex with men (5;6).
- CBOs offer a wide range of services to assist people living with or at risk of HIV (1), including culturally adapted programs to help people along the HIV care continuum (7;8).
- Participants of the Treatment Advocacy program offered at AIDS service organizations across the U.S. exhibit much better antiretroviral adherence rates than non-participants, with an average difference of 15% (7).
- Clients in Treatment Advocacy programs are more likely to utilize a variety of social services, and as a result have fewer unmet needs (7).
- Recent research in Ontario has demonstrated the economic value of CBOs, showing that from 1987 to 2011, community-based HIV prevention programs prevented 16,672 new infections and saved the health care system \$6.5 billion (9).

## References

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## The Issue and Why It's Important

Community-based organizations (CBOs), including AIDS service organizations (ASOs) have been at the forefront of the response to HIV since the epidemic emerged. Many CBOs, particularly small and medium-sized organizations, lack the capacity to plan, implement and evaluate their successes (10). In an era of increasing financial accountability, CBOs may therefore be perceived as having limited effectiveness (10). Given the centrality of CBOs to the HIV response and their close relationships with communities and individuals living with or at risk of HIV, it is important to recognize the value of their work.

**Note:** The literature defines community-based organizations in many ways including “AIDS service organizations (ASO),” “Community based AIDS service organizations (CBAO),” “Community-based centres,” and “Community-based HIV organizations.” For the purposes of this review, we will refer to all of these as simply “community-based organizations” or “CBOs.”

## What We Found

### Cultural competency and trust

When the HIV crisis first emerged, members of the most affected group – gay men – often did not trust the health system (1). CBOs were created to take advantage of existing community organizations that did have the trust of gay men and other groups at risk of HIV (1). Today, the populations most affected by HIV still tend to be marginalized and often experience barriers accessing the services they need (1). CBOs are trusted resources within communities and have existing relationships with other key health services (11). CBOs are often close to their community members both culturally and geographically (12) and they display strong cultural competency skills necessary to work with people from diverse backgrounds (12).

Given the trust that community members have in CBOs, and the cultural competency that CBOs display, they are able to target their services to the multiple health needs of people living with HIV who are less likely to use more traditional health promotion and support services, such as Ontario's universal health care system (2). Examples of CBOs successfully connecting with “hard-to-reach” populations include:

### Vulnerable people living with HIV

Two Ontario-based studies have shown that CBOs are successfully reaching the most vulnerable people living with HIV. One study sought to determine the characteristics of CBO users. The authors found that, compared to non-users, CBO users were significantly less healthy, less able to sustain daily activities, and more often

5. Lorente N, Preau M, Vernay-Vaisse C, Mora M, Blanche J, Otis J, et al. Expanding access to non-medicalized community-based rapid testing to men who have sex with men: An urgent HIV prevention intervention (the ANRS-DRAG study). *PLoS ONE* 2013;8(4):e61225.

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9. Choi SK, Holtgrave DR, Bacon J, Kennedy R, Lush J, McGee F, et al. Economic evaluation of community-based HIV prevention programs in Ontario: Evidence of effectiveness in reducing HIV infections and health care costs. *AIDS Behav* 2015; [Epub ahead of print].

10. Mayberry RM, Daniels P, Yancey EM, Akintobi TH, Berry J, Clark N, et al. Enhancing community-based organizations' capacity for HIV/AIDS education and prevention. *Evaluation and Program Planning* 2009;32(3):213-20.

depressed (2). CBO users also reported more physical disabilities, had lower health-related quality of life scores, were significantly poorer than non-users and were more reliant on government income supports (2). The authors concluded that CBOs were being appropriately accessed by vulnerable individuals and that CBOs were also fostering the entry of vulnerable individuals into the traditional medical system (2).

A second study compared high-use CBO clients to low-use CBO clients. The study found that while all users were likely to be low-income, high users were more likely to be single and live alone (3). They were also more likely to report poorer health outcomes and less use of HIV specialist care (3). However, high-use and low-use CBO clients had similar CD4 counts and viral load levels (3). The two groups also reported similar levels of depression (3). The authors suggested that, not only were CBO services reaching the most marginalized populations, they were helping these individuals maintain functional health status despite their greater vulnerability (3).

## Ethnic minority youth

Data show African American youth have disproportionately higher rates of HIV and other STIs compared to their Caucasian counterparts. This is likely due to structural determinants such as limited access to treatment and preventive healthcare, and distrust of healthcare providers (4). However, STI screening conducted by culturally sensitive CBOs can potentially address these barriers (4). One Pennsylvania-based study examined the effect of a community-based STI screening program on sexual risk behaviour among African American youth who tested positive for an STI (4). The study found that youth who were referred by a CBO to an accepted and respected health care provider decreased their number of sex partners and had less unprotected sex (4). The authors concluded that screening sponsored by culturally sensitive CBOs may increase access to STI treatment services and that screening by CBOs will become increasingly feasible with the advent of rapid and reliable point of care testing (4).

## Men who have sex with men

Stigma, homonegativity and discrimination from health-care providers can discourage members of sexual minorities from seeking and receiving essential HIV prevention, testing and care services (6). Culturally-sensitive CBOs dedicated to a sexual minority group can help overcome these barriers. BCN Checkpoint is a Spanish CBO for men who have sex with men and offers free, anonymous and confidential HIV and STI testing. When researchers assessed the overall number of HIV tests conducted in the region where the BCN Checkpoint is located, they found that, from 2009 – 2011, the CBO detected 36% of all new HIV infections and successfully linked 90% of newly diagnosed individuals to care (6). The authors concluded

11. Pappas G, Yujiang J, Seiler N, Malcarney MB, Horton K, Shaikh I, et al. Perspectives on the role of patient-centered medical homes in HIV Care. *American Journal of Public Health* 2014;104(7):e49-e53.

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that a CBO such as BCN Checkpoint, focusing on a key population at risk, can consume less time and resources than other approaches and also show high efficiency in HIV detection and linkage to care (6).

CBOs can also benefit marginalized men who have sex with men. One French study compared community-based, non-medicalized rapid HIV testing targeting men who have sex with men with standard medicalized testing (5). The community-based testing option (advertised at gay venues) was called “CBOffer” and was offered by community members from a French CBO at a voluntary testing centre. HIV tests were conducted in the evening, outside of the Centre’s regular hours. Standard medicalized testing (“SMOffer”) was offered at the same testing centre during regular hours. Sixty-four per cent of the 330 men who tested sought testing at the CBOffer (5). When the study authors assessed the characteristics of the men who tested at CBOffer, they found that the community-based, non-medicalized HIV rapid testing attracted men who have sex with men who were much less likely to have tested in the previous two years (5). Men who attended CBOffer were also at greater risk of HIV because they were meeting more sexual partners in saunas, backrooms and adult video shops (5). The community-based testing option was therefore attracting a more marginalized group of men who have sex with men.

CBOs are also able to adapt programs to meet the needs of specific populations. For example, to address the prevention needs of transgender persons of colour aged 13 to 24, the U.S. Centres for Disease Control (CDC) funded CBOs to adapt interventions from their Compendium of Evidence-Based Interventions (8). The goal was to make the interventions appropriate for transgender youth. CBOs with prior experience or capacity to deliver HIV prevention services for transgender populations were selected for funding. A study focusing on five CBOs in high-prevalence U.S. cities found that the CBOs were able to successfully adapt the interventions, using approaches that included creating “safe spaces,” collaborating with the local transgender community, hiring transgender staff and recruiting transgender leaders (8).

## Special services

CBOs provide a range of services to people living with or at risk of HIV. The needs of the CBO client base have become more complex as the epidemic has changed (1). Organizations that used to serve people for a relatively short period now provide services to the same clients for 10 years or more (1). According to a survey conducted by the Ontario Ministry of Health and Long-Term Care, a significant portion of people using the services of CBOs have a substance use or mental health problem in addition to HIV, and many live in poverty and lack affordable housing (1). Many CBO clients have such limited resources that HIV is at the bottom of their list of concerns: they need substance use and recovery services, mental health interventions and resources for shelter, medications or food (12).

CBOs are not only helping clients cope with HIV, they are also helping them deal with a range of other problems and linking clients to other services in their community (1). One study listed at least 27 different services provided by CBOs, ranging from HIV testing to educational programming, community outreach, food bank programs and assistance with housing, transportation and legal services (1).

CBOs provide the types of assistance that people living with HIV need to find stability in their lives (13). They also help link clients to other services in their communities (1). Unlike the mainstream medical system, CBOs allow clients to access services anonymously (12) and offer intricate systems of volunteer services, including buddies/companions, benefits experts and prevention educators (12). Volunteer programs often incorporate the perspectives and experiences of people living with HIV (12) and the CBOs themselves provide access to peer support groups that can decrease feelings of isolation and increase self-efficacy and self-esteem (12). In fact, one Ontario study that assessed feelings of social support among high users of a CBO found that – even though many of the high users were single and lived alone – they reported the same levels of social support as low users (3). The study authors noted that the CBO’s drop-in, individual counselling and group counselling sessions were

improving clients' sense of social support and quality of life (3).

CBOs also offer specific programs that have been shown to support people living with HIV throughout the HIV care continuum. For example, "treatment advocacy" programs based in CBOs aim to engage clients in care and support antiretroviral adherence through client-centred counselling and patient advocacy (7). A Los Angeles study examining the effects of treatment advocacy offered through two large CBOs found that treatment advocacy participants were 15% more likely to be adherent to antiretroviral medications and also reported fewer unmet social service needs (7). The authors noted that community-based programs such as treatment advocacy may be critical for engaging and supporting individuals who are reluctant to attend programs within standard medical settings due to mistrust of healthcare workers or treatments (7).

## Economic and social impact

Several authors have noted that the services provided by CBOs are hard to evaluate (10;14). As one author comments, this difficulty in recognizing the full value of CBOs may be due to the fact that many CBOs lack the time and capacity necessary to plan, implement and evaluate their services (10). As a result, CBOs may be perceived as having limited effectiveness when, in fact, they may be very effective (10).

One study has been able to quantify the financial and social impact of CBOs in Ontario. The authors found that, from 1987 to 2011, community-based HIV prevention programs prevented 16,672 new infections and saved the health care system \$6.5 billion (9). Overall, taxpayers saved \$5 for every dollar invested in community-based prevention programs in Ontario (9). It is worth noting that these figures were based on conservative estimates and that the real cost savings and benefits generated by Ontario-based CBOs were likely much greater (9). The authors stressed that even in the post-antiretroviral therapy era, more and more evidence is showing that biomedical and social and behavioural interventions are essential complements to each other and that social behavioural and structural interventions, together with community actions, are important

at each step to help people living with HIV achieve viral suppression (9).

## Forefront of future work

CBOs have been a leading force in the development, dissemination and implementation of best practices in HIV prevention and care (15). They have also been important partners in the recruitment of cohorts for clinical trials and studies on HIV prevention (15). As people with HIV are now living longer, it has been suggested that CBOs possess untapped potential for addressing their health-related needs (16). Given the history of CBOs and their centrality to the HIV movement, they are ideally situated to address other issues as they emerge (15).

## Factors That May Impact Local Applicability

All studies included in this review were conducted in high income countries, including Canada, the U.S., Spain and France. The definition of "community-based organization" may differ between these jurisdictions – as a result, findings may not be fully transferable in all contexts.

## What We Did

We searched Medline and PsycInfo using a combination of text terms HIV AND (community based organization\* OR AIDS service organization\* OR community health centre\* OR community health center\* OR CBO\* OR community based organisation\* OR AIDS service organisation\* ASO OR ASOs). We also conducted Google search using the same word combinations to identify gray literature. All searches were conducted on February 24, 2015 and results limited to English articles published from 2005 to present in high income countries.

## Rapid Response: Evidence into Action

The OHTN Rapid Response Service offers quick access to research evidence to help inform decision making, service delivery and advocacy. In response to a question from the field, the Rapid Response Team reviews the scientific and grey literature, consults with experts, and prepares a brief fact sheet summarizing the current evidence and its implications for policy and practice.

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### Prepared by

Emily White  
Jason Globerman

### Program Leads / Editors

Jason Globerman  
Jean Bacon  
Sean B. Rourke

### Contact

[rapidresponse@ohln.on.ca](mailto:rapidresponse@ohln.on.ca)

### For more information visit

[www.ohln.on.ca/rapid-response-service](http://www.ohln.on.ca/rapid-response-service)



THE ONTARIO HIV  
TREATMENT NETWORK

The Ontario HIV Treatment Network  
1300 Yonge Street, Suite 600  
Toronto ON M4T 1X3

[www.ohln.on.ca](http://www.ohln.on.ca)