

Building a Compassionate Community

Why should we focus on building a compassionate community around HIV?

"Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world." - United Nation Secretary-General Ban Ki Moon

- **HIV/AIDS-related stigma fosters the spread of the disease.** The ramifications of HIV/AIDS-related stigma and discrimination are numerous. Fear of stigma and discrimination keeps people from learning their HIV status, and if positive, from disclosing their status to others and accessing health services. Perceived and enacted stigma can place a huge psychological burden on an infected individual and in so doing contribute to a decline in health status. Stigmatizing attitudes and discriminatory practices of family members and health providers prevent those infected from receiving adequate treatment, care, and support
- **HIV/AIDS-related stigma is a key barrier to access to HIV services and acceptance.** HIV/AIDS-related stigma and discrimination is a persistent problem worldwide. People living with HIV/AIDS (PLWHA) in the greater Sacramento region, as is around the World, face stigma and discrimination in a range of ways, including at home, with family, and in the community, workplace, and health care settings. Stigma and discrimination against HIV-positive people and those perceived to be infected are common in medical settings and act as barriers to seeking and receiving critical treatment and care services.

What are we doing in Sacramento?

Two major communities that have been affected by the stigma of HIV/AIDS have been the African American and the Hispanic communities. Sacramento has several agencies that work with these communities in HIV/AIDS prevention, education and care. A majority of the agencies have developed community specific advisory boards that allow members of the each community to be involved in the development and implementation of prevention and care programs.

There is a speaker's bureau that consists of small number of HIV-positive speakers that go out into the community to speak about living with the disease. They have been able to reach out to approximately 1,000 individuals by participating in community event and classroom level discussions. There is a need for more outreach to these areas so that more and more communities can learn more about the disease and be less stigmatized.

What is the ideal for reducing Stigma and Building a Compassionate Community?

- Community leaders and health care professionals can help diminish the stigma of HIV/AIDS by avoiding biased policies and practices, messages of fear, and implications that HIV/AIDS is a disgraceful disease. Assist people affected by stigma develop the tools to survive it and combat it. Help PLWHA deal with a stigmatizing situation so they do not internalize stigma and discrimination.
- Communities also must encourage acceptance, compassion, and understanding of infected individuals.
- Provide knowledge and education to the public. Increasing the public's basic knowledge about HIV/AIDS helps address the half truths and fear that trigger stigma. Programs can help decrease stigma by increasing knowledge and promoting discussion about HIV/AIDS through the participation of people living with HIV/AIDS, media campaigns, and educational interventions in schools, government agencies, and local businesses.
- Humanize the stigmatized population. Putting the general public in contact with the HIV-positive population can help humanize them. Community mobilization and involvement of groups most affected by stigma (such as injecting drug users, sex workers, and people leaving with HIV/AIDS) also are important.

What are the issues we need to address when it comes to building a compassionate community?

- How can we combat stigma of HIV in African American, Hispanic and gay communities to learn about HIV?
- How can we influence cultural norms and discuss taboo topics including sex, illness & death?
- Is there a gap in culturally and linguistically appropriate resources and services?
- How can we combat people with HIV/AIDS being stigmatized within their communities?
- How can we keep HIV in public spotlight and fight complacency about the disease?
- How can we continue to influence government officials about issues?

HIV/AIDS Stigma Information

HIV/AIDS Stigma: Theory, Reality, and Response – August 2004 *Health Resources and Services Administration - U.S. Department of Health and Human Services*

<http://www.ask.hrsa.gov/detail.cfm?PubID=HAB00353>

Breaking the Cycle: Stigma, Discrimination, Internal Stigma, and HIV *United States Agency International Development (USAIDS)*

http://www.policyproject.com/pubs/generalreport/Breaking_the_Cycle.pdf

The State of HIV Stigma and Discrimination in 2007: An Evidence Based Report *Lambda Legal* <http://www.lambdalegal.org/our-work/publications/general/2007-hiv-stigma-discrimination.html>

Reducing the Stigma of HIV/AIDS Through Understanding, Compassion, and Action *Latino Religious Leadership Project, a program of the Latino Commission on AIDS* <http://www.latinoaids.org/misc/reducingstigma.pdf>

A Heightened National Response to the HIV/AIDS Crisis among African Americans
Department of Health and Human Services – Center for Disease Control and Prevention
<http://www.cdc.gov/hiv/topics/aa/resources/reports/heightendresponse.htm>

National HIV/AIDS Anti-Stigma Initiative <http://www.hivaidsstigma.org/>