

how does stigma affect HIV prevention and treatment?

what is HIV/AIDS stigma?

HIV/AIDS-related stigma is a complex concept that refers to prejudice, discounting, discrediting and discrimination directed at persons perceived to have AIDS or HIV, as well as their partners, friends, families and communities.^{1,2}

HIV/AIDS stigma often reinforces existing social inequalities based on gender, race, ethnicity, class, sexuality and culture. Stigma against many populations disproportionately affected by HIV has been present for a long time in the US. HIV has compounded the stigma of homosexuality, drug use, poverty, sex work and racial minority status.³

HIV/AIDS stigma is a problem in the US and throughout the world. Stigma has been expressed in a variety of ways, including: 1) ostracism, rejection and avoidance of people living with AIDS; 2) discrimination against people living with AIDS by their families, health care professionals, communities and governments; 3) mandatory HIV testing of individuals without prior informed consent or confidentiality protections; 4) quarantine of persons who are HIV infected; and 5) violence against persons who are perceived to have AIDS, be infected with HIV or belong to "high risk groups."¹

how can stigma affect prevention?

HIV/AIDS stigma adds to the stress experienced by HIV+ persons. In addition, it leads to challenges for HIV prevention efforts.

***HIV testing.** Fear of negative social consequences of a positive HIV test result can deter some persons from getting tested. A study of men and women in seven cities in the US found that stigma was associated with a decreased likelihood of being tested for HIV.⁴ People who are HIV+ but haven't tested and don't know they are HIV+ are less likely to try to prevent transmitting HIV to others.⁵*

***Safer behaviors.** Some HIV+ persons may fear that disclosing their HIV status or using condoms may bring partner rejection, limit sexual opportunities or increase risk for physical and sexual violence. A study of rural men who have sex with men (MSM), found that men who thought health care providers in their community were intolerant of HIV+ persons, also reported more high-risk sexual behaviors.⁶*

***Prevention programs.** Stigma surrounding HIV, homosexuality, commercial sex work and drug use make it difficult for HIV prevention services to be offered in a variety of settings. While it is widely accepted that HIV prevention should be integrated into a broader health and community context, many community venues such as churches, businesses, jails, prisons and schools have resisted incorporating frank discussions of HIV.⁷*

how can stigma affect treatment?

HIV/AIDS stigma can also negatively affect the health and well being of HIV+ persons.

***Treatment.** HIV+ persons may not seek treatment or delay going to doctors due to real or perceived discrimination against them. A national study of HIV+ adults found that 36% reported experiencing discrimination by a health care provider, including 8% who had been refused medical service.⁸*

***Support.** Some HIV+ persons don't have an adequate support network because they fear that friends or family will abandon them or suffer the same stigma they do. One study of Asian and Pacific Islanders (API) living with HIV found high levels of internalized stigma. APIs avoided seeking support because they were afraid of disclosure and saw themselves as unworthy of getting support.⁹*

***Adherence.** Experiences of social rejection, disapproval and discrimination related to HIV may decrease the motivation of HIV+ persons to stay healthy. A study of HIV+ men and women found that those who had experienced stigma were also more likely to miss HIV clinic appointments and lapse in adherence to their medication.¹⁰*

Says who?

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what's being done?

Stigma-reduction programs and trainings take place throughout the US and the world. However, it is difficult to measure the effectiveness of programs. As a result, there are few published studies of effective stigma-reduction programs. Most programs use multiple components to address stigma including education, skills building and contact with HIV+ persons on individual and community-wide levels.¹¹

*A school-based program for inner-city high school students in Texas, featured HIV+ speakers to decrease negative attitudes towards HIV/AIDS. The speakers were popular with students and teachers and had a positive impact on attitudes in the short term. Combining HIV+ speakers with a multicomponent HIV prevention and education program produced a greater impact.*¹²

The South Carolina HIV/AIDS Council (SCHAC) instituted an anti-stigma program with three components. First, SCHAC held legislative town hall meetings focused on HIV issues within rural counties. Second, they produced an educational play on the realities of HIV stigma for communities and their local leaders. Third, SCHAC created a statewide marketing campaign to address HIV/AIDS stigma using public service announcements, posters and editorials.¹³

*The New York State Department of Health AIDS Institute (AI) has used multi-level interventions to prevent HIV-related stigma and discrimination. On a policy level, the AI has worked to pass laws and enact policies to protect the rights of HIV+ persons and persons perceived to be HIV+, including confidentiality laws and naming HIV/AIDS in the existing anti-discrimination law. They also provide forums and advisory councils for policy discussions, and set up an office for discrimination issues to handle complaints. On a program level, the AI provides diversity and confidentiality training for healthcare providers, leadership training for HIV+ persons and social marketing approaches for community-wide education and awareness.*¹⁴

what needs to be done?

Knowledge about HIV prevention, transmission and care can offset the stigma that is caused by misinformation and ignorance. Education programs are still needed in many areas and populations, and will continue to be needed for successive generations of young people.⁵

*Stigma exists not simply within individual actions, but within broad social and cultural contexts that need to be addressed in stigma-reduction programs. Organizations and communities must tackle the values, norms and moral judgments that contribute to the stigmatization of HIV+ persons by engaging faith-based organizations, key institutions and opinion leaders that help shape and reinforce societal values.*¹⁵ *Policymakers need to consider the potential consequences of laws to make sure they don't inadvertently increase HIV/AIDS-related stigma.*

HIV+ persons must be involved in designing, running and evaluating stigma reduction programs. One approach is to train and support HIV+ persons to organize to advocate for themselves.¹⁶ Prevention, coping and adherence programs for HIV+ persons should directly address stigma and its effect on HIV+ persons' health and well being.

Programs can also offer cultural competency, confidentiality and awareness training for healthcare workers, counselors and staff at social service organizations including drug treatment, housing, mental health services. Training is especially important in areas where stigma is high, such as rural areas and organizations where there may be few HIV+ clients.

HIV/AIDS-related stigma is unlikely to go away any time soon.¹⁶ While research is being conducted nationally and internationally,¹⁷ more research is needed to measure the effects of stigma and understand what types of interventions work best for which communities. Promising stigma awareness and reduction programs need to be evaluated and published so that effective programs can be widely replicated.

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SC HIV/AIDS Council
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