



HRSA CARE ACTION

PROVIDING HIV/AIDS CARE IN A CHANGING ENVIRONMENT

AUGUST 2003

HIV/AIDS STIGMA

We have all seen the pictures on television: Ryan White was thrown out of school, taunted by his neighbors, and ostracized by his community, all because he had AIDS.

People living with HIV/AIDS in the United States have been the targets of stigma since the first cases were diagnosed. Since then, discrimination in the workplace, in social settings, and even in attempts to secure safe housing have created dire circumstances for those living with HIV disease. This is not a problem confined to the United States. Globally, with more than 42 million people living with the virus, the effects of HIV/AIDS stigma exceed what most of us have the capacity to understand.¹ In the United States and around the world, many communities punish people for simply revealing their HIV status. An HIV diagnosis can cause family members, neighbors, and even medical providers to shun the HIV-infected person.

HIV-related stigma refers to unfavorable attitudes, beliefs, and policies directed toward people perceived to have HIV/AIDS as well as their loved ones, associates, social groups, and communities. The stigma is rooted in prejudices involving gender, sexuality, illness, and race. Organizations serving people living with HIV disease face important questions regarding stigma. How can they provide for patients who live with the very real threat of being ostracized? How can they help individuals cope with stigma? What can they do to help prevent or eliminate HIV-related stigma?

STIGMA: WHAT IS IT?

The well-known social anthropologist Erving Goffman pioneered the study of stigma. Goffman is widely credited with providing the theoretical underpinnings that frame most stigma research. In his landmark book *Stigma: Notes on the Management of Spoiled Identity*, Goffman described stigma as "an attribute that is deeply discrediting within a particular social interaction."² His explanation of stigma focuses on society's attitude toward people who possess attributes that fall short of public expectations. According to Goffman, a person who is stigmatized is "reduced in our minds from a whole and usual person to a tainted, discounted one."³

A number of studies have provided evidence that stigma is associated with delays in HIV testing by people who are at high risk of being infected with HIV.

Certain kinds of diseases carry more stigma than do others. According to Goffman and other researchers, diseases associated with the highest degree of stigma share common attributes:^{4,5,6}

- The person with the disease is seen as responsible for having the illness
- The disease is both progressive and incurable^{7,8}
- The disease is not well understood among the public
- The symptoms cannot be concealed.

HIV infection fits this profile. First, people infected with HIV are often blamed for their condition. Second, although HIV is treatable, it is nevertheless an incurable

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and progressive disease. Third, HIV transmission is not well understood by many in the general population. Finally, although asymptomatic HIV infection can often be concealed, the symptoms of HIV-related illness cannot.⁹ HIV-related symptoms may be considered repulsive, ugly, and disruptive to social interaction.

HIV-related stigma manifests itself in a variety of ways, which may be segmented into the following categories:

- *Instrumental HIV-related stigma*—a reflection of the fear and apprehension that are likely to be associated with any deadly and transmissible illness
- *Symbolic HIV-related stigma*—the use of HIV/AIDS to express attitudes toward the social groups or “lifestyles” perceived to be associated with the disease¹⁰
- *Courtesy HIV-related stigma*—stigmatization of people connected to the issue of HIV/AIDS or HIV positive people.^{11,12}

The devaluation of identity and discrimination associated with HIV-related stigma do not occur naturally. Rather, they

are created by individuals and communities who, for the most part, generate the stigma as a response to their own fears. HIV-infected individuals, their loved ones, and even their caregivers are often subjected to rejection by their social circles and communities when they need support the most. They may be forced out of their homes, lose their jobs, or be subjected to violent assault. For those reasons, HIV-related stigma must be recognized and addressed as a life-altering issue.

HIV/AIDS STIGMA AND THE GENERAL POPULATION

Gregory M. Herek, Ph.D., a professor of psychology at the University of California at Davis, is an internationally recognized authority on HIV-related stigma, prejudice against lesbians and gay men, hate crimes, and antigay violence. As early as 1990, Herek observed that people diagnosed with HIV are viewed more negatively than people diagnosed with other incurable diseases. He also noted that gay men and injection drug users are disproportionately susceptible to

Hate crimes are criminal actions intended to harm or intimidate people because of their race, ethnicity, sexual orientation, religion, or other minority group status.

Source: Herek GM, Gillis JR, Cogan J. Psychological sequelae of hate crime victimization among lesbian, gay, and bisexual adults. J Consult Clin Psychol. 1999;67(6):945-951.

HIV-related stigma and discrimination. Yet, people who acquired HIV through no action of their own are often referred to as “innocent” or “blameless.”¹³ According to Herek, HIV-related stigma is not necessarily a stigma of the diseased; rather, it is often related to perceived lifestyle “choices” of infected populations or to perceptions about racial and ethnic minorities. Stigma may extend to professionals working on behalf of people with HIV disease as well as to volunteers and other caregivers.

A 1991 random-digit-dialing telephone survey conducted by Herek and John Capitanio sought to measure the extent of HIV stigma in the U.S. population. The authors found that 27.1 percent of all participants had a “stigmatizing response” when asked if they felt angry towards people with AIDS. When asked whether people living with AIDS should be separated from the general

Consequences of Stigma

- Deterioration of interpersonal relations
- Negative emotions
- Rejection of the HIV antibody test
- Stress related to the hiding of the condition
- Anxiety
- Depression
- Guilt
- Loss of support
- Isolation
- Difficulties with family dynamics
- Emotional or physical violence
- Deterioration of relations with health care providers

Source: HRSA and George Washington University. Consultation meeting on Stigma. May 22-23, 2003.

population, 35.7 percent of the participants gave a stigmatizing response.¹⁴

Herek and Capitanio conducted a similar follow-up telephone survey in 1992, and a third in 1997. The results suggested increasing levels of stigma and a “hierarchy of blame” regarding HIV/AIDS. They wrote, “In our 1991 survey, for example, 20.5 percent of respondents agreed that ‘people with AIDS have gotten what they deserve.’ Approximately 6 years later, in the 1997 survey, 28.8 percent agreed with the statement, an increase of roughly 40 percent.”¹⁵ And in 1997, even more respondents assigned some degree of responsibility when the question was framed less harshly. The authors drew four major conclusions about HIV/AIDS in the United States:

1. Most heterosexual adults surveyed equate AIDS with homosexuality or bisexuality and, in turn, harbor higher levels of prejudice.
2. Much of the public continues to label people with AIDS as either “blame-worthy” or “innocent”; among those who contracted AIDS through sexual activity, gay men are viewed more negatively than heterosexuals.
3. Some portions of the public equate any same-sex behavior with AIDS. Misconceptions about AIDS perpetuate the view that all homosexual behavior eventually leads to AIDS.
4. A substantial portion of the public harbors exaggerated fears about “symbolic” contact with HIV-positive people, such as touching an article of clothing worn by a person living with

A Comprehensive Approach to Stigma

Interventions to prevent HIV-related stigma and discrimination are integral components of the comprehensive approach to HIV/AIDS described by the New York State Department of Health AIDS Institute. The AIDS Institute provides programs and services in applied settings, including training for clinical and nonclinical providers, consumer education, social marketing approaches for communitywide education and awareness, and support for consumer complaints. For example, the AIDS Institute offers free training and clinical education programs that address prevention of stigma and discrimination. The programs take place at locations throughout the State. Topics include HIV/AIDS confidentiality law, cultural diversity, domestic violence, HIV testing procedures, HIV reporting and partner notification, gender identity and expression in communities of color, and treatment education. The New York State Targeted Provider Education Demonstration Program, funded by HRSA/HAB, builds capacity in minority organizations for education and training of health and human service providers.

HIV disease. These attitudes are most prevalent among people who harbor sexual prejudice.¹⁶

Following a 1999 telephone survey, Herek and colleagues concluded that some expressions of stigma declined during the 1990s.¹⁷ For example, the proportion of people advocating the most drastic measures—quarantine and public identification of people living with HIV/AIDS—has significantly diminished. However, despite reductions in stigma, one-fifth of those surveyed in 1999 feared people with AIDS and one-fourth felt uncomfortable having contact with people with AIDS. Another finding underscored the power of stigma to extend to the economic realm: Nearly one-third said they would avoid shopping at a neighborhood grocery known to be owned by a person with AIDS.

STIGMA AND VIOLENCE

Disclosure of HIV positivity may provoke violence in intimate relationships.^{18,19} Sally Zierler and colleagues studied HIV-positive adults who had been assaulted by a partner or someone important to them since their diagnosis.²⁰ The authors then examined the extent to which HIV status was a cause of the violence. Participants were a nationally representative probability sample of 2,864 HIV-positive adults who were receiving medical care and were enrolled in the HIV Costs and Service Utilization Study. A total of 20.5 percent of the women, 11.5 percent of the men who reported having sex with men, and 7.5 percent of the heterosexual men said they had experienced physical harm since HIV diagnosis. Nearly half of those participants reporting a violent episode cited HIV

seropositivity as the cause. Factors most strongly associated with violence were drug dependence, homelessness, and unemployment.

In another study, Herek and colleagues found greater psychological distress among victims of sexual orientation-based hate crimes than among victims of non-bias-related crimes.²¹ Men and sexual minorities who are open about their sexual orientation are at higher risk for violence than are women or sexual minorities who try to conceal their sexual orientation.

STIGMA AND THE CARE SYSTEM

Research devoted to stigma and access to care falls roughly into three categories:

1. Barriers to care that HIV-positive individuals encounter from HIV diagnosis to death
2. The reluctance of health care providers to treat people with HIV
3. The stigma experienced by providers of ancillary and support services to people living with HIV/AIDS.

“Given the magnitude of this pandemic one could hardly claim that the area of stigma reduction is well studied.”

— Brown et al., 2001, p. 15.

A number of studies have provided evidence that stigma is associated with delays in HIV testing by people who are at high risk of HIV infection.^{22,23} For example, in a study of gay and bisexual men who were unaware of their HIV status, two-thirds expressed a fear of discrimination against people with HIV and cited it as a reason for not getting tested.²⁴

Similarly, a 2000 Kaiser Health Poll found that one-third of survey respondents said that if they were tested for HIV, they would be “very” or “somewhat” concerned that people would think less

of them if they discovered they had been tested.²⁵ Eight percent of people who had never been tested for HIV said that worries about confidentiality played a part in their decision not to be screened.

Over time, studies have shown a decrease in severe reactions to being notified of positive test results; however, research indicates that notification is still associated with HIV stigma-related distress. After a person tests positive, he or she faces many difficult issues, including whether to disclose HIV seropositivity to partners, friends, family, and health care providers as well as how to enter and adhere to care.²⁶

Accessing health care can be a problem for people with HIV/AIDS because the health care system itself can be a source of stigma. Health care professionals, particularly those who infrequently encounter people living with HIV/AIDS, may be insensitive to stigma-related concerns. Moreover, procedures for maintaining patient confidentiality are not always in place and, even where they are, they are not always adhered to.²⁷

Celebrity Disclosure and Stigma

In 1997, researchers examined Earvin “Magic” Johnson’s announcement that he was HIV positive to measure the effect of his disclosure on HIV-related stigma among the general public. Two-wave, random-digit-dialing national telephone surveys were conducted. Johnson’s disclosure took place 3 weeks before Wave II. Results showed that respondents who were highly influenced by Johnson’s disclosure became less intent on avoiding people living with HIV/AIDS (PLWHs). The study also found that direct contact with PLWHs was associated, though not significantly, with less support for coercive AIDS policies and less blaming and avoiding of PLWHs.

Source: Brown L, Trujillo L, MacIntyre K. Interventions to reduce HIV/AIDS stigma: what have we learned? Horizons Program, Tulane University. September 2001. Available at: <http://www.popcouncil.org/horizons/horizons.html>.

Research from earlier in the epidemic revealed that health care providers' fear of contagion and death can have negative effects on their attitudes toward and treatment of HIV-positive patients. Health care providers also may fear stigmatization themselves because of their work with HIV-positive patients.^{28,29,30} The prevalence of such fears may have declined over time, but no evidence indicates that they have been eliminated.

Volunteers as well as nonvolunteers consider HIV/AIDS volunteerism to be more stigmatizing than other forms of volunteerism.³¹ Reports of having been embarrassed, stigmatized, or otherwise made uncomfortable in connection with their volunteer work are more common among HIV/AIDS volunteers than other types of volunteers.³² Research supports the hypothesis that potential volunteers perceive HIV/AIDS volunteer work to be more stigmatizing than cancer volunteer work.³³ Such attitudes can be especially detrimental in the field of HIV care, where volunteers have played a significant role since the onset of the epidemic.

INTERVENTIONS

HIV-related stigma can negatively affect self-esteem and mental health while increasing the risk of discrimination and violence. These factors can foster a reluctance to seek care. HIV/AIDS-related stigma also fuels new HIV infections because it can deter people from getting tested for the disease, make them less likely to acknowledge their risk of infection, and discourage those who are HIV-positive from discussing their HIV status with their sexual and needle-sharing partners.

Creating Acceptance of People Living With HIV/AIDS

In 1998, researchers surveyed 320 Jamaican youth to improve attitudes toward people living with HIV/AIDS (PLWHs) by encouraging acceptance and compassion. Interventions included peer education and workshops, street interviews, conversations with PLWHs, and concerts. The effect of each intervention was measured by the participants' willingness to sit next to, eat with, and visit PLWHs. Analysis occurred through questionnaires, focus groups, and direct observations. Results showed a "significant increase" in positive attitudes toward PLWHs on all measures and a reduction in the number of participants who sought isolation for PLWHs.

Source: Brown L, Trujillo L, MacIntyre K. Interventions to reduce HIV/AIDS stigma: what have we learned? Horizons Program, Tulane University. September 2001. Available at: <http://www.popcouncil.org/horizons/horizons.html>.

Interventions to reduce HIV-related stigma are crucial for improving the care, quality of life, and emotional health of people living with HIV/AIDS. Moreover, reducing stigma may actually help reduce new HIV cases. The importance of HIV-related stigma interventions is highlighted in the Joint United Nations Programme on HIV/AIDS publication *A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination*, which highlights several interventions in the international arena but laments the paucity of documented efforts to challenge HIV/AIDS-related stigma.³⁴ This deficit is also noted by Lianne Brown and her colleagues at the University of California at Davis, who wrote, "Given the magnitude of this pandemic one could hardly claim that the area of stigma reduction is well studied."³⁵

Most of the literature related to HIV stigma focuses on policy and regulatory concerns. Considerably less attention has been devoted to programmatic interventions, which attempt to change attitudes

and behavior. This situation is regrettable because a multifaceted approach that goes beyond legal protections is necessary to change social climates that may legitimize discrimination.³⁶

Legal and Policy Interventions

In the early years of the epidemic, a consensus emerged among public health officials that AIDS must be approached differently from other infectious diseases and sexually transmitted infections. Officials wanted to avoid stigma and mistreatment that could "drive the epidemic underground," which would compromise access to care and services, deter or delay HIV testing, and undermine the effectiveness of HIV prevention efforts. Officials promoted non-coercive prevention measures that respected the privacy and social rights of those who were at risk. Because no treatment for HIV/AIDS existed at the time, mass education, voluntary testing, and counseling were the key elements in this public health strategy.^{37,38}

Public health officials' efforts did not prevent HIV/AIDS-related discrimination, however. Despite legal precedents and protective legislation, discrimination against people living with HIV, as well as against those believed to be HIV-positive, has been reported in the areas of employment, health care, insurance, and education. Ironically, some institutional policies and laws designed to protect people with HIV from stigma can help perpetuate it. For example, privacy laws that aim to protect HIV-positive people from stigma by keeping health information confidential may also contribute to the characterization of AIDS as a "dirty little secret."³⁹

Still, legal protections are essential components of the societal response to stigma and discrimination.⁴⁰ The recognition of the negative consequences of HIV/AIDS stigma prompted the enact-

ment of statutory protections for people living with HIV disease. The confidentiality of HIV-related information, particularly HIV test results, enjoys considerable protection under State laws and the U.S. Constitution.⁴¹

The 1990 Americans with Disabilities Act (ADA) expanded the reach of the Rehabilitation Act of 1973 and made discrimination on the basis of disability unlawful. In *Bragdon v. Abbot* (1998), the first discrimination case involving HIV infection or AIDS to reach the Supreme Court, the Court ruled that Congress intended HIV infection to be included as a disability under the ADA.^{42,43} HIV has been found to qualify as a disability under Federal and State laws protecting the disabled from discrimination in employment; housing; government services; and public accommodations, such as hotels, schools, and medical offices.⁴⁴

Program and Service Interventions

In a review of 21 studies from developed and developing countries, Brown and colleagues analyzed the types of interventions that could help decrease HIV-related stigma.⁴⁵ The review showed that stigma can be reduced through several intervention strategies:

Information. Information can be delivered by advertisements, brochures, information packs, classes, or lecture presentations. This approach frequently includes a factual description of the disease along with details regarding modes of transmission and methods of risk reduction.

Counseling. Information-based approaches are often combined with counseling (e.g., support groups for people living with HIV/AIDS). This strategy provides social reinforcement for positive attitudes, behavior change, and maintenance of safe behaviors. Participants receive personal support for resolving issues with spouses, partners, families, and others in a safe environment.

Coping skills acquisition. Master imagery and group desensitization are two techniques for acquiring coping skills. In master imagery, a person is presented with a hypothetical situation in which he or she has contact with an HIV-positive person and is taught appropriate coping skills for resolving the situation. Group desensitization begins with relaxation training and then progressively exposes the individual or group to a number of situations involving people living with HIV/AIDS. Participants use the newly learned relaxation techniques to

HIV/AIDS Bureau Convenes HIV/AIDS Stigma Consultation

In May 2003, the HIV/AIDS Bureau brought together leading experts on HIV/AIDS stigma to identify key issues in addressing stigma through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act programs.

Together, researchers, program directors, and consumers created a comprehensive picture of how stigma continues to block access to care, negatively affect quality of life, and fuel HIV incidence. Presenters illustrated how some interventions are reducing the effects of stigma in the populations they serve.

The Bureau's consultation is generating important outcomes:

- A literature review, from which this article is abridged, is currently available on the Bureau Web site at <http://hab.hrsa.gov/publications>.
- A detailed summary of presentations made at the consultation is being finalized and will be available at the above Web site in early fall.
- This newsletter on stigma is being distributed to providers in the United States and abroad.

minimize tension during the hypothetical situation.

Contact. Contact with HIV-infected or -affected individuals may be used alone or in combination with other strategies. Contact can create an environment in which the general population can interact with the stigmatized group, either directly or vicariously (e.g., through the media). The theory is that increased personal contact with an HIV-positive person will demystify and dispel misinformation, generate empathy and, in turn, reduce stigma and prejudice. Contact can range from a face-to-face conversation to hearing a testimonial from HIV-infected or -affected persons.

The stigma-reduction interventions described above appear to work. However, most of the interventions were tested on a small number of subjects, and few studies looked at whether changes in attitudes and behaviors were sustained over time.

Today, providers struggle to help those in care cope with HIV/AIDS stigma. However, knowing what should be accomplished and knowing how to make it happen are completely different issues. Research on HIV stigma is not comprehensive, but providers may rely on several fundamental principles (see box).

Throughout history, societies have stigmatized groups of all kinds for various reasons, mostly as a result of ignorance, misconceptions, and superstitions. AIDS is a disease—nothing more. With time and education, AIDS stigma may someday be seen as an artifact of a less enlightened time.

Practical Steps to Prevent HIV-Related Stigma and Discrimination: A Checklist for Public Health Practitioners

Statutory/Regulatory Environment

- Familiarize yourself with applicable laws and regulations in your jurisdiction.
- Initiate or support actions to advance or strengthen protection.

Policy Development

- Involve consumers in program design, development, and evaluation of programs and policies.
- Support and engage other agencies in promoting confidentiality and nondiscrimination.
- Promote community development and mobilization.

Program and Services

- Use public education opportunities to put a human face on AIDS.
 - Involve people living with HIV/AIDS in public education.
 - Show the diversity of the epidemic.
- Support HIV prevention education materials developed by and for communities.
- Maintain a proactive presence in the community (e.g., in schools, at health fairs, at World AIDS Day, and at National HIV Testing Day events).
- Involve and support families and communities (infected and affected).
- Engage leaders from the business community and faith communities (e.g., "Business and Labor responds to AIDS," Faith Forums, Black Church Week of Prayer).
- Develop and implement training, policies, and procedures for all staff activities and programs.
- Integrate within contracts relevant provisions for prevention, care, and supportive services.
- Seek, value, and support a staff reflective of the diversity of communities.
- Provide training and technical assistance on confidentiality, nondiscrimination, and cultural diversity to staff, contractors, and other health and human service providers.
- Educate clinicians so that they are not reluctant to treat people living with or at risk of HIV/AIDS.
- Ensure access to confidential and anonymous HIV testing.
- Integrate HIV prevention into primary care.
- Integrate primary and secondary prevention.
- Communicate that HIV-related discrimination is illegal.
 - Support and promote legal services for consumers.
 - Remain cognizant of issues related to social isolation and stigma in rural areas.
 - Identify and support a staff person(s) in the role of consumer advocate.
 - Implement policies and procedures for complaints.
 - Follow through on enforcement.

Source: Klein SJ, Karchner WD, O'Connell DA. Interventions to prevent HIV-related stigma and discrimination: findings and recommendations for public health practice. *J Public Health Manag Pract.* 2002;8(6):44-53.

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Publisher

U.S. Department of Health and Human Services
Health Resources and Services Administration
HIV/AIDS Bureau

Editor

Richard Seaton
Impact Marketing and Communications

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