

Human Rights **Update****UNDERSTANDING HIV/AIDS STIGMA
AND DISCRIMINATION**

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**NASW HIV/AIDS
SPECTRUM PROJECT**

When the epidemic emerged in 1981, AIDS was perceived as a deadly disease that was transmissible from person to person, as well as closely associated with historically disenfranchised groups and culturally and historically taboo issues such as sexual orientation, drug use, and commercial sex work. The combination of these factors led to societal hostility as well as slow response by state, federal, and country governments. Although both knowledge of HIV/AIDS and government responses have increased, the stigma still persists more than 30 years later.

Stigma and discrimination are universally experienced by persons living with and affected by HIV/AIDS. Most notably, the incidence of HIV infection has steadily increased in communities of color, resource poor populations, and among men who have sex with men, all whom are already subject to prejudice and discrimination (IFSW 2006; CDC, 2011). Stigma is perceived as a major limiting factor in primary and secondary HIV/AIDS prevention and care, and has interfered with voluntary testing and counseling, and access to care and treatments. (Holzemer & Uys, 2004). All things considered, AIDS stigma becomes yet another life obstacle in the path of many of the very people who are already faced with social and economic obstacles. Combating stigma remains an important task for social workers around the globe.

Stigma is experienced at the individual and societal level

HIV/AIDS doesn't discriminate; people do. AIDS stigma can be experienced at both the individual and societal level.

At the individual level, AIDS stigma takes the form of behaviors, thoughts, and feelings that express prejudice against people living with HIV or AIDS, and can also be experienced by persons perceived to be living with HIV/AIDS. Concerns about stigma affect an individual's decision to get tested, access health care, and withhold information about their status from family members, friends, and care providers. Social isolation negatively affects the lives of people living with HIV (HRSA, 2009).

At the societal level, AIDS stigma is manifested in laws, policies, popular discourse, and the social conditions of persons living with HIV/AIDS and those at risk of infection. NASW recognizes that people with HIV/AIDS, and sometimes even those that have been tested for the virus, continue to face discrimination in employment, military service, housing, access to health services, social and community programs, and basic civil and human rights (NASW, 2008). Societal stigma emerges in the form of laws, regulations, and policies that single out people with HIV. For example, local school boards' refusal to enroll HIV-positive children; the criminalization of HIV transmission and forcible segregation of HIV-positive prisoners; and reducing the protections afforded to HIV-positive individuals under the Americans with Disabilities Act (ADA). (NASTAD, 2001). Additionally, social stigma is practiced through failure of public policy and practices, as well as private groups; non-government organizations (NGO's), and faith based organizations that do not recognize or ensure equal rights for gay, lesbian, bisexual, and transgender persons. (Wilson, 2010)

HIV/AIDS Stigma is a Global Problem

Stigma and discrimination associated with HIV/AIDS have played a large role in the HIV/AIDS global pandemic particularly affecting marginalized populations such as gay and bisexual men and men who have sex with men, youth, commercial sex workers, women, and persons who inject drugs. While access to appropriate treatment and care for individuals with HIV/AIDS is generally recognized as a fundamental human right, discrimination prevents individuals from getting tested and seeking or adhering to treatment and care due to the stigma associated with being HIV positive. For example, in the United States, it is estimated that one in five persons living with HIV/AIDS is unaware of their health status (CDC, 2008). Globally, the overall number of people living with HIV has steadily increased as new infections occur each year, with young people (ages 15–24) accounting for an estimated 45 percent of new HIV infections worldwide (UNAIDS, 2008).

An extensive survey by nongovernmental organization (NGO) representatives of the UNAIDS Program Coordinating Board confirmed that people living with HIV, as well as marginalized and at-risk populations, continue to experience high levels of HIV-related stigma and discrimination. Almost half of respondents experienced negative attitudes or exclusion from family members. At least one-third of the sample identified discrimination in the form of loss of employment, refusal of care by health care workers, social or career exclusion, and/or involuntary disclosure. Additionally, a large percentage of respondents in all countries reported internalized stigma: feeling ashamed, guilty, suicidal, and blameworthy (UNAIDS, 2010). While a growing number of countries have adopted laws to protect people living with HIV from discrimination, as of 2007 nearly one third of countries still lacked laws and regulations to prohibit HIV-based discrimination. (UNAIDS, 2008). Ultimately, HIV/AIDS stigma is a global problem, requiring social workers to embrace a coordinated, global solution to tackle its root causes and enable individuals to seek prevention, care, and treatment services without the fear of being stigmatized.

Stigma is an obstacle to HIV prevention, care, and treatment.

The practical and psychological burdens of stigma create formidable obstacles to effective HIV prevention. Individuals at risk, particularly those who are members of

marginalized and at-risk groups, may internalize stigma; with an associated impact being self stigmatizing beliefs and actions (Avert, 2011). Homophobia, stigma, racism, and discrimination negatively affect the health and well-being of gay men and other men who have sex with men (MSM), other members of the LGBT community, and result in the added burden of stress and health disparities (CDC, 2010). Stigma also has the effect of leading some people to believe they are not at risk, as they discount their actual personal risk because they do not identify with a particular group or community. Stigma can also lead to a form of denial that deters some people from testing for HIV or otherwise seeking treatment; even though it is well established that earlier medical intervention can dramatically improve health outcomes. Stigma is a powerful deterrent of individual freedom and self-determination. (Pardasani, M., Moreno, C.L, & Forge, N., 2010)

It is noted that stigma also isolates families. It can discourage households from registering affected children in national support programs, and further limits access to information, prevention, care, and treatment. Globally, support for adults and children affected by the epidemic are provided by underfinanced civil society groups, with limited government support. This results in gaps in funding and services, as well as discrimination in laws and/or policy. (UNAIDS, 2008).

Social workers have a critical role in combating HIV/AIDS stigma and discrimination.

The National Association of Social Workers' *Policy Statement on HIV/AIDS* outlines the profession's role in addressing service delivery, primary and secondary education and prevention, political action, and research. The policy statement notes that HIV/AIDS has become a "mainstream disease," with social workers across fields of practice working with clients with HIV or clients who are at risk of becoming infected with HIV. Given the high incidence of HIV, the global social work profession must take an active stance to mitigate the overwhelming psychological and social effects, including the inequality of access to medical care and the lack of education and prevention in the United States and internationally." (NASW, 2012). The International Federation of Social Workers' *International Policy on HIV/AIDS* addresses the importance of respectful partnerships with persons living with HIV/AIDS, and the profession's ongoing advocacy

HIV/AIDS IS A GLOBAL ISSUE

“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 HIV, 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.” (U.N. Secretary General Ban Ki Moon, 2008).

and support to the global implementation of comprehensive anti-discriminatory policies for people affected by HIV/AIDS. (IFSW, 2006)

The NASW *Code of Ethics* addresses stigma, prejudice, and discrimination on several different levels. The *Code of Ethics* specifically outlines ways in which social workers can deal with discrimination, and clearly states that social workers should not practice, condone, facilitate, or collaborate with any form of discrimination on the basis of race, ethnicity, national origin, color, sex, sexual orientation, gender identity or expression, age, marital status, political belief, religion, immigration status, or mental or physical disability (NASW, 2008).

Social work interventions can make a difference.

Work to dispel the myths and stereotypes about HIV/AIDS.

Provide accurate information about how HIV is transmitted. Know where to refer clients for testing, how to ensure confidentiality, and the range of available treatment options. Seek out professional development continuing education that addresses HIV/AIDS and co-occurring diagnoses. The NASW HIV/AIDS Spectrum Project provides practice information and policy resources.

Work to affect change on a local, national, and international level.

Get involved in community-sponsored events. Lobby your elected officials to increase funding for AIDS education, treatment, and prevention. Advocate with your local and state agencies to support the National HIV/AIDS Strategy. (ONAP, 2010). Speak out against the criminalization of HIV transmission and challenge policies that discriminate persons living with HIV/AIDS. Get involved in global events such as World AIDS Day.

Increase awareness, stay informed, and share information with clients, family and friends.

For example, encourage discussion with family, friends, and colleagues about HIV/AIDS prevention and early intervention strategies. Because HIV/AIDS does not discriminate, everyone is directly or indirectly affected by HIV/AIDS. Keep the lines of communication open in order to tear down barriers, breaking isolation and fear. Encourage use of the *People Living with HIV Stigma Index*, a tool that is designed to measure and detect changing trends in relation to stigma and discrimination experienced by people living with HIV worldwide (IPPF, 2008).

Work toward culturally competent practice with all clients.

Have an awareness and understanding of the implication and role of (for example) racism, sexism, class conflict, and homophobia in meeting the needs of clients and families affected by HIV/AIDS. In addition to a sense of “self awareness” of one’s own culture, work to be sensitive to cultural differences while advocating respect for individual differences. Because cultural competence is not static, maintaining **cultural and linguistic competency** is a long-term commitment (Diaz, 2002; NASW 2007).

The People Living with HIV Stigma Index or ‘Stigma Index’ is a tool created by and for people living with HIV to measure how stigma and discrimination are experienced by people living with HIV. The data gathered from the Stigma Index will be used to 1) highlight success and failures of current programming and 2) design and implement more effective programs around the globe.

www.stigmaindex.org

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