STIGMA AND DISCRIMINATION

HIV/AIDS-related stigmatization and discrimination threaten the effectiveness of prevention and care programs. Fear, ignorance, and denial lead people to react to people living with HIV/AIDS (PLHA) in ways that can have negative effects on individuals, families, and communities. Those at risk or already infected may not seek prevention and care services for fear of being stigmatized by service providers or their community. Despite the scope and severity of the problem, there is little documentation of the causes and manifestations of stigma or consensus on how to mitigate the problem. Horizons, a global operations research initiative on HIV/AIDS prevention, care, and support, has developed a broad research portfolio to better understand the dynamics of stigmatization and discrimination and identify effective responses to the problem.

PLHA Involvement in Community-based Organizations Reduces Felt Stigma
A study of PLHA involvement in community-based organizations in Burkina Faso, India, Ecuador, and Zambia implemented in collaboration with the International HIV/AIDS Alliance shows that such involvement can help PLHA reduce their fear of stigmatization and sense of powerlessness, which contributes to felt stigma. The study also found that because HIV/AIDS is closely associated with illness, death, and multiple sexual partners—often stigmatizing unto themselves—programs should do the following to dispel myths about the disease:

- Include asymptomatic PLHA in prevention efforts and visual communications to show that serostatus cannot be determined by outward appearance.
- Inform people that PLHA can lead long, positive, healthy lives with a number of care and support options, such as treatments for opportunistic infections.
- Emphasize that anyone can become infected with HIV regardless of the number of sexual partners, to dispel the idea that only those with multiple sexual partners contract HIV.

Social Isolation Is a Key Manifestation of Stigma in South Africa
Exploratory research conducted as part of a workplace intervention study in South Africa found that the main manifestation of HIV-related stigma appears to be the social isolation and ridicule of people thought to be positive. Respondents expressed a greater fear of stigma in the community as opposed to the workplace. Most respondents were reluctant to discuss their HIV-positive status with anyone until they became ill and needed assistance. Those who were willing to disclose prior to becoming ill indicated that other services, such as psycho-social counseling, were important. The findings are currently being used to develop interventions to reduce HIV-related stigma for workers and their families. One intervention is providing links between the workplace and the community. A second intervention activity is making people aware of the services that are available to them and the benefits of these services. Indicators for stigma also have been identified and are being used to develop a multi-dimensional measure appropriate for the local context. Study partners include ESKOM and DRA-Development.

Programs Should Address Stigma Among Children
Children both stigmatize and experience stigma. Respondents in a study in Uganda, implemented together with Makerere University and PLAN International, indicate that one of the most common forms of stigma experienced by children affected by AIDS is...
teasing and social isolation by peers. This suggests that children adopt larger societal attitudes toward AIDS at an early stage and should be included in efforts to reduce AIDS-related stigma. Data also indicate that one obstacle expressed by HIV-positive parents in appointing guardians for their children is fear of disclosure. Likewise, some parents worry that their children “would not be able to keep a secret” about the parent’s positive serostatus and thus do not disclose to their children. Preliminary results of succession planning, which supports AIDS-affected families in planning a better future for their children in part through open communication about the virus, indicate a higher rate of disclosure among HIV-positive parents and more positive attitudes on the part of the community toward affected families.²

Research Opens Stigma and Discrimination Discussions in Indian Hospitals
Discussing the results of baseline research on care, stigma, and discrimination of PLHA with staff from three hospitals in India has led to increased interest and action, including the development of PLHA-friendly “gold standards” for hospital programs and treatment by hospital staff. Hospital staff are designing action plans to address constraints and opportunities for achieving these “gold standards” for care of PLHA. This process and the outcomes on quality of care and on staff safety and attitudes are currently being assessed by study partners that include SHARAN, NACO, Institute for Economic Growth, and the Tata Institute.

Programs Can Effectively Address Stigma in Both Indirect and Direct Ways
A review of community-based interventions in Southeast Asia shows that while reducing stigma is rarely the only focus of an intervention, it is nonetheless an important part of many programs. Interviews with staff from community-based organizations reveal that negative attitudes decline as a “side effect” of other project activities. Efforts to reduce stigma at the community level can be integrated into HIV/AIDS programs by facilitating the participation of PLHA, addressing the prevention-to-care continuum, and involving many segments of society in program activities.³

A review of 21 published and reported intervention studies that have explicitly attempted to decrease AIDS-related stigma both in developed and developing countries show that stigma can be reduced through a variety of intervention strategies, including providing information and counseling, fostering coping skills of PLHA to deal with stigmatizing attitudes, and increasing individual contact with PLHA. Most interventions aim to increase acceptance of PLHA among different segments of the general population, while some helped those at risk or already infected deal with felt stigma. Among studies with a control or comparison group that received information alone, adding another intervention such as counseling or coping skills was effective in changing attitudes and behaviors among both those with stigmatizing attitudes and those affected by HIV/AIDS.⁴

January 2002


*Available on the web at www.popcouncil.org/horizons; for a hard copy contact horizons@pcdc.org.