HIV/AIDS
ANTI-STIGMA INITIATIVE

Selected Literature
2000-2004

AED
Center on AIDS & Community Health

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Introduction

This selected annotated bibliography on HIV/AIDS stigma and discrimination was developed for the HIV/AIDS Anti-Stigma Initiative: A Framework for Addressing HIV/AIDS Related Stigma in America. The project is funded by the Ford Foundation and administered by the Academy for Educational Development, Center on AIDS & Community Health.

This bibliography is limited to material published since 2000 and is not designed to be comprehensive. Rather, the articles were chosen for their currency and contribution to the body of literature on HIV/AIDS stigma and discrimination. Articles were selected from literature searches conducted in the MEDLINE, AIDSLINE, HealthStar and AIDS Meetings, HSRProj, and CRISP databases. There is also a wealth of literature on stigma and discrimination in the social sciences and psychology literature which is not reflected in this review. Original annotations were written by project staff for most citations. Author abstracts are reproduced for some citations.

A number of themes emerged from the literature reflecting the devastating pervasiveness and impact of HIV/AIDS stigma and discrimination. As stated by the World AIDS Campaign 2002-2003, *Live and Let Live*, on eliminating stigma and discrimination:

"…Stigma and discrimination are the major obstacles to effective HIV/AIDS prevention and care. Fear of discrimination may prevent people from seeking treatment for AIDS or from acknowledging their HIV status publicly. People with, or suspected of having, HIV may be turned away from health care services, denied housing and employment, shunned by their friends and colleagues, turned down for insurance coverage or refused entry into foreign countries. In some cases, they may be evicted from home by their families, divorced by their spouses, and suffer physical violence or even murder. The stigma attached to HIV/AIDS may extend into the next generation, placing an emotional burden on children who may also be trying to cope with the death of their parents from AIDS.

The stigma of HIV/AIDS is seen as one of the most critical issues inhibiting changes in perception, attitudes and behavior. …"

Source: World AIDS Campaign 2002-2003
on eliminating stigma and discrimination
http://www.unaids.org/wac/2002/index_en.html

The literature selected for this annotated bibliography covers discussions, interventions, and strategies that deal with issues related to stigma and discrimination in the following domains:

- African American Population

- Asian and Pacific Islander Population

- Community Responses

- Confidentiality and Privacy

- Disclosure

- Domestic (USA) Setting

- Education

- Employment and Workplace

- Evaluation

- Gender

- Health Care Systems

- Homophobia

- Individual, Family, and Community

- Instruments Used to Measure Stigma

- International Setting

- Latino/Latina (Hispanic) Population

- Men Who Have Sex with Men (MSM)

- Native American/Alaska Native population

- Policy Change, Policy Formulation, and Legal Reform

- Racism

- Religious or Moral Beliefs

- Willingness of Health Care Providers to Treat HIV-Positive Persons

- Women

The resources included in this report are first categorized within each domain and cited. The resources are again cited (along with their annotations) in an alphabetical list at the end of the literature review.

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AFRICAN AMERICAN POPULATION

Arend ED (2003). The politics of invisibility: HIV-positive women who have sex with women and their struggle for support. J Assoc Nurses AIDS Care 14(6): 37-47.

Black BP, Miles MS (2002). Calculating the risks and benefits of disclosure in African American women who have HIV. J Obstet Gynecol Neonatal Nurs 31(6): 688-97.

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Coon DW, Catania JA, Rebchook GM (2003). G(r)aying: exploring contexts for HIV prevention interventions among 50+ MSM's. Natl HIV Prev Conf July 2003. Atlanta, GA.(abstract no. T2-A1702).

Franklin MO, Alexander L (2003).Overcoming the stigmas associated with HIV/AIDS within African American communities: historical barriers. Natl HIV Prev Conf July 2003. Atlanta, GA. (abstract no.W0-E0902).

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ASIAN AND PACIFIC ISLANDER POPULATION

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Bird M (2003). Prevention with positive American Indians/Alaska Natives/ Native Hawaiians in rural settings. Natl HIV Prev Conf July 2003. Atlanta, GA. (abstract no. M1-F0101).

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Chng CL, Wong FY, Park RJ, et al. (2003). A model for understanding sexual health among Asian American/Pacific Islander men who have sex with men (MSM) in the United States. AIDS Educ Prev 15(1 Suppl A): 21-38.

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Reeves T (2002). Who can I tell? Multi-level serostatus disclosure in urban poor families impacted by HIV/AIDS. (abstract no. ThPeF7980). Int Conf AIDS 14.

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Waugh S (2003). Parental views on disclosure of diagnosis to their HIV-positive children. AIDS Care 15(2): 169-76.

DOMESTIC (USA) SETTING

Arend ED (2003). The politics of invisibility: HIV-positive women who have sex with women and their struggle for support. J Assoc Nurses AIDS Care 14(6): 37-47.

Barnes V, Rosser BR (2002). Evaluation of HIV prevention in rural America: A 13-state comparative study of HIV prevention efforts for men who have sex with men (MSM) in the USA. (abstract no. TuPeG5627). Int Conf AIDS 14.

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EMPLOYMENT AND WORKPLACE

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GENDER

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WOMEN

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Arend ED (2003). The politics of invisibility: HIV-positive women who have sex with women and their struggle for support. J Assoc Nurses AIDS Care 14(6): 37-47.

Type: Analysis of interviews with women of color who are HIV positive
Background: Women in general and particularly women of color who are HIV positive have been overlooked by researchers, health care providers, and the AIDS service community. Low-income African American and Latina HIV-positive women who have sex with women (WSW) face culturally-based stigmas in addition to the larger societal stigmas against homosexuality and HIV. They are also disproportionately affected by poverty, drug addiction, homelessness, sex work, and abuse.
Methods: Sixteen HIV-positive WSW in a large, east coast US city were interviewed to discover how and why they interact with AIDS support networks, their physical, emotional, and psychological needs and their methods of coping with HIV. Fourteen interviews were conducted in person and two were conducted by telephone. The approximately one-hour interview was semi-structured and allowed free dialogue.
Results/Findings: Analysis of the 16 intensive interviews with low-income HIV-positive WSW of color revealed that the impact of patterns of disclosure, risk behavior, utilization of services and interaction with larger communities varied with each individual. Three stages of coping – ineffective, partially effective and effective - were identified along the spectrum. Initiation of the coping process relied first on one's readiness and ability to accept support and change lifestyles and behaviors. Success then relied on the efficacy of utilized support networks which provided emotional support and resources for life stabilization. Successful copers sought and utilized health care, social services and physical and emotional support systems which facilitated disclosure. Barriers to successful coping included lifestyle instability, fears of disclosure and continued risk behavior as well as geographical, linguistic and cultural barriers to seeking support.
Conclusions: Practice implications include identifying policy changes to counter discrimination and ignorance in the medical field, alleviating cultural stigmas against homosexuality and HIV, and increasing interorganizational communication and the availability of culturally competent resources.

Barnes V, Rosser BR (2002). Evaluation of HIV prevention in rural America: A 13-state comparative study of HIV prevention efforts for men who have sex with men (MSM) in the USA. (abstract no. TuPeG5627). Int Conf AIDS 14.

Type: Author abstract/structured interviews
Background: As part of the first major study evaluating HIV prevention in rural states of the USA, we inventoried HIV prevention efforts targeting the major risk population (MSM), and identified strengths and barriers to rural prevention.
Methods: In 2001, in 13 rural states of the USA with MSM-dominant epidemics, we conducted structured interviews with 80 experts (state AIDS directors, CDC project officers, planning group co-chairs, prevention workers, and MSM community leaders) and about 200 community volunteers. Participants evaluated their state's HIV prevention efforts (both overall and for MSM), and identified strengths, barriers, needs and new directions for HIV prevention.
Results/Findings: Barriers for rural states were identified, especially widespread ignorance about homosexuality, social/religious homophobia, and ultra-conservative attitudes in the general population, with resulting greater internalized homonegativity, unsafe sex, and poorer mental health among rural MSM. Key informants estimated they needed on average $847,000 more per state (including $500,000 for direct MSM programs) to adequately implement prevention. Geography, weather, poverty, isolation, and low literacy were named as significant challenges in rural states. At the federal level, de-prioritization of HIV, lack of rural competency and insufficient staff at CDC were named as principal barriers.
Conclusions: The quality of HIV prevention for MSM varies across states in the US. Key informants identified fiscal, social and political factors as the major barriers to success. They identified three priorities: increased funding, education programs to address widespread social homophobia and ignorance in rural states and more infrastructure. Promising interventions identified for rural MSM include Internet-based interventions, weekend sexual health retreats, and interventions for young rural MSM. Funding of research on new interventions for MSM contexts in rural contexts is recommended.

Bauman LJ, Silver EJ, Camacho S (2000). Stigma among mothers with HIV/AIDS. (abstract no. MoPeD2578). Int Conf AIDS 13.

Type: Author abstract/sample survey
Background: HIV/AIDS stigma can cause depression, lower self-esteem and put life and health at risk. The objective is to identify which women with HIV/AIDS feel stigmatized and describe how stigma relates to mental health.
Methods: We recruited a consecutive sample of 237 mothers with late-stage HIV/AIDS disease at first entry into NYC's Division of AIDS Services who had an HIV negative child aged 2-12. 93% of eligible women were interviewed. Stigma was measured by two parallel scales, the Social Stigma Scale (SSS) and Personal Stigma Scale (PSS) (Westbrook & Bauman, 1992).The SSS taps beliefs that "most people" stigmatize people with HIV/AIDS. The PSS taps feelings of personal guilt, self-blame, and rejection.
Results/Findings: Scores on SSS were high (x = 65.5 out of 96), but the mean PSS score was much lower (x = 44.6 of 96). The two scales were not related (r = .08, ns). PSS was unrelated to age, financial status, race/ethnicity, family structure, use of illegal drugs, or severity of HIV illness. Higher PSS was associated with lower education (r = -.25, p>.001). Women with higher PSS scores had poorer self esteem (r = -.58, p>.001), more psychiatric symptoms (r = .23, p>.001), and disclosed their illness to fewer family and friends (r = -.23, p>.001). Those who disclosed HIV to their children had lower PSS scores than those who did not (x = 40.1 vs. 46.3, p>.02). High PSS was related to smaller support networks (r = -.15, p>.03), less support available (r = -.23, p>.001), less support received (r = -.16, p>.02) and less adequate support (r = -.21, p>.001). SSS was unrelated to all these variables.
Conclusions: Many HIV+ mothers did not internalize the prevalent public stigma, but those who did were more depressed, had lower self worth, and had less support from friends and relatives. Further research is needed to identify the factors that protect HIV+ women from internalizing social stigma.

Berger BE, Ferrans CE, Lashley FR (2001). Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. Res Nurs Health 24(6): 518-29.

Type: Author abstract/HIV Stigma Scale instrument
Background: An instrument to measure the stigma perceived by people with HIV was developed based on the literature on stigma and psychosocial aspects of having HIV. Items surviving two rounds of content review were assembled in a booklet and distributed through HIV-related organizations across the United States. Psychometric analysis was performed on 318 questionnaires returned by people with HIV (19% women, 21% African American, 8% Hispanic).
Results/Findings: Four factors emerged from exploratory factor analysis: personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes toward people with HIV. Extraction of one higher-order factor provided evidence of a single overall construct. Construct validity also was supported by relationships with related constructs: self-esteem, depression, social support, and social conflict. Coefficient alphas between .90 and .93 for the subscales and .96 for the 40-item instrument provided evidence of internal consistency reliability.
Conclusions: The HIV Stigma Scale was reliable and valid with a large, diverse sample of people with HIV.

Bernas B (2003). The Breaking Silence project. Natl HIV Prev Conf July 2003. Atlanta, GA. (abstract no. MP-045).

Type: Author abstract
Background: Nearly one in every 10 New York City residents describe themselves as Asian, up from 14 in 1990, according to the 2000 census. The numbers grew at a faster rate than those of any other racial or ethnic group, yet health education and services for them are woefully lacking. This is especially true in the case of HIV - where a combination of cultural taboos/stigma, language and cultural barriers, and neglect from social service and health care providers work together to make access to HIV prevention information and services for A&PIs exceedingly difficult. Objectives of the "Breaking Silence" project are: To raise awareness about HIV; To change social norms that prohibit discussion of HIV and HIV-related

issues; To increase access to HIV information and services for Asian and Pacific Islander communities in New York, particularly immigrant A&PIs who speaks little or no English.

Methods: The two main activities are: Activity 1: Create a poster ad campaign in six A&PI languages (Chinese, Bengali, Urdu, Korean, Tagalog and Japanese) altering A&PI communities about HIV/AIDS and directing them to an informative and referral multi-lingual telephone line. A Coalition approved the final poster design in August 2000. They decided on the following statement: "AIDS and HIV AFFECT YOU AND ME. TALK. ASK. CALL TOLL FREE: 1 866-274-2429." This message was translated into six A&PI languages. In July 2001 the poster ad campaign was implemented. A total of 2,000 posters were posted in the subways and buses throughout New York City. Furthermore, the poster ads were converted to advertisements and were published in various ethnic newspapers. In July 2002, the second media campaign was implemented. An ad message of "I am...(Filipino, Chinese, Japanese, Korean, Pakistani, Bangladeshi). I can't get HIV. Think Again! Get Tested. Call Toll Free 1 866 274 24 29" was translated to five specific AP&I languages, with the exception of Filipino and were then published to the various ethnic newspapers. Activity 2: Implement a multi-lingual Information and Referral Line (Info-line) where A&PIs can learn more about HIV risk reduction in their reduction in their own language and receive referrals for testing and other HIV-related services.

Results/Findings: Info-line received a total of 788 calls from November 2000 thru September 2002. Forty-three percent of those calls were conducted in an AP&I language. Sixty-six percent of the calls were in reference to HIV testing. Of this number, 367 of the callers were referred to APICHA's HIV testing and counseling program. Furthermore, APICHA has conducted a total of 421 HIV testing and counseling from May 2001 to September 2002. Eight clients were identified HIV positive. While all of them were referred to APICHA's case management program, 6 of them accepted the referral and are following through.

Conclusions: The Breaking Silence Project was successful in increasing awareness of and access to HIV information, testing and services. The higher seropositivity rate suggests that APICHA's culturally relevant and linguistically appropriate intervention facilitates access to HIV testing among traditionally marginalized and/or hard-to-reach A&PI populations.

Bird M (2003). Prevention with positive American Indians/Alaska Natives/ Native Hawaiians in rural settings. Natl HIV Prev Conf July 2003. Atlanta, GA. (abstract no. M1-F0101).

Type: Author abstract

Background: HIV-positive American Indians, Alaska Natives and Native Hawaiians living in rural communities often experience HIV/AIDS stigma, sexual orientation and substance use discrimination, and other health disparities which impacts the further transmission of HIV. Effective HIV-prevention and health promotion in these communities needs to occur on a community level in an effort to support the continued health and well-being of Natives living with HIV.

Methods: In this session, participants will learn about the history and factors affecting HIV-positive Natives living in rural communities, and how communities are responding to HIV. Information provided was collected through a focus group and interviews with HIV-positive American Indians, Alaska Native and Native Hawaiians; and interviews with programs and communities addressing HIV on a community-level.

Conclusions: Community readiness to address and support HIV-positive Natives living in rural communities is a key component to effective prevention efforts. Tribal/community leaders, health care providers, and community members are the focus of this effort.

Bird ST, Bogart LM, et al. (2004). Health-related correlates of perceived discrimination in HIV care. AIDS Patient Care STDS 18(1): 19-26.

Type: Analysis of interviews with HIV-positive men and women

Background: The authors examined whether perceived discrimination because of race or socioeconomic status (SES) during interaction with HIV treatment providers was associated with depression, post-traumatic stress from HIV diagnosis, AIDS-related symptoms and health status, health care satisfaction, antiretroviral medication adherence, and missed doctor appointments.

Methods: Participants were 110 HIV-positive men and women (17% female, 51% White) in a Midwestern US city. Face-to-face interviews included interviewer questions as well as self-administered questions measuring perceived discrimination, depression, post-traumatic stress from HIV diagnosis, AIDS-related symptoms, and health care satisfaction. Interviews were approximately one hour and were compensated.

Results/Findings: As other studies have found, the majority of participants had perceived discrimination in their interactions with HIV treatment providers when getting treatment for HIV albeit infrequently. Specifically, 71% reported having experienced discrimination when receiving treatment for HIV based on their race or color, and 66% reported discrimination attributed to their socioeconomic status, position, or social class. Race-based and SES-based discrimination were each associated with greater levels of depression and posttraumatic stress symptoms, greater severity of AIDS-related symptoms, lower perceived general health, and less health care satisfaction. Greater SES-based discrimination was also related to lower adherence to antiretroviral medications.

Conclusions: Experiences with discrimination when getting HIV treatment have a potentially negative effect on health, health care satisfaction and medication adherence. This study did not assess discrimination based on HIV status or sexual orientation. Provider and staff training in enhanced communication, increased awareness of discrimination, and cultural competence may improve patient-provider relationships and patient satisfaction and adherence. Intervention for HIV-positive patients could address perceptions of providers and encourage an active patient role in their health care.

Black BP, Miles MS (2002). Calculating the risks and benefits of disclosure in African American women who have HIV. J Obstet Gynecol Neonatal Nurs 31(6): 688-97.

Type: Qualitative, descriptive study

Background: This study of stigma and disclosure was undertaken as part of a larger randomized clinical intervention to determine the efficacy of a self-care management intervention with African American mothers. Issues related to stigma and disclosure are burdensome for these women with HIV who are already marginalized by race and poverty in an area of traditional culture and values. This study identifies the processes and patterns of disclosure of their HIV diagnosis reported by low-income African American women living in the southeastern United States.

Methods: Nurse visited in the homes of the participants, 48 African American women who were HIV-positive and were primary caretakers of young children. Nurse visited were every two weeks for a total of six visits to provide the intervention. The nurses' extensive field notes were analyzed using content analysis for evidence of disclosure issues.

Results/Findings: The women with HIV were faced with determining "what is at stake" in telling others of their diagnosis. Disclosure issues are generally characterized by the threat of stigma, feelings of shame, and the concurrent need for support. The women's calculus of disclosure involved a careful evaluation of the risks and benefits involved in disclosing their illness. Risks of telling were linked to feelings of personal shame and the threat of societal stigmatization. The benefits of disclosure were primarily fueled by personal needs. Decisions about disclosure were recursive, made and remade over time. Disclosure patterns ranged from secretive (a small group of respondents), to selective disclosure (the majority), to full disclosure (the smallest group).

Conclusions: Issues related to disclosure of a diagnosis of HIV and potential stigma were highly relevant to the group of African American women with HIV in this study. The calculus of disclosure involved weighing the stakes of telling or concealing the diagnosis. Most of the mothers chose a route of selective disclosure. The therapeutic relationships with the study nurses were important in supporting women regarding their disclosure decisions.

Boer H, Emons PA (2004). Accurate and inaccurate HIV transmission beliefs, stigmatizing and HIV protection motivation in northern Thailand. AIDS Care 16(2): 167-76.

Type: Analysis of interviews with a convenience sample of residents of Chang Rai province, Thailand

Background: Accurate and complete knowledge of HIV transmission is important in campaigns to reduce HIV risk behavior. The authors assessed the relation between accurate and inaccurate beliefs about HIV transmission and the emotional reactions to people with AIDS (PWA) and AIDS risk groups, stigmatizing

attitudes and motivation to protect from HIV. The study was done in Chang Rai province, the most severely affected area in the AIDS epidemic in Thailand.

Methods: A convenience sample of 219 respondents of Chang Rai, Thailand completed a structured questionnaire assessing accurate and inaccurate HIV transmission beliefs, emotional reactions towards PWA and AIDS risk groups, stigmatizing attitudes and motivation to protect from HIV according to variables from Protection Motivation Theory. The heterogeneous sample included young and old males and females and persons from various socioeconomic backgrounds.

Results/Findings: Complete accurate beliefs about documented modes of HIV transmission were present in 47% of the respondents; 26% of the respondents held one or more inaccurate beliefs about HIV transmission. Inaccurate beliefs about modes of transmission were significantly related to stigmatizing beliefs towards PWA, to vulnerability of HIV infection and lower self-efficacy in protection. The persons with inaccurate beliefs perceived AIDS as less severe, perceived a lower personal vulnerability and were less motivated to use condoms.

Conclusions: This study suggests that inaccurate beliefs about HIV transmission foster fear towards PWA and homosexuals and more irritation towards PWA and commercial sex workers and are related to distancing stigmatizing reactions and stereotyping of HIV risk behaviors. Stereotyping risk behaviors (e.g. promiscuous behavior) undermines HIV prevention behaviour as people may see themselves at less risk if their behavior is not similar to stereotyped risk behavior.

Brown AU, Ramirez-Valles J (2002). The effects of stigma on community involvement in HIV/AIDS organizations among Latino gay and bisexual men. (abstract no. E11537). Int Conf AIDS 14.

Type: Author abstract/interviews

Background: We studied the effects of stigma on community involvement in HIV/AIDS organizations among Latino gay and bisexual men. Through community involvement in HIV/AIDS-related organizations, individuals develop and maintain a positive sense of the self and become educated on HIV/AIDS risks and preventive behaviors. The stigma towards homosexuality and AIDS may work either as a deterrent or motivator for community involvement. This phenomenon has yet to be studied among Latino gay and bisexual men.

Methods: Eighty life-history interviews were conducted with Latino gay and bisexual men in the U. S. A. (Chicago and San Francisco) in the fall of 2001. All participants have been involved in HIV/AIDS-related organizations as volunteers and/or activists.

Results/Findings: Participants felt stigmatized because of homosexuality and/or AIDS at some point in their lifetime. This stigma has prevented some individuals from getting involved in HIV/AIDS work. For others, it encourages community involvement.

Conclusions: We need to further explore the mechanisms by which the stigma of homosexuality and HIV/AIDS either fosters or hinders community participation. This research will have implications for strengthening community involvement of ethnic minorities in HIV/AIDS prevention.

Brown L, Macintyre K, Trujillo L (2003). Interventions to reduce HIV/AIDS stigma: what have we learned? AIDS Educ Prev 15(1): 49-69. See also http://www.popcouncil.org/pdfs/horizons/litrvwstigdisc.pdf

Type: Review of published interventions

Background: The authors review 22 studies on interventions to decrease HIV/AIDS stigma in developed and developing countries. The intervention strategies included general information-based programs, contact with affected groups, coping skills acquisition and counseling approaches. The target group, setting, type of intervention, measures, and scale of these studies varied. The majority of the studies sought to increase tolerance of persons living with HIV/AIDS among the general population. The remaining studies tested interventions to increase willingness to treat persons living with HIV/AIDS among health care providers or improve coping strategies for dealing with AIDS stigma among persons living with HIV/AIDS or at-risk groups.

Results/Findings: The results suggest that almost all stigma reduction interventions appear to work, at least on a small scale and in the short term. However, the authors highlight the need for comprehensive

multi-channel programs targeting whole communities. They also suggest that access to drugs in developing countries may have important effects on stigma and must be documented.

Conclusions: A number of knowledge gaps remain: interventions, especially those in developing countries, must be rigorously evaluated, documented and published; interventions must be tested in different settings and populations, especially the young; on a small scale, stigma was reduced by some interventions but documentation is needed on national level effects; and work, testing and documentation to determine the impact post-intervention and in areas of gender impact of stigma reduction interventions.

Busza JR (2001). Promoting the positive: responses to stigma and discrimination in Southeast Asia. AIDS Care 13(4): 441-56.

Type: Literature review and description of community-level interventions
Background: Discrimination related to HIV may be legislative, reflecting stigma in policy or law, or community-level, reflecting stigma and discrimination in the family or other structures of civil society such as the workplace, the health sector, religion or the media. The authors review the impact of discrimination and the fears it induces and explores how interventions can counteract community-level discrimination.
Methods: Review of literature including unpublished literature and anecdotal evidence from interviews with project staff throughout Southeast Asia.
Results/Findings: Stigma and discrimination impact the prevention-to-care continuum with barriers to appropriate responses in prevention, identification and acknowledgement, and care and support.
Conclusions: The activities and interventions reviewed represent initiatives in a number of countries and contexts of discrimination but certain common components emerged. The intervention activities all have an emphasis on process, indicating that reducing community-level discrimination can be integrated into any approach to HIV/AIDS. Specific commonalities included the participation of persons with HIV, their increased visibility in the community and supportive groups and networks of persons living with HIV/AIDS. The supportive groups ranged from real social space to virtual communities on the Internet. Addressing the continuum of prevention to care with interventions targeting barriers posed by discrimination along the continuum simultaneously was also important. Lastly, integrating contexts of discrimination (e.g. through involvement of family, schools, religious organizations) can build a comprehensive community-based approach.

Cain RE, Preston DB, Schulze F, D'Augelli AR, Starks M (2003). Quantitative and qualitative research methods for accessing rural men who have sex with men (MSM). Natl HIV Prev Conf July 2003. Atlanta, GA.(abstract no. W0-A0504).

Type: Author abstract
Background: Issue: The social-cultural issues affecting rural men at risk for HIV infection are different from men who live in urban societies. Men who have sex with men (MSM) who live in rural areas constitute a diverse and hidden population. Some identify as gay or bisexual, but some do not, despite engaging in same-sex sexual practices. Some are in same-sex partnerships of varying kinds, some are single, and some are heterosexually partnered or married. Stigma, social isolation, rejection are present among men in urban areas, but a higher population density means that there are more "networking" opportunities where men can meet and get to know one another. In rural areas, these "networking" opportunities are far more limited and, in some places, can be nonexistent. Setting: Rural or non-urban areas of the United States Project: Effects of Stigma on Risk Behaviors of Rural Men who have Sex with Men (MSM)
Results/Findings: The purpose of this presentation is to discuss some of the methods used to access a rural MSM population - successes and limitations - for a research study evaluating stigma, sexual behavior and orientation characteristics.

Chandra PS, Deepthivarma S, et al. (2003). Disclosure of HIV infection in south India: patterns, reasons and reactions. AIDS Care 15(2): 207-15.

Type: Analysis of interviews with HIV-positive persons in south India
Background: The authors assessed ways in which HIV-related disclosure took place and factors that influenced disclosure among persons infected with HIV.
Methods: Data was collected through in-depth semi-structured and open-ended 45-minute interviews with 68 persons (35 men and 33 women). Data was analyzed both qualitatively and quantitatively. Aspects of self-disclosure which were assessed included: extent of disclosure and what was disclosed; identity and number of persons to whom the HIV status was disclosed; reasons for disclosure or non-disclosure; and concerns and worries related to disclosure.
Results/Findings: Voluntary disclosure was noted in 44 subjects (65%); 24 subjects (35%) reported disclosure without consent. Disclosure without the individual's consent is troubling especially because in 75% of the cases, the breach of confidentiality occurred through health professionals. Of those who disclosed, 78% of the subjects reported self-disclosure to family members, 7% to friends and 15% exclusively to health professionals. The high rate of voluntary disclosure to family members indicates the importance of families as a primary emotional and material support system in India. Only half of the subjects disclosed complete and truthful information while in the rest, disclosure was partial or disguised as a less stigmatizing illness. Disclosure disguised as another disease reflects the intensity of the stigma attached to HIV/AIDS in India. Stigma, fear of discrimination, disgrace to family and self and futility were reported as the main reasons for non-disclosure. The majority of the subjects (73%) reported anticipation of negative societal reaction as the main concern following disclosure.
Conclusions: Disclosure is a complex decision and is affected by perceived stigma, anticipated response from others and the possibility of gaining access to care. HIV-related counseling services are not freely available in India and practices related to confidentiality and disclosure are not uniform. The rate of disclosure by a health care professional without patient consent highlights the need for training in test-related counseling and ethical aspects of HIV-related disclosure.

Chng CL, Wong FY, Park RJ, et al. (2003). A model for understanding sexual health among Asian American/Pacific Islander men who have sex with men (MSM) in the United States. AIDS Educ Prev 15(1 Suppl A): 21-38.

Type: Descriptive narrative with conceptual model
Background: Understanding the social construction of sexuality is important for understanding social roles and sexual health among Asian American/Pacific Islander (AAPI) men who have sex with men (MSM). Many AAPI cultures do not dichotomize heterosexual and homosexual orientations. HIV prevention is complicated by perceived connections between sexual behavior and a person's social role or sexual orientation.
Methods: Description and literature review of social roles or sexual orientation related to stigma, shame and loss of face among AAPI MSM
Results/Findings: The authors propose a model for understanding sexual health among AAPI MSM based on the premise that AAPI MSM develop their sense of self in a social-cultural environment marked by racism, homophobia and immigrant status. The conceptual model of impact domains developed by the authors encompasses a dynamic cultural process.
Conclusions: The first impact domain is the home country pattern of cultural norms including sexual mores, shame or stigma, sexual attitudes, sexual behavior, and drug use/abuse. These cultural norms are modified by the impact domain of migration/immigration experience. Lastly, these norms, beliefs, and practices are influenced by the process of acculturation as these men adjust to life in the United States. Each domain has its own implications for HIV prevention efforts. The authors state three conclusions: popular behavioral models which ignore important cultural practices, beliefs and attitudes of AAPI MSM will not work with this population; cultural background including home country norms, migration and acculturation experiences have significant effects on risk behavior and therefore on HIV prevention and interventions; and three, social-cultural factors related to AAPI MSM must be integrated into research designs and program structures.

Clark HJ, Lindner G., et al. (2003). Stigma, disclosure, and psychological functioning among HIV-infected and non-infected African American women. Women Health 38(4): 57-71.

Type: Data on both HIV-infected and non-infected women from the Family Health Project
Background: The authors focus on HIV/AIDS related stigma among HIV-infected women African American women and demographically similar non-infected women at risk of contracting HIV. HIV is on the rise among African American women and these women are less likely to receive social support, increasing their experience of stigma. The perceived stigma also likely affects their decision to disclose HIV seropositive status. This study examines perceived AIDS-related stigma over a six-year period across HIV-infected and non-infected African American women. The study also examines whether disclosure of HIV seropositive status moderates the relationship between stigma and psychological functioning.
Methods: The participants in the study included 98 HIV-infected and 146 non-infected African American women, between the ages of 18 and 50 in New Orleans, Louisiana. Data was collected at four points across six years as part of the Family Health Project, a longitudinal investigation of the psychological functioning of inner-city African American women and their children. Assessments included measures for stigma, disclosure and psychological functioning.
Results/Findings: The HIV-infected women perceived a significantly higher level of AIDS-related stigma than non-infected women at all four assessments. Among these women, an increased level of perceived stigma corresponded with a decreased level of disclosure and psychological functioning. The authors surmise that non-infected women may be less aware of stigma because they are not affected by it in daily life. The perceptions of stigma did not significantly change over time for the entire sample or within either HIV group. The finding that stigma did not decrease over six years may show that anti-stigma campaigns are not addressing family stigma.
Conclusions: For HIV-infected African American women, greater stigma was associated with poorer psychological health if they chose to disclose their status to several categories of "others" than if they did not disclose. At this level of family, stigma is most damaging because support for the HIV-infected person is so essential. Future research and education efforts should target family stigma, the potential consequences of disclosure and the psychological functioning of African American women with HIV/AIDS.

Cobb M, De Chabert JT (2002). HIV/AIDS and care provider attributions: who's to blame? AIDS Care 14(4): 545-8.

Type: Random design study of beliefs of social workers
Background: Research is beginning to examine the public's attitude toward individuals who are HIV-positive or have developed AIDS. Findings suggest that society continues to stigmatize and blame those at-risk. The authors used Weiner's Attribution Theory, an attributional model of helping behaviors, to examine the beliefs of social service providers who work directly with individuals affected by HIV/AIDS. One goal was to determine how job classification (e.g. management versus outreach staff) affects attributions. The study also explored how the gender of the hypothetical individual at-risk for HIV influenced attributions made by providers.
Methods: Forty-six (28 female and 18 male) HIV/AIDS social service providers from three community-based organizations were randomly assigned a demographic questionnaire, a hypothetical scenario depicting an individual at-risk for HIV/AIDS because of multiple high-risk behaviors and attribution questions. The gender of the individual at risk was manipulated. At the conclusion of the scenario, participants completed a questionnaire designed to assess attributions of responsibility, blame, anger and willingness to provide assistance.
Results/Findings: Results of the study show that social service providers who perceive individuals as more responsible for their illness report increased anger, attribute more blame and express less willingness to help those at-risk for HIV/AIDS. Providers tended to attribute more anger to and were less likely to help male targets compared to female targets.
Conclusions: This research in a small sample of HIV/AIDS social service providers suggests that despite growing numbers of media campaigns and national distribution of information regarding HIV and its transmission, people continue to stigmatize and place blame on those at-risk. Gender appears to influence attributions. The authors suggest integrating information about attributions into training

programs for HIV care providers, especially focusing on self-discovery of negative perceptions and ways to reduce responsibility and blaming judgments.

Coon DW, Catania JA, Rebchook GM (2003). G(r)aying: exploring contexts for HIV prevention interventions among 50+ MSM's. Natl HIV Prev Conf July 2003. Atlanta, GA.(abstract no. T2-A1702).

Type: Author abstract
Background: MSM still constitute the overwhelming majority of HIV/AIDS cases in the 50 and older population. However, older MSM's sexuality and primary prevention needs, as well as their unique situations and contexts for HIV risks, are relatively unexplored. This formative research examines key themes to aid in the development and evaluation of HIV interventions for older MSM's.
Methods: MSM 50 years of age and older who reported having male sexual partners in the last 5 years were invited to participate in either a focus group or an in-depth individual interview. Men were identified through their participation in a recent probability based epidemiological study of adult MSM residing in San Francisco, as well as through snowball sampling and local advertisements. The project systematically gathered data to clarify our understanding of older MSM's HIV risks and the contexts that place them at risk for HIV transmission.
Results/Findings: 85 eligible MSM's age 50 and over participated in the project. Recruitment resulted in a substantially diverse sample with 63.5% of the study participants being age 50-59, 36.5% over age 60, and 33% of the total sample self-identifying as MSM of color (10.8% Latino/Hispanic, 12.9% African American, 4.7% Asian/Pacific Islander; 3.5% Native American and 1.2% as multiracial). Fifty-five MSM participated in five separate focus groups and 30 in in-depth interviews. Participants ranged in age from 50 to 80 (mean age = 57.9 years), and reported an average of 8.8 sexual partners in the last year. Approximately a third of all participants were in a committed relationship. Several key themes emerged including: pervasive internalized and externalized ageism; social support losses due to the AIDS epidemic (particularly among 50-59 year olds) and other social losses that increase loneliness, limited social venues for older MSM; an increased desire for intimacy; and, an interest in mentoring opportunities to give back to younger generations of MSM.
Conclusions: Results suggest new HIV campaigns need to be launched that target older MSM. These interventions need to address the tremendous stigma older MSM experience in the community as well as a number of their social and informational needs (e.g., housing, medical, sexual functioning and financial needs). Providing mentoring opportunities with younger generations of MSM's may prove beneficial across age groups. Finally, more men in their 50's reported substantial losses from the HIV/AIDS epidemic; this and other differences across cohorts indicate an array of strategies is needed.

David D, Augustine J, Mahesh L, Benoit F (2002). Disclosure as a tool in combating discrimination, stigma and social exclusion. (abstract no. ThPeG8309). Int Conf AIDS 14.

Type: Author abstract
Background: In a country (India) rich in traditional and cultural beliefs, sex is looked down as a taboo. The link of HIV/AIDS as a result of sexual behaviour has addressed existing social system for people living with HIV. The situation is severe in the case of women living with HIV. The source of infection has been the determining factor in accepting women living with HIV/AIDS. Disclosure has been an effective means in combating the existing situation of stigma and discrimination. The openness of one's status has been implemented in college programmes, public meetings and other intervention programmes of the project.
Results/Findings: Disclosure has been an effective tool in creating an enabling environment for people living with HIV. Disclosure has effected a change in the attitudes of many people in the society thus gaining an acceptance for people living with HIV. This has also resulted in better understanding towards people living with HIV, thus reducing stigma.
Conclusions: Disclosure can be used as an effective means in combating stigma and discrimination. More intervention programmes involving people living with HIV would result in a greater change, as disclosure is a major component in it.

Eroglu D, Newman DR, Peterman TA (2002). Gauging stigma associated with HIV-infected persons. (abstract no. ThPeE7913). Int Conf AIDS 14.

Type: Author abstract

Background: Stigma adversely affects many persons. Single indicators have been used to gauge stigma related to HIV-infected persons. We studied changes in these indicators and propose a multi-item measure as a better way to gauge stigma.

Methods: Surveys were mailed in 2000 and 2001 in the US to representative samples of adults. Respondents indicated on a 5-point scale their agreement with statements used as indicators of stigma.

Results/Findings: 2353 surveys were returned (75%) in 2000 and 3719 (66%) in 2001. Some changes suggest decreased stigma. Fewer persons agreed in 2001 than in 2000 that: it should be a crime if an infected person knowingly has sex with another (63% to 76%); foreigners with HIV should be barred from entering US (46% to 53%). Yet, other changes suggest increased stigma. Fewer agreed in 2001 than in 2000 that: it is good to provide clean needles to drug addicts to prevent HIV, (45% to 56%); or that US government should pay for treatment of uninsured persons with HIV, (31% to 38%) (for all differences, p<.01). Opposing changes on single items suggest different trends in stigma. To search for commonality, all 24 items were factor-analyzed using 2000 data. 4 factors emerged with satisfactory reliability (Cronbach's Alpha > .70 for all). Two reflect negative stereotyping (NS) and willingness to discriminate (WD) against HIV-infected persons and are proposed as measure of stigma. The other two indicate compassion (C) and support (S) for favorable policies toward HIV-infected persons. Identical factors emerged in 2001 with acceptable reliabilities. Comparison of the proposed measures show no change in stigma from 2000 to 2001: 9.5 and 9.6 for NS; 26.2 and 25.6 for WD; 17.6 and 17.4 for C and 18.9 and 18.5 for S.

Conclusions: Single indicators of stigma can be driven by other factors (e.g., political views or economic concerns) in addition to stigma. Reliable and valid multi-item scales should be used to measure stigma.

Fesko SL (2001). Disclosure of HIV status in the workplace: considerations and strategies. Health Soc Work 26(4): 235-44.

Type: Interviews with 18 HIV-positive persons

Background: Disclosure of HIV status to employers or coworkers can create opportunities for medical and social support but it may also result in stigmatization, discrimination or disruption of personal relationships. This qualitative study was undertaken to obtain a better understanding of the factors that influenced HIV-positive individuals' decisions to disclose their health status in the workplace.

Methods: Interviews with open-ended questions were conducted with a convenience sample of 18 HIV-positive individuals who continued to work after their diagnosis. The research questions were about the workplace experiences of the individual including the *when*, *why* and *how* of disclosure and changes in employment situation since disclosure. Respondents were also asked what supports would be useful to them when dealing with workplace issues. A system of codes was developed to condense the verbal information from each interview.

Results/Findings: Several studies on disclosure found that most HIV positive individuals did not tell their employers or coworkers. In this study, six respondents fully disclosed their status to everyone in the workplace; seven persons disclosed their status selectively and requested confidentiality and five persons told no one.

Conclusions: The most frequently cited reasons for disclosing HIV status were to explain choices they were making as they interviewed for a job; concerns about job performance and the need for accommodations. The individuals who disclosed their HIV status selectively or disclosed to no one gave reasons as disease progression, personal acceptance of the diagnosis, the preference for privacy, the nature of the work environment and fear of possible consequences. The individuals who did not disclose identified social isolation as a primary problem with maintaining their secret; other research has also shown that nondisclosure may lead to depression, anxiety and alienation. The practice, policy, and research implications for social workers are also discussed. In social work practice, these include helping an HIV-positive person weigh the risk versus the benefits of disclosure in the workplace. Continuing research on factors contributing to disclosure decisions, the effect of work site variables on disclosure and

accommodation, individual rights under the Americans with Disabilities Act, and the individual decision-making process is also needed.

Fife BL, Wright ER (2000). The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer. J Health Soc Behav 41(1): 50-67.

Type: Social Impact Scale used in sample of persons with HIV/AIDS or cancer
Background: The authors studied the impact of stigma on the self by illness type (HIV/AIDS and cancer). They studied the effects of the stigma on self-esteem, body image, and personal control, specifically testing the hypothesis that the individual's perception of stigmatization accounts for significant differences in the impact of the illness on the self. Four dimensions of perceived stigmatization - social rejection, financial insecurity, internalized shame, and social isolation - were examined as mediators and moderators of the effects of HIV/AIDS versus those of cancer.
Methods: The sample included 130 persons with HIV/AIDS and 76 persons with cancer. Illness severity was controlled for by including a measure of functional health status. Perception of stigma was measured using the Social Impact Scale and a Likert-type scale for responses developed specifically for this research. Data was analyzed to answer two questions: 1) does the type and degree of stigma experienced by persons with HIV/AIDS and cancer differ?, and 2) what is the impact of stigma on the self in these two groups?
Results/Findings: There was clear evidence that stigma is a central force in the lives of people with cancer as well as people with HIV/AIDS. The effects of cancer and HIV/AIDS seem to be felt primarily through the mechanisms of stigma and the type of illness does not appear to directly affect any dimension of self-perception.
Conclusions: Generally, the conceptualization of the self of stigmatized people has focused on a single dimension of the self, usually self-esteem. This study on three components of the self – self-esteem, personal control and body image- show that different dimensions of the stigma experience and the conceptualization of the self come together, shaping adaptation. The findings in this comparative study highlight the need for research into the causal processes underlying self-change among stigmatized people.

Franklin MO, Alexander L (2003).Overcoming the stigmas associated with HIV/AIDS within African American communities: historical barriers. Natl HIV Prev Conf July 2003. Atlanta, GA. (abstract no.W0-E0902).

Type: Author abstract
Background: African Americans are painfully aware of the penetrating stains of stigmas, there lasting and too often devastating effects on our personal and professional quality of life. Historically there have been constant reminders that the African American experience is often perceived as different, of lesser value, and that these internalized feelings of oppression and indifference, triggers in some individuals, similar treatment of the less fortunate and the politically powerless.
Methods: This interactive workshop will explore the pain and impact of personal stigmas and the role it can play in working with individuals who have been impacted by HIV/AIDS. The workshop will look at the stigmatization of HIV/AIDS; which includes issues of sexuality, homosexuality, gender, and drug use. The intent of this session is to facilitate an inward look at personal bias experiences and use that view to self evaluate how we act on those experiences, within the community and more specifically, how these emotions impact our work in caring for person's infected with HIV/AIDS. Also, this session will engage and challenge participants to renew their thinking, regarding personal bias and to hold organizations and individuals accountable who continue this cycle of oppression and stigmatization.
Results/Findings: Learning objectives: At the end of the presentation, participants will be able to 1) describe the manner in which stigmas associated with race/gender/class and sexuality impact their daily living, 2) discuss ways that various stigmas affect our ability to provide service and care, 3) discuss personal observations and experiences with the Black church, with reference to prejudice/biases/stigma, 4) discuss methods and strategies to employ in overcoming stigmas.

Garcia DI, Ramirez-Valles J, Valbuena N (2003). "...it's a secret we have to keep": measuring HIV/AIDS stigma among Latino gay men. Natl HIV Prev Conf July 2003. Atlanta, GA.(abstract no. T3-A1302).

Type: Author abstract
Background: Objectives: The stigma that people with HIV/ AIDS encounter can have serious consequences. The stigma associated with HIV may influence people's decision regarding whether and when to be tested for the virus, it may deter people from seeking medical, social and psychological care, and preventing disclosure of serostatus to others, which in turns may increase isolation when social support is needed.
Methods: This study analyzed 80 life histories of Latino gay men (40 in Chicago; 40 in San Francisco) of which 41% were HIV positive. Using content and interpretative analysis, HIV-related stigma was examined.
Results/Findings: The analysis of the data resulted in the identification of three areas of HIV/AIDS-related stigma: perceived (e.g., most people are uncomfortable around someone with HIV/AIDS), experienced (e.g., my family is ashamed of me because I have HIV/AIDS), and internalized (e.g., I am embarrassed to tell others that I have HIV/AIDS). An instrument with 49 items was developed in English and Spanish to measure the 3 areas of stigma (17 perceived, 17 experienced, and 15 internalized), and will be pilot-tested to assess psychometric properties.
Conclusions: Measures of HIV/AIDS stigma need to be culturally and context based to increase validity. The items developed may be used to assess and test hypotheses about HIV/AIDS stigma.

George-Barber DA, Davis-King D (2003). A capacity building model for HIV/AIDS prevention case management services for women in a primary care clinic setting. Natl HIV Prev Conf July 2003. Atlanta, GA. (abstract no. TP-127).

Type: Author abstract
Background: Issue: The CDC CHOICES Prevention Case Management program is an approach to HIV/AIDS risk reduction that maximizes the opportunity to identify and effectively reach high risk women who might otherwise go unidentified by traditional medical care delivery systems and/or be inaccessible to traditional community-based HIV/ AIDS prevention programs. Setting: The program is geographically located in a multi-ethnic health district in Los Angeles County. It is physically situated within the constellation of services provided by a comprehensive primary care clinic (community-based organization). It services predominantly racial/ethnic minority women and their families who are clients and/or residents of the service community at risk for HIV/AIDS.
Methods: Project: The prevention case management program operates within the primary care clinic as one of the core functions of the clinic. Several months were spent appending and revising clinic procedures and policies that would fully integrate the delivery of program services within a traditional medical milieu. Every individual seeking services who is sexually active and 13+ years of age is offered free a HIV test, and receives a HIV risk assessment and knowledge

Herek GM, Capitanio JP, Widaman KF (2002). HIV-related stigma and knowledge in the United States: prevalence and trends, 1991-1999. Am J Public Health 92(3): 371-7.

Type: Comparison of telephone survey results from the decade of the 1990s
Background: Data on the existence and persistence of societal stigma towards persons with HIV/AIDS can aid in formulating health policy responses, designing programs to prevent HIV transmission and reducing the persecution of persons with HIV/AIIDS. The authors assessed data on the prevalence of AIDS stigma and misinformation about HIV transmission in 1997 and 1999 and examined trends in stigma in the United States during the 1990s.
Methods: Telephone surveys with national probability samples of English-speaking adults were conducted in the period 1996 to 1997 (n = 1309) and in 1998 to 1999 (n = 669). To examine trends, findings were compared with results from a similar 1991 survey.

Results/Findings: Trends in AIDS stigma throughout the 1990s were compared through the three surveys. Analyses were made on questions related to support for punitive policies, negative feelings towards persons with HIV/AIDS, responsibility and blame, beliefs about HIV transmission and discomfort and avoidance. The analysis suggested that while overt expressions of stigma declined throughout the 1990s, inaccurate beliefs about the risks posed by casual social contact increased, as did the belief that people with AIDS deserve their illness.

Conclusions: Comparison of the three surveys found that beliefs and opinions that provide a foundation for AIDS stigma unfortunately persist; AIDS remains a stigmatized condition in the United States. Stigma still exists nearly two decades into the US epidemic. Educational efforts have successfully communicated how HIV is transmitted but work is needed to educate the public that AIDS is not spread by casual contact. The persistence of discomfort with PWAs, blame directed at PWAs for their condition, and misapprehensions about casual social contact must be addressed in HIV prevention and education programs and policies. To effectively combat HIV, AIDS stigma must be eradicated.

(2000). HIV-related knowledge and stigma--United States, 2000. MMWR Morb Mortal Wkly Rep 49(47): 1062-4.

Type: Internet-based public opinion survey
Background: Identifying and removing barriers to the use of voluntary HIV counseling and testing services may increase the number of persons at risk for HIV who receive these services. One barrier to testing is stigmatization both of individuals infected with HIV and groups most affected by HIV, including men who have sex with men and illicit drug users. To measure public attitudes and knowledge about HIV transmission to determine the prevalence and the correlates of stigmatizing attitudes, an Internet-based national public opinion survey was conducted.
Results/Findings: One of the study limitations is that results are based on only one question about stigma which comprises a range of attitudes, beliefs and behaviors. However, the findings suggest that most US adults do not hold stigmatizing views of person with HIV/AIDS. The respondents who were misinformed about HIV transmission were significantly more likely to give a stigmatizing response suggesting that increased understanding about transmission may lower levels of stigmatizing beliefs.
Conclusions: Overcoming stigma, including prejudice and active discrimination, is an important step in removing barriers to voluntary HIV testing and counseling. Data from surveys like this will help direct and assess efforts to overcome barriers.

Kalichman SC, Simbayi LC (2003). HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. Sex Transm Infect 79(6): 442-7.

Type: Analysis of interviews with a cross-sectional sample of residents in a black township in Cape Town, South Africa
Background: Voluntary HIV antibody counseling and testing (VCT) to reduce high risk sexual practices and decrease rates of sexually transmitted diseases is a cornerstone of HIV prevention However, studies have shown that only one in five South Africans aware of VCT have been tested. The authors examined the relation between social and cognitive factors such as HIV testing history, attitudes towards testing, and AIDS stigma.
Methods: Men (n = 224) and women (n = 276) living in a black township in Cape Town completed venue intercept surveys; 98% were black, 74% age 35 or younger. Measures included demographic characteristics, HIV testing history and attitudes, HIV risk behavior history, HIV prevention knowledge, and AIDS stigma.
Results/Findings: Among participants, 44% had been tested for HIV, 53% had not been tested and 3% refused to respond whether they had been tested. Risks for exposure to HIV (excluding never having used a condom) were comparably high among people tested and not tested. The authors surmised that a substantial number of untested individuals were probably HIV infected. Attitudes toward VCT, controlling for demographics and survey venue, showed that individuals who had not been tested for HIV and those tested but who did not know their results held significantly more negative testing attitudes than individuals

who were tested, particularly people who knew their test results. Compared to people who had been tested, individuals who were not tested for HIV had significantly greater AIDS related stigmas; ascribing greater shame, guilt, and social disapproval to people living with HIV.
Conclusions: Efforts to promote VCT in South Africa require education about the benefits of testing and, perhaps more important, anti-AIDS stigma campaigns and HIV prevention interventions. Ongoing structural and social marketing interventions such as mass media campaigns and public demonstrations to reduce AIDS stigmas will probably decrease resistance to seeking VCT. Research should also explore additional barriers to voluntary counseling and testing, including attributions of causes of HIV infections, availability of treatments, and beliefs about HIV treatments.

Karchner W, Klein S, O'Connell D (2002). Methods for the reduction of HIV-related stigma and discrimination in New York State (NYS): the role of the AIDS Institute. (abstract no. ThPeG8269). Int Conf AIDS 14.

Type: Author abstract
Background: Stigma and discrimination are two enemies of public health in the battle to prevent new HIV infections. Comprehensive HIV prevention programs must acknowledge and address these issues so that state and local health departments can meet the challenges through policy and program development. Established by statute in 1983, the NYS Department of Health AIDS Institute is responsible for coordinating the State's response to the epidemic. As the epicenter of the domestic (USA) HIV/AIDS epidemic, NYS has confronted a myriad of issues related to HIV stigma and the resultant discrimination, often in the absence of experimental models and without the benefits of other's experiences.
Results/Findings: Multiple strategies to address HIV related stigma and discrimination are necessary and essential to reduce the negative consequences of such policies and practices on the most affected communities. Bold short-term and long-term approaches are necessary to ensure that these enemies of public health don't defeat the advances realized to date.
Conclusions: Strategies to address HIV stigma have included: a strong HIV confidentiality statute, enforcement of state and federal privacy protections, comprehensive HIV clinical education that addressed institutionalized bias and cultural divides, active involvement of business and faith communities, education and leadership trainings for persons living with HIV and AIDS to promote parity in health planning dialogue, access to legal service providers who are knowledgeable about HIV and effective advocates, an ongoing commitment to interagency dialogue and service coordination around policy and program development and a recognition that HIV stigma, in conjunction with the discriminatory nature of such factors as racism, homophobia, sexism, poverty and drug use, continue to pose formidable challenges.

Kawonza EM, Dixon C (2002). Evaluation of Terrence Higgins Trust's HIV Stigma Campaign. (abstract no. G12567). Int Conf AIDS 14.

Type: Author abstract
Background: HIV stigma manifests itself in a number of ways, e.g. the perception that certain types of people get HIV and the fear and misunderstanding regarding transmission. HIV stigma within African communities has been identified as important for prevention and care outcomes. Past experience shows that the public is reluctant to discuss HIV and AIDS and black African communities are concerned about becoming scapegoats for the presence of HIV in the UK. Ensuring the voluntary and confidential participation of Africans and African organisations in the implementation, distribution and display evaluation of the campaign is important for the campaign's success.
Methods: The campaign comprised three posters depicting images from Black civil rights campaigns with bold captions about the nature of HIV prejudice. Images of segregation and racism were used to encourage people to question their HIV prejudices. Posters and press adverts were made available to Africans and businesses and venues frequented by Africans. Evaluation of the campaign examined its effectiveness, acceptability, perceived relevance and engagement at a personal and community level. A qualitative methodology was used to enquire into awareness, perceptions, attitudes and sensitive subject area of the study and unpack people's attitudes, belief systems and experiences that underpin them. A

range of participants was needed to reflect variation in HIV status, experience of the range of campaign distribution and different community and personal identities.

Results/Findings: The evaluation provided an insight into the impact of the campaign and draws lessons for future campaigns. The campaign's success has implications for wider attitudes to HIV and take-up of preventative measures and treatment.

Conclusions: Evaluation of HIV campaigns and resources should form integral parts of future health promotion. Such evaluations must actively engage with the targeted communities.

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

Type: Author abstract/discussion of interventions

Background: Stigma and discrimination exist in many forms, undermining individual and community health. Interventions to combat stigma and discrimination are essential to prevent the spread of human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS). Health departments, and others, can benefit by mounting specific interventions against these threats to public health. In New York State, interventions against HIV-related stigma and discrimination are integral components of the comprehensive approach to HIV prevention. For maximum impact, multiple interventions are employed at both policy and program levels. This article summarizes the need for interventions, discusses practical examples from actual experience, and presents the synergy of multiple interventions in a logic model.

Knowltan AR (2002). Social network approaches to HIV prevention and care: theoretical and methodological considerations of intervention. (abstract no. ThOrE1501). Int Conf AIDS 14.

Type: Author abstract/ social network analysis

Background: Theory-based research may help identify potential targets and strategies of intervention to promote HIV prevention and care among populations living with HIV/AIDS. Social theories suggest that social - compared to individual - level intervention may be more powerful for effecting and sustaining behavior change. The paper summarizes our social contextual research findings for instructive discussion of how research findings and theories of social influence, social norms, and social capital may inform unified intervention for HIV prevention and care.

Methods: Social network analysis was used to identify structural, functional, and relational network characteristics associated with behavioral risk (n=503) and medical service seeking (n=297) among HIV seropositive injection drug users in Baltimore, U.S.A. Sociodemographics of participants' network members were also assessed.

Results/Findings: Specific forms and sources of social support were associated with sexual and injection risk behaviors, formal medical care seeking, and network provision of informal care. Findings elucidate how the social stigma of drug use affects the social and economic marginalization of drug users, particularly female drug users, and its effects on their HIV risk and care seeking behaviors. Findings suggest the influence of female support on health behaviors, and the potential roles of sex partners and supportive kin and non-kin alike in affecting access to health resources.

Conclusions: Social network analysis may aid in identifying individuals who influence a population's health behaviors and access to health resources. These individuals may be important targets for intervention approaches that capitalize on their potential influences on social norms of behavioral risk and service seeking, and mobilizing community informal HIV care. Findings may aid in understanding social theories and research methodologies relevant for developing unified approaches to HIV prevention and care.

Kraft JM, Beeker C, Stokes JP, et al. (2000). Finding the "community" in community-level HIV/AIDS interventions: formative research with young African American men who have sex with men. Health Educ Behav 27(4): 430-41.

Type: Data from qualitative interviews

Background: Young African American men who have sex with men (MSM) may be viewed as "double minorities" defined by race and by sexual orientation and they may view participation in community change as not desirable, feasible or effective. Asking these men about their own and others' experience is important for understanding communities. The authors used qualitative methods to gain an understanding of community groups and sense of community among this group of men in preparation for community-level interventions.

Methods: Using "community identification", a qualitative assessment strategy, data from 76 qualitative interviews with 18- to 29-year-old African American MSM in Chicago and Atlanta were examined to identify perceptions of "community" and components of a community-level HIV/AIDS intervention.

Results/Findings: The data suggested that community development, including changing norms and increasing social support, may be necessary before participation in community-level interventions to change community conditions is feasible. The men who reported feeling part of gay African American communities characterized communities in terms of settings, social structures, and functions, including social support, socialization, and mobility. However, many men felt marginal to both African American and gay White communities because of perceived homophobia and racism. Further, building bridges between gay African American communities and the broader African American communities can address conditions that influence both behavior and community participation in change activities.

Conclusions: Three interrelated changes to promote the development of gay African American communities were identifying leaders, creating new settings for nonsexual meetings and interactions, and creating opportunities for dialogue between MSM and African American community groups to address homophobia and negative perceptions of homosexuality.

Kuhns LM, Ramirez-Valles J, Valbuena N, Cantu C (2003). All in the family: sexual orientation stigma among Latino gay men. Natl HIV Prev Conf July 2003. Atlanta, GA. (abstract no. T3-A1303).

Type: Author abstract

Background: Objectives: Recent findings suggest that stigma regarding sexual orientation may be particularly prevalent in the Latino community. This stigma may have a major impact on individual health and sexual risk behavior. The aim of this study was to develop a comprehensive measure of sexual orientation stigma among Latino gay and bisexual men that includes three dimensions: perceived, experienced, and internalized stigma.

Methods: Community-wide recruitment was used to select a convenience sample of 80 community-involved Latino gay and bisexual men (40 Chicago, 40 San Francisco); semi-structured life history interviews were conducted in English and Spanish. Data were analyzed following ethnographic methods for narrative and life histories. Sexual orientation stigma items were developed and compared with existing measures. A total of 63 items were created in English and Spanish.

Results/Findings: Analysis across the life history and along the three dimensions of stigma (perceived, experienced, and internalized) uncovered family life as an important source of stigma. Societal expectations and norms regarding gender are channeled through the family resulting in attempts to change behavior, verbal abuse, alienation, and displacement of Latino gay men.

Conclusions: Many aspects of sexual orientation stigma identified in previous research were also found in this study. In addition, these data reflect culturally specific sources of stigma. Based on these findings an instrument was drafted to obtain more comprehensive and detailed measurement of sexual orientation stigma which reflecting perceived, experienced and internalized stigma. The instrument will be evaluated and revised in future research.

Lansky A, Fleming PL, Holtzman D, Frey RL (2002). A decade of AIDS-related knowledge, attitudes, and beliefs in the United States--BRFSS, 1990 - 2000. (abstract no. WePeC6183). Int Conf AIDS 14.

Type: Author abstract/survey data
Background: General population surveys complement behavioral surveillance targeted to high risk groups to inform for HIV prevention activities. With low prevalence of risk among the U.S. general population, these surveys also are important for monitoring HIV-related knowledge, attitudes, and beliefs.
Methods: We analyzed data from the Behavioral Risk Factor Surveillance System (BRFSS), a state-specific, population-based random telephone survey of adults aged 18 - 64 years. We examined three categories of questions: AIDS Knowledge (1990 - 1992), AIDS Stigma (1990 - 1994), and AIDS Education for Children (1990 - 2000). From weighted data aggregated across states, we calculated annual prevalence estimates.
Results: Knowledge increased over time: the proportion reporting that persons infected with HIV can feel well and healthy increased from 72.4% to 83.0%; similarly, knowledge of the availability of drugs to treat AIDS increased from 51.6% to 57.9%. Stigma and Education for children did not change: questions indicated that many respondents would not be willing to work near a person with AIDS (annual prevalence estimates ranged from 13.9% to 18.2%), and a high proportion would not eat in a restaurant where the cook had AIDS (range: 57.0% to 64.5%). About half believed that AIDS education should begin in elementary school (range: 47.4% to 50.2%).
Conclusions: Knowledge about AIDS increased in the early 1990s, but stigmatizing beliefs about people with AIDS persisted. Many changes in the epidemic have occurred since the mid-1990s when these data were collected; thus, they are now useful as a baseline for future assessments. Items on general population surveys should be rotated periodically to assess public opinion on current developments in the epidemic, yet repeated at intervals to be able to monitor trends.

Lee R, Kochman A, et al. (2002). Internalized stigma among people living with HIV-AIDS. AIDS and Behavior 6(4): 309 - 319.

Type: Secondary analysis of sample data
Background: HIV is highly stigmatized but little research has examined the internalization of stigma by seropositive people.
Methods: Secondary analysis of baseline data from a sample of bereaved, HIV-positive men and women who had been recruited for a coping skills intervention study. Participants included 268 HIV-positive individuals, 94 women and 174 men from Milwaukee and Madison, Wisconsin, and New York City. The assessment battery was a structured clinical interview and a self-administered questionnaire. The following measures were included in the battery: demographics, current health status, Grief Reaction Index (GRI), Coping with Illness (CWI) measure, perceived social support using the Instrumental Support Evaluation List (ISEL), Functional Assessment of HIV Infection (FAHI), Structured Interview Guide for the Hamilton Depression and Anxiety Scales (SIGH-AD) and the Beck Hopelessness Scale (BHS). Data was analyzed (1) to assess the prevalence of internalized HIV stigma among men and women in the sample, (2) to identify characteristics of individuals with high and low levels of internalized HIV stigma, and (3) to examine the association between internalized HIV stigma and psychological distress while controlling for other factors.
Results/Findings: The majority of the sample experienced internalized HIV stigma related to their serostatus. Individuals who experienced high internalized HIV stigma had been diagnosed with HIV more recently, had families less accepting of their illness, were less likely to have ever attended an HIV support group, knew fewer people with HIV and were more worried about spreading their infection to others. In the sample, heterosexuals and the participants from Milwaukee and Madison, Wisconsin had higher levels of internalized HIV stigma. Internalized HIV stigma contributed significantly to depression, anxiety and hopelessness.
Conclusions: The impact of internalized HIV stigma on an individual level impacts the quality of life of HIV positive men and women. Clinicians should explore the effects of internalized HIV stigma on their clients' sense of identity, their relationships with others and their ability to manage their illness. The association found between internalized HIV stigma and spreading infection suggests that clinicians

should address communication in relationships and possible barriers to safer sex practices. Further policy and research work should address the structural, political and social processes that generate stigma.

Lemoins N (2002). Still here. (abstract no. TuPeE5111). Int Conf AIDS 14.

Type: Author abstract/community awareness project
Background: People with HIV, their caregivers and loved ones, as well as people at risk of contracting HIV often feel invisible. There has been a blitz of rosy media images of people thriving with the help of the new drug cocktails, as if HIV/AIDS had been eradicated. The reality is that people with HIV/AIDS are still struggling with the manifestations and ramifications of the disease and the complicated side effects of the new medication.
Methods: The project consists of 15 billboard sized (48"x78") postcards that were displayed on transit kiosks in San Francisco and a window front in Berkeley. Funded by both the San Francisco Arts Commission and a grant from the Portrero Nuevo fund, they went up December 1 in honor of World AIDS Day. Each postcard has a hand tinted black and white photographic portrait of a resident or art program participant of a local housing and support community for low-income people living with HIV/AIDS. Below the photo is a postcard with a message inscribed in the individual's hand about his or her experience of living with HIV. The picture and message are surrounded by an image of healthy red blood cells, and stamped with a piece of HIV related art. Two of the three artists collaborating on this project are living with AIDS.
Results/Findings: The feedback has overwhelmingly been that the visual aspect of the work, combined with the personal writings of the participants, drew people in who may or may not have had a connection to HIV. The fact that the work is not advertising, coupled with the community based 'street' availability made it even more accessible. Participants had a rare opportunity to be seen and heard creatively.
Conclusions: Involve people with HIV in projects about HIV with a prevention message, and/or to educate about life with HIV. Use art to draw people in, make connections and counter stigma. Utilize local community based and governmental funding sources and resources to make the work visible and accessible.

Lew-Ting CY, Hsu ML (2002). Pattern of responses to HIV transmission questions: rethinking HIV knowledge and its relevance to AIDS prejudice. AIDS Care 14(4): 549-57.

Type: Analysis of telephone survey data
Background: Recent studies have highlighted people's comprehension of casual contacts and false HIV transmission modes. The authors explore the impact of misinformation on HIV/AIDS prevention, specifically linking HIV transmission knowledge to prejudicial and stigmatizing attitudes towards persons with HIV/AIDS. The authors emphasize the comprehension patterns of HIV transmission that emerged from the knowledge responses.
Methods: Data was derived from the 'Health Attitudes and Health Seeking Behavior Study', a telephone survey of a nationally representative sample of persons aged 20 to 70 from April to May 1997 in Taiwan. A total of 2,471 respondents who had heard of AIDS and knew that it was infectious were included in the analysis. The HIV/AIDS items were mixed with other health-related questions and generally included HIV transmission knowledge, sources of AIDS information, attitudes towards HIV testing and persons with HIV/AIDS and safer sex behavior. Based on answers to four transmission-route items (blood transfusion, mother-fetus, sexual contacts, needle sharing) and two casual-contact items (shaking hands and sharing utensil), a variable 'pattern of knowledge performance' was constructed. Respondents were clustered into five knowledge groups: well-informed, uncertain, anxious, neglectful, or poorly-informed.
Results/Findings: Bivariate and multivariate analyses and the profile constructed by differentiating patterns of responses resulted in evidence of various degrees of discrimination against persons with HIV/AIDS. It appeared that the anxious tended to overestimate the risk of casual contacts while the neglectful and poorly-informed underestimated the risk of the true routes of HIV transmission.
Conclusions: Analysis supported the assumption that knowledge performance reflects one's risk perceptions. The authors recommend that effective AIDS prevention campaigns and interventions must communicate the harmlessness of casual contacts. They further recommend that the design for

increasing the risk perception of the correct HIV transmission routes should differ from that of reducing the risk perception of the casually transmitted routes.

Lichtenstein B, Laska MK, Clair JM (2002). Chronic sorrow in the HIV-positive patient: issues of race, gender, and social support. AIDS Patient Care STDS 16(1): 27-38.

Type: Semi-structured interviews and a quantitative measure of depression
Background: There is a high rate of depression in HIV-positive persons and several studies have highlighted the medical and psychosocial factors which may play a role. The authors used Olshansky's (1962) concept of chronic sorrow to examine the dimensions of depression and coping and the social support needs of 21 HIV-positive men and women in Birmingham, Alabama. Olshansky's definition of chronic sorrow as cyclical, pervasive and progressive is a useful framework for studying depression in persons with HIV/AIDS. The authors also used social-psychological theories of change, such as Erving Goffman's theory of discredited identity, to explore the transitions from "normal" to diseased "self" in chronically ill persons. They discuss deviance and mortality as common themes associated with depression in persons with HIV/AIDS, with stigma emerging as a gender-related factor.
Methods: The sample included 21 African American and Caucasian men and women who were HIV-positive. The combined methodology consisted of narrative interviews and a quantitative assessment of depression using the Center of Epidemiological Studies on Depression [CES-D] Scale.
Results/Findings: Two major differences, centering on stigma and social support, emerged from the interviews. More than half of the subjects scored as depressed, with African American women scoring significantly higher than Caucasian men or women. Chronic depression resulted from loss of employment, financial problems, social isolation and poor health. The women were likely to be stigmatized because they were often outsiders in AIDS networks and were also subject to stigmatizing assumptions in heterosexual communities. Most of the homosexual men were protected from the worst effects of stigma because of their ties to the gay community ("a communal self") and associated health networks.
Conclusions: Based on these preliminary findings, stigma should be considered a marker of chronic depression in HIV-positive persons and support programs should take account of social isolation and stigma. One step is to insure consideration of variables such as race, gender and parenthood in AIDS community programs. Responsive, inclusive support programs are especially important for African American men and women, who comprise the majority of HIV-positive persons in the US.

Lyon ME, Woodward K (2003). Nonstigmatizing ways to engage HIV-positive African-American teens in mental health and support services: a commentary. J Natl Med Assoc 95(3): 196-200.

Type: Hospital/clinic based model for HIV-positive African-American adolescents
Background: The authors describe a non-stigmatizing hospital/clinic based model for providing support services and for increasing medical adherence among HIV positive inner city African-American adolescents. They describe the elements of nonstigmatizing mental health interventions as: adapting elements of successful programs from the research literature, conducting focus groups with patients and their families in creating the program, consciously not labeling the patients as HIV-positive, removing practical barriers such as transportation and childcare, and creating skills-oriented, culturally-sensitive and life-affirming interventions focusing on healthy living.
Methods: The clinic-based program was designed using elements common to successful programs. Since 1988, the clinic has served more that 200 HIV-positive adolescents, of whom 94% are African American.
Results/Findings: HIV-positive inner city African-American youth can be successfully recruited and engaged in hospital based programs. The experience in this clinic suggests that targeting youth developmental issues at multiple levels is more successful than a direct approach to risk reduction, mental health treatment and medication adherence. The authors highlight the need for rigorous quantitative research to evaluate the effectiveness of such programs and to secure government funding.
Conclusions: The authors review the elements of their successful clinic-based model for providing medical and mental health services to HIV-positive African American inner city adolescents. They

highlight that research (especially specific to disease and culture) is needed to evaluate interventions to overcome the health consequences of stigma on utilization of available medical and mental health services.

Madru N (2003). Stigma and HIV: does the social response affect the natural course of the epidemic? J Assoc Nurses AIDS Care 14(5): 39-48.

Type: Review of the theory of stigma and discussion of its historical background
Background: The author examines social responses to previously stigmatized venereal diseases and compares these responses with social responses to HIV. Using Janet McGrath's theoretical framework for analysis of social responses to the natural course of infectious disease, the author analyzes the effects of the social response of stigma on HIV.
Methods: Discussion of historical context of stigma and use of Janet McGrath's theoretical framework to examine social response to HIV
Results/Findings: The author traces social responses to venereal diseases from gonorrhea and syphilis to infectious diseases such as HIV and examines prevention efforts, responses and community, legal, and religious efforts through history. She uses McGrath's theoretical framework to consider the appropriateness of the social response to the AIDS epidemic by assessing whether stigma eliminates the source of infection; eliminates adequate contact between the source of the infection and susceptible individuals; decreases infectivity of infected individuals; or decreases susceptibility of uninfected individuals.
Conclusions: Analysis of social responses to the AIDS epidemic with McGrath's framework highlights that stigma has not diminished the extent of the epidemic and in fact, has enhanced it. As the epidemic evolves, discourse is also evolving from assignment of blame to the issue of vulnerability.

Malebranche DJ, Peterson JL, et al. (2004). Race and sexual identity: perceptions about medical culture and healthcare among Black men who have sex with men. J Natl Med Assoc 96(1): 97-107.

Type: Qualitative data from focus groups
Background: Black men who have sex with men (BMSM) in the US are disproportionately affected by HIV with prevalence estimates at approximately 33%. Up to 93% of these men are unaware of their HIV status. Through data from focus groups, the authors describe the healthcare experiences including communication, trust and issues of support of BMSM and explore the social issues that influence barriers to care, communication, and adherence in medical settings.
Methods: Eight focus groups (participants n=81) in New York City and state and Atlanta, GA consisted of open-ended questions with optional probes. Participants were compensated.
Results/Findings: The study was designed to describe the healthcare experience of BMSM, the perceived influence of their race and sexuality on these experiences, perceived barriers to healthcare utilization, the quality of doctor-patient communication, and the factors affecting adherence in this population.
Conclusions: The themes of money, acquiring health insurance, perceived lack of confidentiality and an impersonal medical system were common external barriers. Internalized barriers were rooted in distrust of the medical system, fear of the health risks of being both black and homosexual, and perceiving healthcare as synonymous with receiving bad news or judgment or discrimination. Increasing the number of ethnic and sexual minority providers, expanding current definitions of cultural competency curricula at academic institutions, targeting future research efforts on BMSM, and improving the structural and communication barriers within healthcare settings should be incorporated into HIV prevention and routine healthcare interventions for BMSM to improve the quality of outpatient medical experiences for these men.

Manchester J (2002). The involvement of people with HIV: the personal is political. Int Conf AIDS 14.

Type: Author abstract/discussion of qualitative study
Background: Since the mid 1990's, a major strategy to reduce the stigma of HIV and increase the effectiveness of the response to the HIV pandemic has been to increase the visibility of people living with HIV/AIDS. It was hoped that our voices and faces would make the epidemic visible and bring about a change in people's behaviour and attitudes. The GIPA principle, (Greater Involvement of People Living with HIV/AIDS) led to a proliferation of projects and programmes that aspired to involve people living with HIV in local and national public health strategies of information, education and service provision. The involvement of people living with HIV has become an HIV and development mantra. However the perspectives of people living with HIV with regards to disclosure, empowerment and partnership have rarely been analysed and subsequently GIPA often fails to translate into practice. This study found that HIV positive people are motivated to disclose and participate for many reasons, some of which contrast with their 'partners'. HIV is an intensely personal matter, yet it is also a national and global concern, hence the personal is political. This paper, written by a co-founder of the International Community of Women Living with HIV/AIDS (ICW), explores the views and experiences of some people living openly with the virus in South Africa, Uganda and Zimbabwe.
Methods: The paper is based on a qualitative study, which was completed in October 2000, and also draws on interviews, published literature and email discussions since then. The experiences and opinions expressed are analysed through three main themes: disclosure, empowerment and partnerships. Coming to terms with a stigmatized, life-threatening disease is difficult but the interviewees reported a sense of genuine empowerment by regaining self-esteem and some control over their situation. The interviewees described the ways that they felt that they had personally benefited from being involved in HIV work.
Results/Findings: There have been many achievements but they have rarely been given the opportunity to further their own skills and personal development. Without relevant training they struggle to participate and involvement can feel like tokenism. The paper analyses what kinds of partnerships exist and highlights those which are the most successful in terms of their socio-political impact and those which give the most personal satisfaction to those involved.

Mancilla M (2002).The seroconcordant couple: the dynamics of HIV+ individuals who chose, partner or have intimate relationships with other HIV+ individuals. (abstract no. ThPeD7641). Int Conf AIDS 14.

Type: Author abstract
Background: Many HIV+ individuals are involved in relationships with another HIV+ person whether by seroconversion in an existing relationship or through active choice. The dynamics and challenges in having a successful relationship along with HIV need to be broadened. The historical parameters that focused on safer sex on one end and death/grief issues on the other don't recognize the rich middle ground of Intimacy and relationship maintenance for HIV+ individuals and couples.
Methods: Increased longevity and health for many HIV+ individuals mean they are increasingly develop their own social networks and often romantic attachments to other HIV+ Individuals. Whereas, many HIV+ individuals in the past despaired over ever having love again in their lives, new treatment choices as well as increased numbers living and loving with this disease are challenging this belief.
Results/Findings: HIV Positive status is no longer carries the same stigma it once did and many people who themselves are positive state they prefer dating, having sex or relationships with other HIV+ people. Unique responses include Positive Only Personals, parties and internet sites where issues of disclosure, discrimination or infection are minimized or not relevant in these environments. Implications for HIV prevention will also be considered when HIV+ individuals primarily freely select those within their own status as an issue of conscience, comfort and attraction. HIV cannot be spread within this construct.
Conclusions: Social outlets along with support and resources need to be strengthened, developed or duplicated for HIV+ single individuals as well as couples who share the same positive serostatus. Discussion includes how they navigate, issues from bareback sex, reinfection, variations in their own health status and the unique empathy and support they can provide one another.

Mbwambo J, Nyblade L, Mathur S, Kilonzo G, Kopoka P, MacQuarrie K (2002). Effect of stigma on the provision and utilization of health care. (abstract no. ThPpE2152). Int Conf AIDS 14.

Type: Author abstract/qualitative data
Background: HIV related stigma and the resulting discrimination is increasingly recognized as a barrier to care and treatment in sub-Saharan Africa, yet little data exists to help us address this problem.
Methods: Qualitative methods are being used in two areas in Tanzania to study the causes, manifestations, and consequences of stigma and resulting discrimination in health care and community settings. Data is being collected from the community and health care providers. A cohort of PLHA (15 men, 45 women from VCT and ANC clinic sites) is being followed for a year to document experiences with stigma and discrimination.
Results/Findings: Preliminary results confirm that a complicated mix of factors, especially stigma, impedes provision and utilization of health care. Health care workers may be reluctant to care for PLHA because they: fear infection (due to lack of knowledge and protective supplies), have judgmental attitudes about PLHA, have to decide who receives treatment in resource poor environments, experience burnout, feel hopeless, and fear secondary stigma and discrimination. PLHA may also be reluctant to access health care, for complex reasons. Some fear poor care and that in seeking health care their positive status will become known, resulting in stigma and discrimination outside the health care setting. PLHA also fear that once their families know they are HIV positive, they may be reluctant to expend scarce resources on health care. PLHA may also self-stigmatize, attributing their infection to "bad" behavior, making them less likely to access health care and support.
Conclusions: Service providers need on-going training and support to deal with providing care in a difficult work environment and opportunity to process their own issues with HIV/AIDS that may lead to stigma and discrimination within the health care system. PLHA need support to understand how stigma is affecting their utilization of health services and how to overcome this.

McGuire J (2000). Inclusion, representation, and parity: the making of a public health response to HIV in _The Emergence of AIDS. The Impact on Immunology, Microbiology and Public Health._ Washington, DC: American Public Health Association. p. 181-205.

Type: Overview of new frameworks, partnerships and roles formed by the public health response to HIV
Background: The author provides an overview of the evolution of the public health responses to HIV in the US. The discussion is framed in the CDC's planning and programmatic requirements for states and localities accessing prevention funds: "inclusion, representation, and parity." The author discusses how these philosophical and structural responses to the epidemic encompass the multifactoral challenges of AIDS.
Methods: Historical overview and literature review
Results/Findings: The new frameworks of public health practice reflect the changing nature of the epidemic as public health administration, practice and financing respond to the tripartite forces of lethality, uncertainty and stigma. In examining the responses ranging from the activism of affected communities to the multidisciplinary coalitions of practitioners and researchers, the author finds that public health has embraced the centrality of antidiscrimination in infectious disease case-finding, prevention and care; the preventive role of ecological and harm reduction theories of risk and behavior change; new models of environmental/ecological, wellness and palliative care and support for treatment adherence.
Disease surveillance, treatment and prevention efforts have fostered new partnerships between epidemiology and the law, between clinical research and primary care and between prevention and clinical services. The domain of HIV surveillance and reporting is still contested as the privacy concerns of individuals are balanced with the public health responsibility of the state related to name reporting and contact tracing. The new roles and evolving functions of peers, consumers, volunteers and the government reflect the collaborative health planning in public health arenas. The innovation and growth of public health may affect public health broadly but this legacy of HIV has yet to be realized.

Miller M, Neaigus A, Serner M, Godfrey C (2002). Nobody knows but me and God. HIV infection disclosure in an African American community. (abstract no. WePeE6451). Int Conf AIDS 14.

Type: Author abstract/qualitative data
Background: African Americans have the highest HIV and AIDS incidence in the US. Disclosure of HIV status by infected individuals may help to prevent the spread of HIV, especially in high prevalence populations. Little is known about the extent of HIV disclosure, or to whom infected individuals may disclose.
Methods: As part of a pilot study of African American women drug users and their sex partners, 8 life history interviews and 2 focus groups were conducted with HIV infected respondents in New York City, March 2000-May 2001. Discussions covered HIV testing, HIV disclosure, and sex practices.
Results/Findings: The 12 women and 6 men ranged in age from 26 to 53. All were current or former drug users, including several drug injectors; most believed they had been infected through unprotected sex. Most respondents had been HIV tested only once. Reasons for HIV testing included confirmation of suspicions of being HIV infected, testing in conjunction with other infections (e.g., TB), and being in prison. Several respondents reported traumatic disclosure experiences. Disclosure was most often restricted to family members and to sex partners with whom a serious relationship was contemplated. Several respondents had told no one. Disclosure to family members sometimes revealed an extensive network of HIV infection among close relatives who had not previously disclosed. Women were more likely to disclose to family members than men. Both men and women were reluctant to disclose to casual sex partners, with whom inconsistent condom use was common. Strategies preparatory to disclosure included assessing an individual's perceptions and thoughts about the AIDS epidemic.
Conclusions: The stigma attributed to HIV infection restricts African American drug users from disclosing their infection status. Individual strategies may be insufficient to increase disclosure. Social and societal support is needed to reduce the harmful consequences of disclosure in high prevalence areas.

Mills RG, Binder L, Bond D, Pede TD, Greer D, Hillson G, Margolese S, Rosenes R (2002). Serodiscordant relationships: talking about being positive with our negative partners or vice-versa. (abstract no. E11632). Int Conf AIDS 14.

Type: Author abstract/workshop
Background: Combination therapies and better diagnosis and treatment of opportunistic infections have improved the quality of life and the length of life for many people living with HIV/AIDS. As a result, HIV positive individuals are considering forming relationships, now that they have a more secure future. The stigma of being HIV infected is not as it once was, and negative individuals are entering into serodiscordant relationships with less fear of being left alone or burdened with excessive care giving for ill or emancipated HIV positive partners.
Methods: This workshop consists of a brief introduction followed by a workshop organized around key topics for discussion by individuals who are participating in a serodiscordant relationship or who are in the process of considering entering into a serodiscordant relationship. Individual disclosure will not be discussed but will be assumed a non-issue. Participants will be taken through such topics as: Talking about HIV, SEX: Is it still alive, just as lively or livelier?, Engaging our Partners, Supporting the Negative Partner - Feeling Safe, and Managing your Affairs. Other relevant topics for discussion may come up for consideration while completing the discussion outline.
Results/Findings: Through frank and honest discussion of the above topics and other topics that might come up, participants will recognize the solid possibility of carrying on strong and long term relationships of a serodiscordant nature. The shared discussions will lead to a better understanding by participants of common and unique challenges of being in a serodiscordant relationship.
Conclusions: Participants will be empowered to enter into, help others enter into or strengthen their own serodiscordant relationship as a result of their shared experiences.

Mischan TM (2002). Reducing stigmatization and discrimination in aging populations. (abstract no. ThPeG8276). Int Conf AIDS 14.

Type: Author abstract
Background: Due to ageist stereotypes, most local communities and planning bodies focus current care, treatment, social service, outreach and prevention programs toward younger populations and lack culturally specific and age appropriate health promotion and prevention messages towards HIV/AIDS issues in older populations. As a very clear at-risk demographic, the older populations are rarely targeted with HIV/AIDS prevention education or care and treatment information. Lack of awareness, knowledge, risk-perception and prevention education may be as instrumental in the transmission of HIV infection as additional risk factors in the older adult population.
Methods: The aging, ethnically diverse population with HIV/AIDS is increasing and living longer in urban and rural areas. They face additional challenges with multiple chronic health conditions related to disease management. Stigmatization from ageism, sexism, racism, homophobia, and poverty coupled with HIV contribute to despair, depression and complicated health care behaviors in an already vulnerable population. Community volunteers and peer support provide educational seminars, workshops and health fairs to an already largely silent invisible population.
Results/Findings: Aging and geriatric HIV/AIDS places a great demand on communities for help and social resources since most individuals delay testing and present in later stages of disease manifestation for medical care. Providing a safe, confidential, culturally and age specific environment benefits individuals and communities while improving utilization of local resources. Communication with healthcare providers, peers, and family members concerning intimate details about life presents additional barriers to testing and treatment.
Conclusions: Design, fund and implement age and culturally appropriate prevention messages, treatment services, and social services programs toward naturally aging infected and affected HIV/AIDS population.

Nakai AE, Devlin T, Davis AM, Aragon B, Rose E (2003). Storytelling for empowerment: Native American/Alaska Native community-level prevention strategies. Natl HIV Prev Conf July 2003. Atlanta, GA. (abstract no. TOP-010).

Type: Author abstract
Background: Culturally-competent prevention interventions maximize resources in rural areas through community mobilization and involvement. Setting: Rural Native American/Alaska Native Communities-Alaska, Oregon and Wisconsin. Project: Using creative approaches to prevention, Native American/ Alaska Native communities have developed culturally-competent strategies for mobilizing community members as central force in rural prevention efforts. Integrating traditional and contemporary resources, these communities have used social marketing, storytelling and media development to decrease stigma and raise awareness around the need for HIV/STD prevention. Community education forums, peer education training, and youth and elder gatherings have also supported the development of community-centered prevention networks.
Results/Findings: Programs selected for this group presentation have demonstrated success in building capacity for HIV prevention in rural communities through empowering community members to become active in the prevention efforts. The involvement of elders and cultural leaders, and the use of traditional and contemporary storytelling have been effective ways of breaking down denial, fear and stigma to mobilize Native communities to address HIV risk.
Conclusions: Lessons learned: Culturally-relevant education messages such as traditional stories and cultural teachings are effective ways of increasing awareness and support for HIV prevention in Native American/Alaska Native communities. The role of community involvement and empowerment is also a key to core mobilization and the development of wholistic prevention approaches. Community-focused prevention strategies increase the level of social capital in rural Native communities, enhancing resources available for HIV/STD prevention.

Nemoto T, Operario D, Soma T, et al. (2003). HIV risk and prevention among Asian/Pacific Islander men who have sex with men: listen to our stories. AIDS Educ Prev 15(1 Suppl A): 7-20.

Type: Qualitative data from focus groups
Background: Researchers have argued that racism and homophobia contribute to heightened health risks for men of color who have sex with men but the perspectives of Asian and Pacific Islander men who have sex with men (API MSM) are not well represented in the HIV prevention literature. The authors undertook this study to explore the psychological, social and cultural factors contributing to HIV risk and protection for API MSM. They describe culturally specific factors related to HIV risk and protection for API MSM and identify appropriate intervention strategies for this population.
Methods: In five focus groups convened over a year, API MSM (N = 38) identified psychological, social, and cultural factors related to HIV risk and protection. Focus groups were guided by nondirective open-ended questions. Six themes influencing HIV risk emerged from group discussions: (a) dual-identity status, (b) coming out and disclosure issues, (c) relationships and dating, (d) substance use, (e) sexual risk reduction strategies, and (f) health and social services.
Results/Findings: The focus groups identified a range of factors associated with HIV prevention services for API MSM. Dual ethnic and sexual identity (API and gay) emerged as a prominent issue of discussion. Other findings suggest that multilevel strategies must address the unique psychosocial and behavioral HIV risk factors among API MSM, such as dual stigma stemming from homophobia and racism, discomfort with sexuality, power dynamics and stereotypes in relationships with Caucasian men, substance use, and low utilization of health and social services.
Conclusions: To reach the diverse API community, HIV/AIDS prevention and intervention services must be culturally competent, acknowledging the roles of culture, ethnic and sexual identity, and social contexts as determinants of psychological and sexual health. This broader view of sexual health and HIV risk and vulnerability in API MSM must consider the roles of family, obligations, emotions, community, stereotypes and power dynamics in relationships.

Parker R, Aggleton P (2002). HIV/AIDS-related stigma and discrimination: a conceptual framework and an agenda for action. Washington, DC: Population Council/Horizons. 28p.
http://www.popcouncil.org/pdfs/horizons/sdcncptlfrmwrk.pdf

Type: Conceptual framework
Background: The authors propose a conceptual framework to inform thinking about the processes of stigma and discrimination, about the way these processes relate to HIV/AIDS and about potential interventions to address and minimize the impact of stigma and discrimination. They analyze the sources of stigma and discrimination, highlight the limitations of current thinking while arguing that stigma and discrimination must be understood as social rather than individual processes, and identify an agenda for research and intervention.
Conclusions: The authors propose new approaches to research, programming and interventions especially in three areas: exploratory and hypothesis-generating studies to inform investigative studies taking into account social, cultural, political and economic determinants of stigma and discrimination; investigative studies to inform policy and strategy; and strategic and policy-oriented studies to inform program implementation. In-depth research focusing on the social context rather than the behavioral and psychological dimensions of HIV/AIDS-related stigma and discrimination is encouraged.

Phillips KD, Sowell RL (2000). Hope and coping in HIV-infected African-American women of reproductive age. J Natl Black Nurses Assoc 11(2): 18-24.

Type: Author abstract/controlled experiment
Background: African-American women of reproductive age, particularly those living in the southern United States, represent a disproportionate number of women with HIV/AIDS. Often women who become infected with HIV in the South must cope not only with the disease, but with economic stresses and racial stigma as well. Faced with these changes, these women experience increased distress and loss of hope. The purpose of this study was to examine levels of hope in a group of HIV-infected African-American

women and to identify coping strategies that were associated with women maintaining a sense of hope for the future.

Methods: A descriptive design was used to test the relationships between hope and coping strategies used by HIV-infected African-American women. Reported levels of hope were significantly lower for study participants than for women with breast cancer or for hospitalized adults with cancer who were receiving chemotherapy.

Results/Findings: Statistically significant positive relationships were observed between hope and the total coping score (r = .37, p = .009) hope and managing the illness (r = .47, p = .001) and between hope and spiritual activities (r = .40, p = .004). A statistically significant negative relationship was observed between hope and avoidance coping (r = -.35, p = .009).

Pierret J (2000). Everyday life with AIDS/HIV: surveys in the social sciences. Soc Sci Med 50(11): 1589-98.

Type: Literature review and critical assessment

Background: The author reviews social science studies on persons living with HIV/AIDS using notions developed in the sociology of illness. The questions of whether the research has stimulated new questions or led to reformulations in research paradigms is examined in terms of the methodological limits encountered in collecting and analyzing data and the theoretical limits of the notions used in the research.

Methods: Review and analysis of literature

Results/Findings: The author identifies methodological issues related to data collection, specifically, the recruitment of HIV-positive participants for studies and the stance (e.g. disclosing, bearing witness, telling life stories, seeking help or counseling) they adopt during interviews. The author analyzes studies focusing on adjustment strategies and the issues of stigmatization, identity and illness trajectory. She suggests that early AIDS research focused on reactions to stigma but later research turned to strategies for managing stigma, from reactive to proactive, and studies of stigmatization as a dynamic process as a person renegotiates and redefines life during each illness phase.

Conclusions: The author raises a number about the implications of new HIV/AIDS therapies which lengthen the lives of HIV-positive persons on the field of social science research. She suggests the need for new large-scale longitudinal studies and research on sexual activity as a social activity along with continued research on the consequences of AIDS in the workplace and the family.

Piot P (2001). Stigma, bias present barriers in fight against AIDS pandemic. AIDS Policy Law 16(18): 5.

Type: News article on conference speech

Results/Findings: Speaking at the United Nations World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance (http://www.pch.gc.ca/progs/multi/wcar/event-act/wcar_e.shtml) in 2001, Dr. Peter Piot, executive director of UNAIDS, stated that discrimination takes many forms. HIV-related stigma and discrimination may include being denied access to health care services, being denied housing and employment, being turned down for health insurance or refused entry into foreign countries and in some cases, suffering physical violence and even murder. HIV/AIDS has also caused a major development crisis in sub-Saharan Africa and has impacted economic and social development in Asia, Latin America, the Caribbean and Eastern Europe. Piot said, "Combating stigma is essential to break the vicious cycle that links AIDS to poverty, racism and gender inequality."

Poindexter CC. (2004). Medical profiling: narratives of privilege, prejudice, and HIV stigma. Qual Health Res 14(4): 496-512.

Type: Qualitative interviews with HIV-affected caregivers

Background: A married couple who believe that their HIV-infected adult daughter has been victimized by medical profiling was interviewed by the author who was interested in HIV stigma. The parents believed that their daughter's gender, race, education, appearance, and socioeconomic status contributed to her

not receiving an accurate diagnosis despite repeated medical examinations. In their perception, the missed diagnosis meant that their daughter missed her chance for early intervention. The author examines in detail how these parents separately tell similar stories, probably representing the explanation they have jointly constructed to explain what they see as a failure of medicine.

Methods: Analysis of narrative interviews with caregivers of HIV –infected persons

Results/Findings: The author uses this interview as an example of stereotyping by health care professionals which can have serious consequences for HIV testing and intervention. She discusses the social construction of AIDS and the preconceived ideas, stereotypes and "otherness" which may delay testing and diagnosis.

Conclusions: The author discusses the use of such a narrative analysis within a grounded theory qualitative study. The particulars of the narrative are an example of "othering"; profiling may have delayed the daughter's HIV diagnosis and therefore endangered her life. The author suggests that HIV stigma is a double-edged sword, cutting in both directions.

Poindexter C (2000)."It don't matter what people say as long as I love you": the stigma of raising HIV-affected or HIV-infected grandchildren. (abstract no. TuOrD446). Int Conf AIDS 13.

Type: Author abstract

Background: Grandparents raising grandchildren is not a new phenomenon in the U.S.; however, it has emerged as an especially pressing problem in the HIV epidemic. Most surrogate parents for children who are orphaned by HIV are relatives over age 50. They are caring for bereaved and/or chronically ill children at a time when they had expected to be released from child rearing and when they are facing their own aging and health issues. This presentation highlights the experiences and comments of eight grandmothers in Chicago and Boston who are raising HIV-infected or HIV-affected grandchildren. Through their participation in open-ended interviews which generated qualitative data, the women articulated the impact of HIV-related stigma on their lives.

Methods: Using the framework of associative stigma, internalized stigma, and stigma management, the presenter highlights the voices of the research respondents and draws implications for gerontologists, child care workers, HIV professionals and health care providers.

Results: Findings were that disclosure, confidentiality, and trust of formal services are profound concerns for grandparents who are raising HIV-positive and HIV-affected children. Stigma has implications for the caregivers which are personal, interpersonal and socio-political. Unlike their peers who are caring for relatives with less stigmatized conditions, HIV-related elder surrogate parents are highly vulnerable to secrecy, shame, isolation, complicated grief, and stigma, which contributes to emotional stress and isolation.

Conclusions: There is a mixture of ageism and AIDS phobia which creates an atmosphere of isolation, invisibility, and discrimination for the population of HIV-affected grandparents. They are being neglected both by the Aging Service network and the AIDS Service network. In order to right this gap, practitioners, policy-makers, and researchers need to highlight the realities of HIV-affected grandmothers and help to lessen the stigma which keeps them hidden.

(2002). Population Council/Horizons Research Update. Addressing HIV/AIDS Stigma and Discrimination in a Workplace Program: Emerging Findings. Washington, DC: Population Council/Horizons. 4p. http://www.popcouncil.org/pdfs/horizons/eskombslnsum.pdf

Type: Research update on intervention study in KwaZula-Natal, South Africa

Background: The Horizons Program and ESKOM, the main South African power company, are conducting an intervention study to explore the manifestation of stigma and discrimination in the workplace, family and community; contribute to the development of appropriate quantitative measures for stigma; and inform stigma-reduction intervention activities.

Methods: A total of 379 structured interviews were conducted with workers (male) from ESKOM's field-based worksites. One female family member of most workers was also interviewed (n=351); the majority of the female participants were sexual partners of the workers.

Results/Findings: The key findings were: workers fear stigma more than discrimination in the workplace; the main manifestation of stigma is social isolation and ridicule; persons with HIV/AIDS are negatively blamed and judged for their illness; concerns about casual contact with persons with HIV/AIDS are minimal; women fear stigma more than men; stigma by association affects many groups; and stigma is associated with underuse of workplace voluntary testing and counseling and other HIV/AIDS activities.
Conclusions: Promoting workplace stigma-reduction may include training for managers, peer educators, and counselors; developing strategies to address secondary stigma; coordinating response between the community and the workplace; emphasizing couples counseling to reduce blame directed at women; and addressing both stigma and discrimination.

Porter JD, Bechhofer L, Cross P, Edmondson B (2003).Understanding the increased risk of LGBQ youth for sexual health outcomes. Natl HIV Prev Conf July 2003. Atlanta, GA. (abstract no. TP-058).

Type: Author abstract
Background: The CDC has prioritized lesbian, gay, bisexual, and questioning (LGBQ) youth as being in a high-risk situation for HIV infection. The risk for HIV infection and sexually transmitted diseases for male adolescents who have sex with other males is well-documented (Rosenberg & Biggar, 1998; Ryan and Futterman, 1998). Recent data analyses from the Massachusetts Youth Risk Behavior Survey (YRBS) indicated that male youth reporting sexual activity with both male and female partners demonstrated a consistent pattern of higher AIDS risk behaviors when compared to young. Young lesbian or bisexual women also appear to be at higher risk for unintended pregnancy (Saewyc, 1999). Understanding the increased risk of LGBQ youth for sexual health outcomes such as HIV, STDs, and unintended pregnancy is paramount in providing effective preventive services. LGBQ youth experience the same health and mental health concerns as their heterosexual peers. In addition, LGBQ youth may also be confronted with the stigma and potential isolation associated with disclosure or peer group perception of a homosexual or bisexual orientation during adolescence. For example, in research findings released from the National Longitudinal Study on Adolescent Health (Resnick et al., 1997), youth who reported same sex attraction or relationships also reported higher levels of emotional distress, greater use of marijuana, and earlier sexual debut. Additional analyses of data from the Add Health survey revealed that girls and boys who reported same-sex attraction or relationships were also at higher risk for becoming involved in a physically dangerous fight and being attacked. (Russell, Franz & Driscoll, 2001). Victimization of LGBQ adolescents appears to be an important variable in understanding associated health risk behaviors. Recent analyses of Massachusetts YRBS data found significant interaction effects between an LGBQ sexual orientation and reports of high victimization in schools related to the adolescent health risks of smoking, alcohol use, marijuana or cocaine use, and sexual risk behaviors (Bontempo & D'Augelli, 2002). Adolescence is a developmental period marked by fluidity, including sexual behavior. Although a relatively small number of small number of youth identify as lesbian, gay, or bisexual in population based adolescent samples (Remafedi, Resnick, Blum & Harris, 1992; Garofolo, Wolf & Wisslow, 1999), a larger and often non-overlapping percentage of youth report engaging in same-sex or both-sex sexual behavior (Goodenow, Netherland, & Szalcha, 2002; Robin, Brener, Donahue, Hack, Hale, Goodenow, 2002). HIV prevention programs and additional preventive health services are needed to address the specific needs of all LGBQ youth. School-based counseling, health, and mental health professionals have key roles to play in providing role-appropriate services to help reduce the risk for HIV infection and other health problems among these adolescents.
Methods: This program will provide an overview of the efforts in three states to increase the delivery of preventive health services, including HIV prevention, to LGBQ Youth: Connecticut, Delaware, and Michigan.
Results/Findings: Each of these states has had success in providing outreach to school-based and/or community-based professionals in increasing their efforts to deliver role-appropriate services and programs in risk prevention, including HIV infection, and health promotion to LGBQ adolescents.

Pulerwitz J, Stewart R, Esu-Williams E (2002). Gender-related aspects of HIV/AIDS stigma and disclosure. (abstract no. ThPeE7783). Int Conf AIDS 14.

Type: Author abstract/survey
Background: HIV/AIDS-related stigma and disclosure can manifest and impact men and women differently. As part of a larger project to improve HIV services and decrease stigma for workers of a South African power company, and members of their households, differences in perceptions and experiences were explored.
Methods: A survey addressing utilization of HIV services, HIV risk, disclosure, and stigma was administered to a census sample of 379 male workers and 351 of their female household members. The response rate for workers was 69% and for household members was 93%.
Results: Both men (58%) and women (50%) agreed that if a member of their family had HIV/AIDS, they "would want it to remain a secret." A minority of both men and women expressed stigmatizing attitudes towards people living with HIV/AIDS, such as discomfort with shaking hands of PLHA, eating from the same plate, or sharing work tools. But, men were significantly more likely to express stigmatizing attitudes than women ($p < .05$). Women (58%) were significantly more likely than men (37%) to agree that women with HIV were treated worse than men with HIV. And, women were also more likely than men to believe that if they disclosed an HIV positive status to their sexual partner, they would be abandoned ($p < .05$).
Conclusions: Both men and women have concerns about disclosing to those outside the family, but women have more fears of stigma and discrimination were they to be HIV positive than men do. In fact, men express more stigmatizing attitudes than do women. Interventions must be responsive to women's perception and their experience of additional stigma and discrimination.

Ramirez-Valles J (2002). The protective effects of community involvement for HIV risk behavior: a conceptual framework. Health Educ Res 17(4): 389-403.

Type: Conceptual framework
Background: The author presents a conceptual framework of the protective effects of community involvement in HIV/AIDS-related groups and organizations for HIV sexual risk behavior among gay and bisexual men. The framework provides specific suggestions of hypotheses, methodologies and populations for future research and provides a guide for prevention programs based on the active and direct involvement of participants, particularly communities of color. It defines community involvement as a construct encompassing type of activities, length and frequency of involvement, and the meaning participants attach to their involvement.
Results/Findings: The framework is organized according to four major paths: (1) community involvement and its moderating association on poverty, homophobia and racism and sexual risk behavior; (2) community involvement in HIV/AIDS as a means to reduce sexual risk behavior through its effects on four mediating factors (i.e. peer norms, self-efficacy, positive self-identity and alienation); (3) cultural and social-specific barriers and facilitators of community involvement (i.e. motives for participation, poverty, acculturation, stigma and perceived opportunities); and (4) burnout as a potential negative consequence of community involvement in HIV/AIDS-related organizations and groups.
Conclusion: The author presents a conceptual framework focused on community involvement as a protective factor for HIV/AIDS risk behavior. The author suggests implications of this framework for future research including how and to what extent community involvement affects individuals' health and the design of health prevention programs based on direct and active community participation. Specifically, future research should gather data from individuals with varying degrees of community involvement, should encompass longitudinal or experimental research designs and should address the group-specific variables of non-White populations.

Ramirez-Valles J, Brown AU (2003). Latinos' community involvement in HIV/AIDS: organizational and individual perspectives on volunteering. AIDS Educ Prev 15(1 Suppl A): 90-104.

Type: Qualitative survey and structured interviews
Background: Community involvement (e.g., volunteerism, activism) in HIV/AIDS was defined in this study as individuals' unpaid work on behalf of others, or for the collective good, and in the context of formal or semiformal organizations and social networks, taking place outside the home and the family. Research has shown that involvement in HIV/AIDS-related organizations may be an effective prevention strategy as individuals develop a positive sense of self, maintain HIV preventive behaviors, and create community change. The authors examined the types of activities, motives, consequences, and deterrents to community involvement among Latino gay men through both community organizations' and Latino gay men's perspectives.
Methods: The study took place in Chicago and included telephone interviews with HIV/AIDS community-based organizations (CBOs) (N = 62) and in-depth interviews with Latino gay men (n = 6 volunteers; n = 7 not volunteers). The CBOs were asked to identify their experiences with volunteers, especially Latino volunteers. Latino gay men were asked to discuss types of volunteer activities, motives, consequences (including sexual practices) and deterrents to participation.
Results/Findings: Organizations have few Latino volunteers; two organizational factors, unchallenging volunteer activities and racism, were identified as barriers to community involvement. Some individuals suggested that the Latino culture promotes informal helping behaviors, potentially more task-oriented (e.g. taking someone to the grocery store). For individuals, the deterrents to involvement are stigma of HIV/AIDS and homosexuality, racism, and apathy. On the positive side, a driving force for community involvement for individuals was increased self-esteem, a sense of empowerment, coping, reciprocity, social connection, helping others, HIV/AIDS knowledge and safer sex behaviors.
Conclusions: The study found evidence that community involvement may have positive effects on individuals' mental health and sexual risk behavior. Deterrents to community involvement may be rooted in individuals' attributes, sociocultural milieu or organizational features. Future work should include CBOs and communities as well as individuals in efforts to promote involvement. Further research may need to explore the extent to which the group identity model applies to Latino gay men.

***Reducing stigma and discrimination related to HIV and AIDS: training for health care workers. Trainer's manual and participant's handbook* (2004). New York, NY: EngenderHealth.
http://www.engenderhealth.org/res/offc/hiv/stigma/**

Reece M (2003). HIV-related mental health care: factors influencing dropout among low-income, HIV-positive individuals. AIDS Care 15(5): 707-16.

Type: Prospective data collection on mental health care for persons with HIV
Background: HIV-related mental health care can improve psychological functioning and support treatment adherence and communication with medical providers. The authors built on existing research by using a theoretical approach (the health belief model, Rosenstock, 1974) and considering HIV-specific constructs such as stigma to identify predictors of dropout and to assist the mental health clinic in developing interventions to retain clients in care.
Methods: Data was collected prospectively on 132 HIV-positive individuals presenting for mental health care at an inner-city HIV-related mental health clinic located in a large metropolitan area of the Southeastern USA. Data was analyzed to assess associations between study variables and whether participants returned for care following an initial mental health assessment. Hierarchical logistic regression analyses were conducted to determine the extent to which the addition of measures of health beliefs and HIV-related stigma enhanced the predictive capacity of a dropout model that included demographics and health status measures.
Results/Findings: Of the 132 participants, 68.2% returned for care following the mental health assessment session and 31.8% did not return for subsequent care.
Conclusions: Those who did not return for care had higher levels of perceived barriers to mental health care, higher levels of HIV-related stigma, were more likely to be of non-White ethnicity and had lower T-

cell counts. The most significant predictor of mental health care dropout was the perceived barriers construct of the health belief model. The four predictors of dropout – ethnicity, perceived barriers, HIV-related stigma and decreased T-cell count - suggest that mental health providers need to ensure that care systems are responsive to the social and cultural characteristics of HIV-positive clients who are likely to be highly disenfranchised. New insights can also be gained by the continued collaboration of academic researchers and community-based health providers.

Reeves T (2002). Who can I tell? Multi-level serostatus disclosure in urban poor families impacted by HIV/AIDS. (abstract no. ThPeF7980). Int Conf AIDS 14.

Type: Author abstract/ Child Life Program description
Background: The impact of "the secret" of HIV status in complex family structures has not been adequately addressed. Multi-level serostatus disclosure in families is a phenomenon that needs attention.
Methods: The Child Life Program works with 450 families from poor urban settings. HIV disclosure has changed dramatically in treatment rich environments for two reasons: 1) women are living longer, and 2) the successful reduction of mother to child transmission. This paper will discuss new challenges faced by families around HIV disclosure.
Results/Findings: Because of stigma around disclosure, HIV positive parents are forced to choose which children can keep "the secret" in the family and/or community. This has resulted in multi-level serostatus disclosure in families.
Conclusions: Parents require intensive education and support around the consequences of multi-level serostatus disclosure. Equally critical, families need post disclosure support to normalize the experience of HIV in the family.

Roberts MW (2003).HIV/AIDS workplace responses in action: early results of the SMARTWork six-country program. Natl HIV Prev Conf July 2003. Atlanta, GA.(abstract no. T2-E1001).

Type: Author abstract
Background: Workplace-based HIV/AIDS prevention education and care and support programs -- and policies at the national and enterprise levels -- can help reduce HIV transmission, stigma, and discrimination. Establishing effective and sustainable programs requires engaging business managers, labor representatives, and government officials -- which in itself is a challenging process.
Methods: Setting: Workplaces in six developing countries: Dominican Republic, Haiti, Nigeria, Ukraine, Vietnam, and Zimbabwe. PROJECT: The SMARTWork [Strategically Managing AIDS Responses Together] workplace program is a program of the Academy for Educational Development (AED), with funding provided by the U.S. Department of Labor, Bureau of International Labor Affairs and the U.S. Centers for Disease Control.
Results/Findings: The program is less than two years old and results are still preliminary. Early results indicate that a tripartite framework -- involving business, labor, and government -- for policy and program development can be forged, even where such relationships are novel or historically conflictual. However, creation of such a framework requires considerable time, and is likely to be delayed by political and/or economic crises. Project provided technical assistance also needs to be tailored to the cultural and workplace contexts, as well as to the evolving understanding of needs and goals of the tripartite partners.
Conclusions: Workplace-based programs and policies that are developed with meaningful involvement of business, labor, and government representatives offers greater potential for creating effective programs that reach all employees with HIV/AIDS prevention education and care and support skills than do previous workplace approaches that typically target only private sector managers.

Robinson LA (2002). Disclosure after a sibling's death from AIDS. Fam Community Health 25(1): 22-31.

Type: Semi-structured interviews
Background: Much of the research on sibling bereavement has focused on the pediatric experience, particularly on deaths from cancer. The authors describe patterns of disclosure among adults after a sibling's death from AIDS. In these cases, bereavement and loss may be complicated by AIDS stigma.
Methods: Data about AIDS disclosure was collected from a cross-sectional sample including 87 adults from separate families. Interviews with siblings of a person who had died from AIDS were audio taped and content analyzed. A taxonomy of adult disclosure emerged from analysis of the interviews.
Results/ Findings: Six categories of disclosure emerged: Purposeful, "If Asked I Tell," Selective, Protective, Restricted, and Avoidant. Categories differed across three dimensions: usual method of telling, the goal of the method of disclosure (from raising AIDS awareness to self-preservation to protecting the family) and the underlying belief about public disclosures.
Conclusions: Siblings disclose variably after their brother's or sister's death from AIDS for personal and family reasons. In bereavement contexts characterized by stigma, bereaved siblings consider many potential consequences before choosing how they will tell others that their brother or sister died from AIDS. Future research could determine whether there is a pattern of disclosure associated with positive outcomes, thereby enhancing health professionals' abilities to support the bereaved.

Santana MA, Dancy BL (2000). The stigma of being named "AIDS carriers" on Haitian-American women. Health Care Women Int 21(3): 161-71.

Type: Focus group with convenience sample
Background: AIDS-related stigma has impacted many Haitians since their identification as a high-risk group in the early days of the AIDS epidemic. This study explored the long-term effects AIDS-stigmatization has had on Haitian women living in the United States.
Methods: A pilot study was conducted in a small convenience sample of Haitian-American adult women in the Chicago area. Twenty-five Haitian women were recruited for one focus group in Chicago which lasted approximately two hours; eleven women actually attended the focus group. Research questions were: 1) in what ways has the AIDS epidemic affected the lives of Haitian-American women in the United States?; 2) in what specific situations are Haitian-American women most likely to be affected by the AIDS epidemic?; and 3) what kind of descriptive labels have been used to describe Haitians?
Results/Findings: The long-term effects of AIDS-stigmatization fell into five categories: rejection by the dominant society, self-doubt, effect on self-esteem, effect on intimate relationships, and rejection by Haitians within their community. The stigma of being named an AIDS high risk group has lingered. Stigma has a powerful impact on the psychological and social development of people. To counter the negative effects of the AIDS epidemic and the stigma particular to Haitians, intervention strategies should be developed and tested. Social policies too must reinforce the idea that individuals cannot be judged by external characteristics.

Schiff M, McKay M, et al. (2003). The role of personal contact with HIV-infected people in explaining urban, African American preadolescents' attitudes toward peers with HIV/AIDS. Am J Orthopsychiatry 73(1): 101-8.

Type: Secondary data analysis from baseline data from CHAMP Family Program
Background: This study describes African American youths' attitudes toward peers with HIV/AIDS and identifies correlates of these attitudes based on the contact theory. The study tests hypotheses of the contact theory that preadolescents' close relationships with people with HIV/AIDS will be related to positive attitudes towards peers with HIV/AIDS and that mothers' attitudes and their communication about HIV/AIDS will be related to preadolescents' positive attitudes.
Methods: The data analyzed was derived from baseline data from a sample of African American, urban mothers, and their youth (n = 197) participating in a family-based HIV prevention program.

Results/Findings: In support of contact theory, having close relationship to persons infected with HIV/AIDS was highly related to preadolescents' attitudes towards peers with AIDS. However, support from maternal authority figures, maternal attitudes or communication variables had no relation to youth attitudes.

Conclusions: This study provides useful data on a large sample of urban, African American youth and their families, a group often underrepresented in research. Future research should expand on all conditions for contact—equal group status within the situation, common goals, intergroup cooperation, and authority support—to produce positive attitudes towards peers with HIV/AIDS so that the contribution of close relationships and friendships can be accurately estimated. Other research and clinical implications include incorporating persons with HIV/AIDS into primary prevention programs, peer sharing by youth with HIV/AIDS, exploring the relation between mothers' opinions and their children's attitudes and improving communication between mothers and children.

Schulman D (2003).A new strategy to encourage more persons to be tested: referral of newly-tested HIV positive persons to legal services for counseling on protecting privacy to prevent discrimination. Natl HIV Prev Conf July 2003. Atlanta, GA. (abstract no. M2-E0202).

Type: Author abstract
Background: The CDC recently adopted a guideline in its Revised Guidelines for HIV Counseling, Testing, and Referral that recognized the role of private attorneys in changing the climate of stigma and discrimination that discourages so many people from coming forward to be tested. The CDC recommended that, "Clients who test positive should be referred to legal services as soon as possible after learning their test result for counseling on how to prevent discrimination in employment, housing, and public accommodation by only disclosing their status to those who have a need to know." (MMWR, Nov 9, 2001, 50(RR-19): 1-57, http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5019a1.htm). The Los Angeles City Attorney's Office proposed the guideline to the CDC.

Methods: The author, who drafted the proposal, will describe the HIV Legal Checkup Project of Los Angeles, which is the model for this preventive legal counseling approach, and discuss its foundations in the newly-emerging public health field of health and human rights. He will also discuss efforts around the country to develop similar projects, and ways that test clinics and prevention counselors can assist in that development.

Simmons R (2002). Towards developing a comprehensive program for effective HIV prevention among racially oppressed gay and bisexual men. (abstract no. F11865). Int Conf AIDS 14.

Type: Author abstract/ Us Helping Us program description
Background: Effective HIV prevention is difficult for black gay/bisexual men because they experience racial and social oppression. Their marginalization results in low self-esteem and a sense of isolation and powerlessness that fosters the self-devaluation of their lives and the lives of their sexual partners. Substance abuse and chronic depression are common. Such psychological and emotional trauma hinders the adoption of HIV risk reduction behaviors. An effective HIV prevention program must address their psychological and emotional state with comprehensive individual, group and community-level interventions.

Methods: Founded by black gay men, Us Helping Us (UHU) is an AIDS organization that specializes in peer-led HIV prevention programs for black gay and bisexual men. UHU offers individual, group and community-level interventions, including: HIV counseling and testing, case management, substance abuse counseling, psychotherapy, support groups, holistic health classes, spirituality workshops, anonymous HIV telephone counseling, condom distribution, and anti-homophobia social marketing. The goal of UHU is to increase HIV risk reduction behaviors and self-esteem enhancement through comprehensive support services and community building. This paper will show how each program component achieves the overall goal of HIV prevention.

Results/Findings: UHU has developed a comprehensive program that empowers gay/bisexual men by providing for their psychological and emotional needs. The UHU program provides a social support network that fosters risk reduction behavior.

Conclusions: To be effective, a HIV prevention program for black gay/bisexual men must address the psychological and emotional trauma they experience as racially and sexually oppressed minorities. Such a program must enhance the mental health of the individual, foster community building through group and community interventions, and work to reduce racism and homophobia in the society.

Surlis S, Hyde A (2001). HIV-positive patients' experiences of stigma during hospitalization. J Assoc Nurses AIDS Care 12(6): 68-77.

Type: Author abstract/data collection from sample
Background: The aim of this research study was to explore, within an Irish context, HIV-positive patients' experiences of hospitalization and particularly their experiences of nursing care. This article reports on one of the dominant themes to emerge in the study--the experience of stigma during hospitalization among persons with HIV.
Methods: A volunteer sample of 10 former inpatients of hospitals in the Republic of Ireland's capital, Dublin, was interviewed in depth, and the resulting data were analyzed using a qualitative content analysis.
Results/Findings: Findings indicate that while some participants experienced stigma from nurses, such stigma was stratified according to the means by which the disease had been contracted, with drug users expressing the greatest feelings of stigma from nurses. Data also suggest that the type of nursing care favored by many participants was that of segregated care within specialized units. This type of care was preferred because it enabled the patient to avoid being discredited by other patients who did not have the virus. This environment also offered the potential of social support from other patients with similar diagnoses. Finally, patients experienced breaches in confidentiality because of institutional policies that made their disease conspicuous and from some nurses' nonchalance in handling information about their disease. The analysis used in this study draws on Goffman's conceptualizations of stigma to explain the social process underlying the accounts given by study participants.

Swendeman DT, Comulada WS, Lee M, Rotheram-Borus MJ (2002). The impact of stigma on the adjustment of young HIV+ persons. (abstract no. ThPeE7916) Int Conf AIDS 14.

Type: Author abstract
Background: HIV is a highly stigmatized disease in the U.S. The impact of HIV related stigma can be compounded for those most likely to be infected with HIV who are also stigmatized due to their race/ethnicity, sexual orientation, and SES, or because they acquired HIV through their own risk behaviors (e.g., substance use, bartering sex). Experienced and perceived stigma are anticipated to decrease personal adjustment, influence how HIV+ persons disclose and cope with stress, and impact mental health problems, transmission behaviors and substance use.
Methods: Young HIV+ persons aged 13 to 29 (n=180) were recruited in 3 U.S. AIDS epicenters (Los Angeles, New York City, San Francisco) in 1999-2000. Youth were African American (23%), Latino (32%) or mixed race/ethnicity (25%); about 50% used hard drugs recently; most had no income; 65% were gay/bisexual.
Results: HIV+ youth who experienced more HIV related stigma were more likely to be clinically depressed and anxious, attempt suicide, be sexually abused, trade sex for money or drugs, use hard drugs, use more negative coping strategies (e.g., depression/withdrawal, non-disclosure coping, passive problem solving, self-destructive escape) and were less likely to disclose HIV status to sex partners. Gay and bisexual youth who experienced stigma related to their sexual orientation had higher emotional distress, less social support, more negative coping styles, higher lifetime drug use, higher recent jail experiences, felt poorly about their HIV status, and were less likely to disclose HIV status to sex partners.
Conclusions: Interventions must be designed and mounted to reduce stigma regarding HIV in the general population. The negative impact of stigma is clear on the HIV+ person; interventions to assist in inoculating HIV+ persons from the consequences of stigma must be implemented broadly.

Taylor B (2001). HIV, stigma and health: integration of theoretical concepts and the lived experiences of individuals. J Adv Nurs 35(5): 792-8.

Type: Literature review and discussion
Background: The author explores individual concepts of health and the role of stigma in HIV. She considers stigma and power in the context of concepts of health and health and illness behavior. The balance of power and knowledge particularly in relation to the health care setting are examined from both structural and interpersonal perspectives.
Methods: Literature review
Results/Findings: Stigma is a social construct which has significant life impact both on individuals infected with and affected by HIV. Individuals may experience differing stigma with some population groups regarded as "innocent" (e.g. hemophiliacs, infants) and others as "responsible" for their illness. Alonzo and Reynolds have suggested that stigma may also change dynamically throughout the HIV illness trajectory through phases of "at risk", "diagnosis", "latent" and "manifest". The author also explores the concepts of "felt" and "enacted" stigma in the workplace and in relation to health professionals and patients with HIV/AIDS.
Conclusions: Societal attitudes towards HIV/AIDS can stigmatize individuals, affecting their illness behavior and their perceptions of and the provision of health care they receive. Health care professionals are called on to positively affect these experiences and to engage in local and national debate to inform policy development.

Unger HV, Hunter J, Reeves T, Ehrhardt AA (2002). Stigmatization of HIV-positive mothers who have sex with women. (abstract no. ThPeE7893). Int Conf AIDS 14.

Type: Author abstract
Background: AIDS-related stigma reinforces prejudices towards marginalized groups in society and has adverse effects on service provision to people with HIV/AIDS. HIV-positive mothers who have sex with women constitute an understudied population that is prone to stigmatization on multiple grounds. This pilot study explores the impact of multiple stigmas on the interactions of these women with service providers and peers.
Methods: Semi-structured interviews were conducted with 14 key informants associated with 10 community based organizations in New York City. The sample includes service providers, HIV activists, peer educators, clients and caretakers, six of whom are HIV-positive mothers with same-sex sexual experience.
Results/Findings: Stigmatization occurs in relation to women's HIV infection, sexual relationships with women, bisexuality, race/ethnicity, drug use, incarceration and sex work experience. As HIV-positive women they are generally assumed to be heterosexual, especially since they are mothers. Those who self-identify as bisexual or lesbian often encounter sexual prejudice from service providers, family members and HIV-positive peers and are ostracized in the lesbian community. As a result, levels of secrecy, social isolation and sub-optimal service provision are high. Key informants stress the need to reduce stigmatizing and discriminatory practices to improve social service and health care provision to HIV-positive bisexual and lesbian mothers and their families.
Conclusions: HIV-positive mothers who partner with women are subject to multiple stigmas that affect service provision and further increase their social marginalization. How they experience and cope with these stigmas, especially their skills of resisting and challenging stigmatization, needs further investigation.

Valdimarsson O (2002). Working beyond borders -- lessons learned from regional anti-discrimination advocacy campaign on HIV/AIDS. (abstract no. ThPeE7919). Int Conf AIDS 14.

Type: Author abstract/regionally organized anti-discrimination campaign
Background: Though there is growing global recognition of the importance of advocacy campaigns on HIV/AIDS-related issues, reducing stigma and discrimination of People Living with HIV/AIDS (PLWHA) remains a complex task. It requires local communities to work together to overcome the sensitivities of the

issue. It also requires a multi-faceted approach to tackle its complexity. Yet, there have not been many opportunities for communities, volunteers and people from different fields of expertise to act jointly on the issue.

Methods: This paper will show how regionally organized advocacy campaign can provide opportunities to local community to act together to tackle the problems of discrimination against PLWHA. The paper will highlight the complexities and sensitivities of issues related to HIV/AIDS discrimination and stigmatization, and describe the way in which these may be overcome by promoting community participation, cooperating across borders and bringing together multi-sectored expertise beyond individual sectors. The findings are based on a regional campaign organized on the 2001 World AIDS Day in which more than 20 Red Cross/Red Crescent National Societies and branches in the Asia-Pacific region participated. 50,000 people were provided with the opportunity to attach messages of care for PLWHA to balloons that were released simultaneously throughout the region.

Results/Findings: A regionally organized HIV/AIDS anti-discrimination campaign has enabled local communities and professionals and volunteers working in the field to act together beyond physical, structural and cultural constraints.

Conclusions: The paper recommends that cross-border/cross-sectoral interventions in HIV/AIDS related work - at community, organisational and governmental levels - are an effective tool in fighting HIV/AIDS stigmatization, and in advocating for anti-discrimination activities for PLWHA.

Valdiserri RO (2002). HIV/AIDS stigma: an impediment to public health. Am J Public Health 92(3): 341-2.

Type: Editorial

Results/Findings: Dr. Valdiserri acknowledges that stigma is a complicated issue with roots in the domains of gender, race, ethnicity, class, sexuality and culture. Nevertheless, he urges the public health community to confront the impact of HIV/AIDS stigma through public education about HIV transmission, through programs that reflect the needs and preferences of the groups for whom they are intended, by examining ourselves for subtle or subliminal manifestations of stigma and finally, by supporting research in the domains of intervention, program operations and policy formulation. Dr. Valdiserri notes that the CDC's 5-year HIV Prevention Strategic Plan released in 2001 states that "stigma hampers prevention" and lists research and programmatic strategies to minimize the impact of HIV/AIDS stigma.

Vance D. (2003). Strengths and barriers in conducting research among older adults with HIV. Psychol Rep 92(3 Pt 1): 949-50.

Type: Analysis of interviews and field notes from a qualitative study

Background: Pharmaceutical advances mean that the number of aging people with HIV is increasing. There is little research on how people with this disease are aging; the author undertook the interviews to identify the strengths and barriers to studying older adults with HIV.

Methods: Twenty community-dwelling, demographically varied, older adults with HIV (average age 44.8 years) were interviewed. All had been living with HIV for an average of 10.1 years. The process included a face-to-face interview, field notes after each interview and a log of recruitment efforts. The Attitudes Towards People with HIV Questionnaire was also administered.

Results/Findings: Three research strengths were identified: professional cooperation, participants' willingness, and topic of interest. Self-selection bias, recruiting people with high HIV-related stigma, and test-savvy individuals were potential barriers to research.

Conclusions: As the number of aging persons with HIV increases, research is needed on this population. The author identified strengths and barriers to research in this group. He suggests that changing one's approach to recruitment (to avoid "test-wise" subjects or self-selection), rapport building and addressing stigma as a potential hindrance to recruitment may mitigate research barriers.

Waugh S (2003). Parental views on disclosure of diagnosis to their HIV-positive children. AIDS Care 15(2): 169-76.

Type: Analysis of interviews of 13 families
Background: Parents of HIV-positive children are known to delay disclosure of diagnosis. This study examines the concerns that parents attending a South London family clinic had about disclosure of diagnosis to school-aged children with HIV, to establish the stages they were at in terms of the disclosure process and to find out what plans they had regarding further disclosure.
Methods: Thirteen families with vertically-infected children who did not know their HIV diagnosis were included in the study. An interview covered three areas: parental perception of their child's understanding about their illness, communication in the family about illness and disclosure of diagnosis. Parent perception of the child's diagnosis was assessed suing the Understanding Illness and HIV Scale Part A.
Results/Findings: Like the findings of other studies in this field; parents in this study generally partially disclosed information about the illness without naming it and delayed full disclosure. The most frequently given reason for delay in talking to their child about HIV was fear that the child may accidentally reveal their diagnosis, thereby simultaneously revealing maternal HIV status and exposing the family to potential stigmatization, discrimination and prejudice.
Conclusions: There was a high level of parental concern about disclosure of HIV status to young children especially with regard to accidental disclosure of the diagnosis by the child. Parents wanted to delay telling their child about their diagnosis, tried to provide enough information to answer the child's questions but struggled with moving towards full disclosure. These findings highlight the need for family support through the disclosure process.

Weiss MG, Ramakrishna J (2001). Conference examines need for more study of AIDS stigma. AIDS Policy Law 16(18): 4.

No abstract available.

Winestein K (2002). "**Are You HIV Prejudiced?" - an integrated media approach to tackling stigma and discrimination associated with HIV and AIDS. (abstract no. B10329) Int Conf AIDS 14.**

Type: Author abstract/ National AIDS Trust pilot media campaign
Background: Over the last two decades HIV and AIDS has emerged as one of the most challenging public health problems in the UK. The HIV epidemic has been accompanied by intensely negative public reaction to people presumed to be living with or indeed affected by HIV and AIDS. Today, the stigma and discrimination associated with the disease is still as pervasive, impacting daily on the lives of people with HIV and AIDS and those closest to them.
Methods: This paper will demonstrate how the National AIDS Trust developed a new integrated pilot media campaign which questions a respondent's level of prejudice towards people living with HIV and AIDS. This campaign rolled out in London and Manchester during January 2002. Elements will include the evidence base, campaign interpretation, creative concepts, media implementation, PR activity, analysis of press coverage, a case study, web tracking, findings from positive people's focus groups and monitoring evaluation.
Results/Findings: The NAT initiative, although innovative, will not shift attitudes in the short term. This will take years of sustained campaigning and a much greater media spend. Partnership working across many sectors is an essential component in increasing the impact of this campaign. This partnership approach, which should include those living with HIV, needs to be encouraged and expanded.
Conclusions: The "ARE YOU HIV PREJUDICED?" campaign is an example of non-clinical AIDS awareness work that must play its part fully in a national HIV and Sexual Health Strategy. It aims to increase awareness and understanding of the impact of HIV prejudice for individuals and communities in order to increase and reinforce wider knowledge of the continuing HIV epidemic.

Worthington C, Myers T. (2003). Factors underlying anxiety in HIV testing: risk perceptions, stigma, and the patient-provider power dynamic. Qual Health Res 13(5): 636-55.

Type: Analysis of interview transcripts using a grounded theory approach
Background: Diagnostic testing often engenders client anxiety. In this study, the authors used a grounded theory approach to examine the situational and social factors underlying anxiety associated with HIV testing. They posed two research questions: what factors underlie HIV testing anxiety, and what implications do these factors have for HIV testing provision and diagnostic testing services generally?
Methods: Transcripts from semistructured interviews with 39 HIV test recipients in Ontario, Canada (selected based on HIV serostatus, risk experience, geographic region, gender, and number of HIV tests), were analyzed; emergent themes from the interviews were integrated with existing research literature. The interviews were conducted as part of the HIV Test Experience Study. A grounded theory approach was used for data analysis.
Results/Findings: Analysis of the interviews revealed four themes: perceptions of risk and responsibility for health, stigma associated with HIV, the patient-provider power dynamic, and techniques used by test recipients to enhance control in their interactions with providers.
Conclusions: The authors conclude with a discussion of service implications including modifications to information provision during the test session, attention to privacy and anonymity, and sensitivity to patient-provider interactions. The participants' anxiety related to stigma was reflected in areas they deemed important: the privacy of testing, including confidentiality, anonymity and test privacy; concern over the test provider's demeanor; behavior and understanding of the recipient's perspective; and lastly, the method of blood taking.

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