AIDS As a Moral Disease, Once Again
How Government Policies on Abstinence Promotion Teach Old-School HIV Stigma in the U.S. and Uganda
— Suzy Subways, Editor, Solidarity Project

People often talk about stigma when describing challenges in fighting HIV/AIDS. Stigma can underlie a spectrum of human rights violations—from neighborhood snubbing or family rejection to denial of medical care, to outright mob violence and murder. Suggested remedies range from what can be painstakingly slow cultural work and sensitivity training to aggressive enforcement of legal protections. But what is the solution when stigma is a top-down phenomenon?

Governments can infuse HIV stigma deeply into a nation, with cold, hard cash to back it up—operating at levels of power far above the misinformed family that sets a paper plate and plastic ware at the HIV+ person’s place-setting at holiday visits. As we arm individuals to fight stigma at the family and community level, we also need to demand that governments stop spreading stigma and start addressing its consequences.

There is now ample evidence that the funding of abstinence-only policies brings systemic promotion of HIV stigma. And the data show that abstinence-only-until-marriage programs don’t work for preventing HIV. If we can pull their massive funding—especially in the U.S. and Uganda, which are held up as models for other countries—we’ll also dismantle a powerful source of stigma and blame that hurts people living with HIV as well as members of marginalized groups like sex workers, LGBT people, and sexually active girls and women.

Under the abstinence education provision of the U.S. welfare reform law signed by President Clinton in 1996, teachers who receive the funding must say, “sexual activity outside of marriage is likely to have harmful psychological and physical effects.” The federally funded Sex Respect® curriculum teaches that “the best ways to avoid AIDS are: Remain a virgin until marriage…. Avoid homosexual behavior.” Lessons like these blame the AIDS epidemic on gay men, imply that people living with HIV got it through bad behavior, and feed into stereotypes about sexually active girls that make all young women more vulnerable to blame and coercion.
HIV stigma is built upon existing inequalities. For example, HIV positive women are often blamed for their husbands’ illness, even if they are abstinent before marriage and faithful to their husbands. “After my husband’s death, I also tested positive for HIV,” Ugandan AIDS activist Beatrice Were says. “My in-laws wanted to grab my property, take my children and marry me to my brother-in-law. Although I was still a young woman then, I struggled.” In the early 1990s, Were started the National Community of Women Living With AIDS (NCWOLA), fighting discrimination, domestic violence and marital rape. Now, as a result of U.S. policy, she says, “we are seeing a new wave of stigma through a moralization of the disease by new and radical evangelical groups.”

The U.S. Christian Right once opposed AIDS funding on the basis that the virus was a judgment from God. Now, they are reveling in hundreds of millions of HIV prevention dollars that fund them and their allies to promote that same AIDS-as-punishment message around the world—especially in Uganda. President Yoweri Museveni and his wife Janet have welcomed the influx of U.S. abstinence-only cash and changed Uganda’s HIV prevention tune accordingly. In a 2004 speech, he called AIDS “a moral problem” and said that condoms should only be for sex workers. Examined next to a 2001 statement by Peter Piot of UNAIDS that HIV stigma comes from shame because “the sex or drug injecting that transmit HIV are surrounded by taboo and moral judgment,” Museveni’s new approach appears to be a clear case of intentional stigmatization.

This stigmatization is opening the door to a new wave of HIV infection in the nation once touted for its success rolling back high HIV prevalence. In the first two years of Uganda’s new “abstinence and be faithful”—only approach, condom use declined and the HIV rate nearly doubled—from 70,000 in 2003 to 130,000 in 2005. And on December 6, Uganda’s AIDS Commission announced that the biggest proportion of those newly positive people—42%—got the virus while married. Yet young women are not warned about risks within marriage, and once they test positive, they will increasingly be treated like they have sinned.

Although Ugandan youth are at high risk for HIV, condoms are only appropriate for the orphans, internally displaced and street youth, government officials claimed in a 2005 Human Rights Watch report. But marginalized youth still don’t get adequate outreach. And LGBT communities are “erased from all HIV programs,” one activist told Human Rights Watch. Queer youth are expelled or beaten at school assemblies, and adults face imprisonment and torture.

Like Museveni’s comment that condoms are for sex workers, stigmatizing approaches say that HIV is a problem for other people—people who others should look down on and isolate in order to feel (falsely) safe. But like racism and homophobia, AIDS is a social disease, one that affects everybody—and one that we all have a responsibility to fight. That fight must include the highest levels of governments that are promoting stigma instead of promoting public health and human rights.
Clear, useful definitions of HIV stigma from Eldis

“In Their Own Words,” a horror show of what U.S. abstinence-only programs teach

The Education of Shelby Knox – a 2005 PBS docudrama about a virginity-pledging Texas girl who becomes a pro-condom sex-ed and gay-rights activist

Uganda’s HIV prevention controversy, from South Africa’s Health-e, 8/14/06:

Beatrice Were, profiled by Women’s e-news, 2/21/06:

Beatrice Were interview with UNAIDS, 11/28/06:

Pan-African Treatment Access Movement statement against abstinence-only policies, 11/30/05

“HIV, Stigma, and Rates of Infection: A Rumour Without Evidence,” PLoS 10/06. A challenge to study our assumptions that stigma hinders HIV prevention

Behind the Music: Challenging Stigma-Fueled Violence in Jamaica, and Advancing Rights Throughout the Caribbean

— Julie Davids, Executive Director, CHAMP

In November 2004, Human Rights Watch released the report Hated to Death: Homophobia, Violence and Jamaica’s HIV/AIDS Epidemic. It begins with an account of the 2004 murder of Brian Williamson, founding member of the Jamaica Forum for Lesbians, All Sexuals and Gays (J-FLAG) in his home from multiple knife wounds:

Within an hour after his body was discovered, a Human Rights Watch researcher witnessed a crowd gathered outside the crime scene. A smiling man called out, “Battyman [homosexual] he get killed!” Many others celebrated Williamson’s murder, laughing and calling out, “let’s get them one at a time,” “that’s what you get for sin,” “let’s kill all of them.” Some sang “boom bye bye,” a line from a popular Jamaican song about killing and burning gay men.

Released into an environment of overt stigma and violence against gay people and people with HIV, the report drew criticism and anger from public officials. Jamaica AIDS Support, which had started to use photographs and videotaped testimonies to document violence against their clients, needed to figure out how to not fuel the fires of controversy and instead move to dialogue on the harsh realities faced by their clients and staff. Rather than accepting requests for media interviews that they expected to be inflammatory rather than constructive, they focused on dialogue with key government and religious officials on the link between stigma and violence.
“We identified five people and arranged to have one on one meetings to talk about the reality of what was being described in the report and what we had seen over a decade of working with the communities,” explains Robert Carr, Executive Director of JAS at that time.

These meetings led to transformations. One government official who met one-on-one with a wheelchair-bound violence survivor became very helpful in getting medical records from the hospital and lodging a complaint with the public defender. A high ranking official in a powerful church committed to taking a public stand to defend the rights of lesbian and gay people and to working on his institution’s policies on people with HIV.

Although violence is still a chilling reality for people with HIV and gay men, Carr points to increased sensitivity among police charged with investigating attacks. The international Stop Murder Music coalition drew attention to the homophobia of some Jamaican performers (and while the UK-based coalition declared a truce in 2005, activists in the US have continued to work to block concerts here by performers with homophobic repertoires), and brought resources and international support to J-FLAG. However, a presentation at the MSM pre-conference prior to the International AIDS Conference in Toronto this summer, Carr stressed that the impact of the process of change will unfold over a course of years, requiring clarity about long-term vision that can’t depend on the presence or absence of donor funding.

While anti-gay violence has been its most visible edge, stigma in Jamaica and elsewhere in the Caribbean also affects people with HIV, sex workers and other marginalized people. Yet, people from the grassroots working within and across vulnerable groups did not have a forum for collaboration – a problem that hit home for Carr when he found himself to be just one of two grassroots representatives at a high-level meetings with dozens of “technical experts” on stigma and discrimination.

The Caribbean Vulnerable Communities coalition emerged as a new effort this year to link populations that share the common issue of being structurally vulnerable because of the way our societies are constructed, including inmates, sex workers, orphans and other vulnerable children, youth, men who have sex with me, substance users, and undocumented persons and refugees.

People in the United States can play two types of important roles in supporting Caribbean human rights initiatives in HIV/AIDS: taking action in solidarity with Caribbean activists, and holding our own government accountable for policies that impact their work.

“Some of the formal ways [US government policies impact the Caribbean] are issues of migration, visas and travel, as well as attitudes towards drug users,” says Carr. “There’s a lot of money pumped into anti-trafficking work and very little into harm reduction, much more support for motor boats, policemen and helicopters. We’re vulnerable to the issue of the response to sex work being overtaken by ideology that sex work is trafficking and all sex work is wrong. Those larger debates have a very strong impact on us here.”
“When we talk about removing sodomy laws or decriminalizing sex work, we get the ideological backlash from people who have been informed, if not trained, by conservative evangelical pastors and organizations [in the United States] that are feeding information to organizations here,” Carr explains. A recent consideration of a constitutional revision on privacy was attacked by a Christian group asserting that the right to privacy is about condoning homosexuality and same-sex marriage. Carr pointed to their full-page ad in major newspapers as evidence of outside finances and support.

Colin Robinson, author of *Psst. Homophobia Causes AIDS. Pass it On*, is working as a point person to link others doing work on stigma in Caribbean American communities, and can be contacted at Soucouyant@aol.com.

“It’s very helpful and important to us to have an informed grassroots support base in the United States. There are diasporan communities, people applying for asylum, colleagues in different parts of the States trying to do supportive work in the Caribbean – they need support from fellow grassroots workers in US cites,” Carr stresses. “Remember us and do not let us drop off the map.”

**Take Action**

*Stop U.S. Government-Funded HIV Stigma Worldwide*

The PATHWAY (Protection Against Transmission of HIV for Women and Youth Act of 2006) Act was introduced by Representative Barbara Lee (D-CA) in the House. It would help fix Bush’s global AIDS initiative, known as PEPFAR. It would eliminate the requirement that one-third of all prevention dollars be spent on abstinence-only programs. It would also address the real prevention needs of women and girls by helping community organizations that promote women’s rights. Check out the “Legislation and Policy” section at PEPFARWatch for more information.

*Invest in REAL Prevention Here at Home*

The REAL (Real Education About Life) Act, introduced by Rep. Lee in the House and Frank Lautenberg (D-NJ) in the Senate, would create the only federal funding stream for comprehensive sex education in schools, equipped with accurate information about their sexual health, including how to use a condom. Visit Advocates for Youth or No New Money for more information.

**What Can YOU Do?**

If you have two minutes, tell your representative to co-sponsor the PATHWAY and REAL Acts. If they’ve already signed on, thank them. Call the congressional switchboard at (202) 225-3121 or send an email through the websites listed above.

If you have 20 minutes: Speak out at a support group or staff meeting about these issues, and pass around a cell phone so everyone can call the congressional switchboard to say how they feel.
If you have an hour:

• Send a 150-words-or-less letter to the editor supporting these bills. Send copies to your representative and senators. Click here for contact information for your local media outlets.

• Meet with a program director, board member, or executive director of local AIDS Service Organization (ASO) to ask them send an organizational letter of support for both bills to Congressmember Lee’s office.

Stay involved:
• Email Health GAP and click on “Join the Health GAP Action Network” to work on global issues.
• Sign up for Advocates for Youth’s “3 Rs” (Rights, Respect, Responsibility) campaign to fight for comprehensive sex ed
• If you’re in high school, join the Youth Activist Network
• Find out what’s up with abstinence-only programs in your state.
• To attend a grassroots activist training on these issues, or to learn more about activating service organizations for advocacy, contact Sarah Howell, director of CHAMP Academy or call 401-427-2302 x 2.

Stepping Up Against Stigma

Stigma in the South: The Fight for Prevention and Care in the United States

A man dies of AIDS without ever being tested, because he prefers to die with the support of his family thinking he was dying of cancer. Others drive hours for doctor visits where nobody knows them, getting substandard care because they can’t see their own doctor during an emergency. People die on waiting lists for AIDS drugs without widespread public outcry for the state to fork over funds to provide treatment to all.

“The effect of stigma has a huge impact on who will get testing and care,” explains Robert Greenwald, director of the Treatment Access Extension Project (TAEP).

“In Massachusetts, I can tell people, ‘Get tested. Get care. We’ve created as safe an environment as possible,’” Greenwald says. “We have strict confidentiality laws, no criminalization of HIV transmission, no mandatory partner notification, and strong anti-discrimination laws.”

In other areas of the country, especially in the South, the same cannot be said – and Greenwald believes that combating stigma at the community and policy level are both important components of expanding access to care. TAEP is arming local leaders with practical strategies to organize around stigma in order to build the power to increase treatment and care. You can reach them through their website, where you can also find a state-level toolkits for fighting Medicaid cuts, get help picking a Medicare Part D plan, and more.

Here are some of the strong and growing groups standing up to stigma in the South:
**AIDS Action in Mississippi**

*Their current campaign is a fight for access to housing for people with HIV/AIDS*

Jessica Mardis: mardis@aidsactionms.org, 601-672-6574

Valencia Robinson: robinson@aidsactionms.org, 601-672-6564

**North Carolina Harm Reduction Coalition**

This state-wide coalition fights stigma against drug users, provides training on harm reduction services and strategies, and advocates for the state to allow pilot syringe exchange programs.

Thelma Wright: thelcycle@aol.com, (336) 454-5632

Les Strayhorn: lesstray@yahoo.com, (336) 586-0062

**Regional AIDS Interfaith Network (RAIN, Charlotte, NC)**

RAIN engages the religious community in conversations about HIV/AIDS, encouraging a theology of love and care for all persons and affirming their inherent worth and dignity in the face of social structures and policies that too often overlook or deny their needs.

Rev. Deborah C. Warren: d.warren@carolinarain.org, 704-372-7246

Rev. Amy E. Brooks: a.brooks@carolinarain.org, 704-372-7246

**South Carolina Campaign to End AIDS (SC-c2ea)**

SC-c2EA is demanding an end to waiting lists for AIDS drugs, as four people have already died on the ADAP waiting list this fall.

Karen Bates: scaplwa@aol.com, 803-750-5259

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**India: AIDS Activists Take on Stigma by Challenging Sodomy Law**

Imposed in 1860 under British imperialism, India’s Section 377 law criminalizes gay sex—and by extension, condom outreach to men who have sex with men (MSMs) and transgender people.

In 2001, police in the city of Lucknow raided and sealed the offices of two NGOs working on HIV interventions with MSM, and arrested four workers. They were charged with conspiring to commit "unnatural sexual acts" under Section 377, were kept in captivity for more than 45 days and were refused bail on two occasions by the lower judiciary before being granted bail by the High Court. One of the arrested was granted bail only in January 2002—more than seven months after he was arrested.

The Naz Foundation, a New Delhi-based AIDS service and advocacy organization, is challenging Section 377 with a lawsuit that has gained influential support as it winds through the courts. As police continue to harass and extort HIV prevention workers, Section 377’s state-mandated homophobic stigma keeps prevention tools away from people at high risk for HIV.

**Contact:** Kim Mulji, Executive Director, Naz Foundation UK Office: london@nfi.net, +44 (0) 20 8563 0191
Something I Never Want To Hear Again…
A Listening Exercise from CHAMP Academy

Stigma exists not just in the world outside our organizations but within them as well.

Our assumptions or lack of information about the incredibly diverse range of people and communities affected by HIV, paired with the shortage of resources that can encourage competition between groups, means that we can find ourselves promoting the stereotypes that can perpetuate the stigma we are supposed to be fighting!

Whether we are talking about “down low” men as perpetrators or “youth who think they are invulnerable” or “women in denial” or “gay men who get all the resources for their own community,” we risk making our own community members and/or our potential allies into one-dimensional cartoons, and fueling the fires of stigma that keep us divided and vulnerable.

There are training resources we can use to start to really see and hear each other, and to move forward as a diverse, united force seeking justice for all. Training for Change, a Philadelphia-based institute that has trained activists around the world, calls it direct education, and has hundreds of tools on their website.

Rather than traditional education, which gives all the expertise to textbooks and teachers, direct education invites the expertise of the people themselves. Direct education is about liberation and empowerment -- going to the direct source of wisdom: the group itself!

Direct education is rooted in experiential or popular education, started by Brazilian educator Paolo Freire -- and then adds to it.

Here is an exercise used by the CHAMP Academy, in the tradition of direct education:

What I Want You to Know, What I Never Want to Hear Again:
A Listening Exercise
Time: 60 – 120 minutes, depending on size of group

Step 1: The whole group brainstorm a list of “communities” or “groups” that they are a part of. This could include racial or ethnic identities, gender, HIV status, sexual orientation, life experiences (such as people who have been incarcerated) or other groups.

Step 2: If the list becomes long, the facilitator can work with the group to consolidate the list to a shorter list of groups that people would like to be a part of. The facilitator should point out that there is no pressure for people to restrict their lives to one identity or group, but for the purposes of the exercise, people should pick one group that they identify with.
Step 3: Participants should work for 15-30 minutes in groups of 3-8 people to focus on the following questions:

1. What do you want others to know about your group?
2. What do you never want to hear said again about your group?

One person in the group should be the notetaker. There is no need to come to consensus about the answers to the questions, but if there are several answers that really resonate with the small group, that should be emphasized.

Step 4: Each small group reports back to the whole group. At the conclusion of each small group presentation, other participants are invited to “mirror back” what the group has said. This means that they paraphrase what the group has said, not interpret what they have said or add additional questions or information. It is an invitation to show that people are listening, not to enter into a debate or dialogue.

We recommend that the facilitator set several ground rules for discussion during the report-back and after the session ends, including:

• People who are not members of a small group should limit their questions to small group members to “clarifying” questions that help them understand the group’s answer, not that challenges their answers or gives a perspective from someone who was not a member of the small group.

• Members of the small groups may not wish to discuss their answers or engage in dialogue on their answers after the session is over, so people should ask permission of each individual before assuming they would like to have further discussion of their answers.