

## **CHANGE Takes Time**

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## VIEWPOINT

# CHANGE Takes Time

The long, hard struggle to alter US policy on HIV/AIDS assistance shows that advocacy can deliver a real payoff.

BY SERRA SIPPEL

**I**n 2003, then-President George W. Bush signed into law a new measure to combat the global AIDS crisis. The President's Emergency Plan for AIDS Relief, or PEPFAR, was one of the most widely recognized accomplishments of his administration. At the dedication of his presidential library this past April, Presidents Carter, Clinton, and Obama all heaped praise on Bush for saving millions of lives in Africa.

Yet from the start, PEPFAR was saddled with funding restrictions that undermined efforts to slow the spread of HIV. Among those provisions were rules that rigidly tied funding to support for premarital sexual abstinence. For all of the good that PEPFAR has done, such restrictions have compromised the health and human rights of the law's intended beneficiaries—women and girls, in particular.

At the Center for Health and Gender Equity (CHANGE), we spent nearly a decade working to change federal law and to revise administrative policy on HIV prevention. We partnered with a broad coalition of advocacy groups—organizations that focus on AIDS research and prevention, women's health, and human rights—to push for policy changes in the face of fierce opposition. As a result of our joint advocacy, the US Congress in 2008 passed legislation that eliminated an earmark for abstinence-only programs, and in 2011 the Obama administration replaced the Bush-era abstinence policy with policy guidance that supports a wide range of measures to counter the AIDS epidemic. Today, thanks to these legislative and administrative achievements, PEPFAR funding supports prevention programs and interventions that

are based on proven best practices, a commitment to human rights, and a respect for scientific research.

Reaching that point was an extraordinary challenge. It required patience, persistence, and years of grindingly slow trench work. Change doesn't happen overnight. Flaws in PEPFAR policy that might seem self-evident on the ground in Botswana and Zambia are all too easily ignored in the power corridors of Washington, DC, where ideology often takes precedence over science and human rights. Again and again, we watched in frustration as members of Congress and other policymakers rejected science-based arguments in favor of policies that reflect narrow views of morality—views that do not accord with social reality. The struggle against such attitudes made the already Herculean effort to save lives even

more difficult. Ultimately, however, we were able to marshal evidence-based research to improve US global HIV/AIDS policy.

## GOOD PROGRAM, FLAWED POLICY

By 2003, the AIDS crisis had reached a sobering level of intensity. That year, according to the United Nations' annual AIDS report, 4.3 million people became newly infected with HIV. During that period, moreover, the patterns of infection were shifting in significant ways. In sub-Saharan Africa, AIDS was on its way to becoming a women's disease. Today, about 60 percent of people in the region infected with HIV are women. In many countries, the highest rates of new infections are among young married women and sexually active adolescent girls. Worldwide, unprotected sex accounts for 80 percent of new HIV infections.

Despite evidence of those realities, PEPFAR in its original form contained several elements that hampered prevention efforts. Most distressingly, the law included an "abstinence earmark"—a requirement that one-third of all funds allotted to preventing the sexual transmission of HIV be spent on providers that promote an abstinence-until-marriage policy. This policy became known as the ABC approach: *Abstain* until marriage. *Be faithful* in marriage. And if those steps fail, use *Condoms*.

In effect, US law promoted the erroneous assumption that sex within marriage is always safe. In fact, women from Botswana, Nigeria, Uganda, and Zambia—4 of the 15 nations designated as target countries under the PEPFAR law—have told us that they contracted HIV from their husbands. Hard evidence supports this anecdotal information: Studies show that most HIV infections acquired during heterosexual sex occur within couples who are married or living together.



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The ABC policy stigmatized the use of condoms, treating them as a last-resort option that was relevant only to those who are sexually immoral. Under the ABC model, a woman could hardly ask her husband to use a condom; doing so would be tantamount to accusing him of infidelity, or to admitting her own infidelity.

The law also included a provision that became known as “the anti-prostitution loyalty oath.” It required any organization that receives PEPFAR funds to make an explicit pledge in opposition to prostitution and sex trafficking. As a result, sex workers—a population that is at very high risk of HIV infection—often became ineligible for treatment and prevention programs.

Our best opportunity to change these policies came in 2008, when Congress was due to reauthorize the law. US Representative Tom Lantos, then chairman of the House Foreign Relations Committee, had drafted a bill that not only removed the abstinence earmark and the anti-prostitution pledge, but also added a new provision that sought to integrate family planning into HIV-prevention programs. Family planning should be an element of PEPFAR, we believe, because women who are at risk of unintended pregnancy also tend to be at risk of HIV infection. Research, moreover, shows that linking family planning to HIV interventions increases both awareness and use of HIV-prevention services.

As final debate on this bill began in early 2008, Lantos died of cancer. His death created a void that we could only partially fill. Opponents came out swinging. They accused us of “hijacking” PEPFAR to turn it into an “abortion bill.” They suggested that providing treatment for sex workers amounted to “pimping.” Our allies in Congress became skittish, and our coalition frayed. As a result, our push to include a family planning provision in the bill fell short. We also failed to make headway against the anti-prostitution rule. Still, the reauthorization bill that passed in 2008 brought a significant change to how the US government funds global HIV-prevention programs. With that law, which remains in effect today,

Congress jettisoned the abstinence-funding requirement. (PEPFAR administrators, however, must notify Congress if less than half of the money spent on HIV prevention goes to abstinence-based programs.)

The legislative struggle in 2008 set the stage for landmark policy changes under the Obama administration. In 2011, for example, the administration replaced the ABC policy with comprehensive prevention guidance. And although PEPFAR legislation remains silent on family planning, it no longer prohibits use of that policy option: US officials now have the flexibility to develop and implement PEPFAR-funded programs that combine HIV prevention with family planning measures.

#### SCIENCE-BASED STRATEGY

Achieving these policy changes required us to mount an advocacy campaign that unfolded on multiple fronts. We used old methods (a postcard campaign, a call-in day) and new ones. Our online operation made information easily accessible to activists, policymakers, and members of the public. We recruited grassroots activists in key states, and we took our campaign to political “outsiders,” encouraging them to apply pressure on lawmakers in their home districts. We built a strong coalition that encompassed groups as disparate as Planned Parenthood and the United Methodist Church. To publicize our cause, we partnered with a celebrity group that included Ed Harris, Bonnie Raitt, and Alfre Woodard.

Our most persuasive messengers were African women on whom PEPFAR had a direct impact. These women spoke at public forums and met with lawmakers in venues where they could share their personal stories. On one occasion, for example, I took an HIV-positive women's-health advocate from Botswana to meet with high-ranking members of the Senate Foreign Relations Committee. No one could have explained more passionately than she did the critical need for a comprehensive prevention program.

But the real game changer came in the form of science-based research. We pressed

lawmakers to authorize studies that would examine the effectiveness of PEPFAR. Members of Congress might reject our facts and figures, but it would be much harder for them to dismiss the findings of congressionally mandated reports. In one such report, the Government Accountability Office (GAO) concluded in 2006 that the abstinence-based funding requirement “presented challenges” for 17 of the 20 PEPFAR country teams that the GAO studied. A report by the Institute of Medicine (IOM), an arm of the National Academy of Sciences, went a step further. The authors of that report, which came out in 2007, recommended eliminating the abstinence-until-marriage funding restriction.

Subsequent research has not only supported our advocacy project, but also vindicated it. A far-reaching evaluation of PEPFAR that IOM published this past February found that recent revisions to the law had improved the effectiveness of HIV-prevention programs for people who live daily at elevated risk of the disease. The report, requested by Congress, confirmed that policy changes in Washington had substantially improved in-country programs by including more comprehensive approaches.

The elimination of the abstinence-only policy remains tenuous. That's why the latest IOM report is so crucial. We now have clear evidence that removal of the abstinence earmark and implementation of the 2011 policy guidance have given people greater access to HIV-prevention programs that meet their needs. Thanks to a rare confluence of factors, we are thus able to demonstrate the real impact of our ongoing advocacy project.

We will continue to press for changes that will make more people (including sex workers) eligible for PEPFAR programs. We will also continue to push for increased awareness of the role that family planning can play in the prevention and treatment of HIV. Meanwhile, as PEPFAR celebrates its first decade of existence, it is better equipped to stem the AIDS epidemic. The key to that outcome, we believe, has been the marriage of science-based research and rights-based health policy. ■