

Executive Summary:

Improving U.S. Global AIDS Policy for Young People

President George W. Bush introduced the President's Emergency Plan for AIDS Relief (PEPFAR) in January 2003.¹ Responding, Congress passed the *U.S. Leadership against HIV/AIDS, Tuberculosis, and Malaria Act* and authorized \$15 billion for PEPFAR over five years.² PEPFAR has made gains against HIV/AIDS, mostly by providing life-extending anti-retroviral therapy (ART) in the 15 focus countries and 100 plus other bilateral countries receiving its funds. Including young people—both infected and uninfected—as critical target groups is essential; yet, PEPFAR inadequately addresses the pandemic among youth.

PEPFAR's current authorization will expire in fiscal year (FY) 2008, and the 110th Congress has begun scrutinizing its policy structure, funding earmarks, and impact. Reauthorization offers an opportunity both to examine how PEPFAR affects youth and also to make important changes.

Why the concern about youth? Every day, more than 6,000 young people ages 14 through 24—more than two million youth each year—become infected with HIV.³ The global community, including the United States, made commitments to youth regarding the HIV/AIDS pandemic:

- ◆ By 2005, reduce HIV prevalence by 25 percent among youth ages 15 to 24 in the most affected countries; by 2010, reduce HIV prevalence 25 percent among youth worldwide.⁴
- ◆ By 2005, ensure that at least 90 percent of youth ages 15 to 24 have the information, education, and services they need to reduce vulnerability to HIV infection; by 2010, ensure access for 95 percent of the world's youth.⁵
- ◆ Expand youth-friendly, sexual health education and strengthen reproductive and sexual health programs.⁶

Unfortunately, the targets for 2005 were not achieved, and 2010's targets seem farther away than ever. Despite rapidly growing numbers of HIV infections among youth, the world community has not yet implemented effective prevention. Around the globe, the vast majority of youth have little understanding of HIV transmission or how to protect themselves against HIV infection.⁷

PEPFAR aims at large-scale, rapid impacts on HIV/AIDS in 15 focus countries where the pandemic is particularly severe: Botswana, Cote d'Ivoire, Ethiopia, Guyana, Haiti, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda, Vietnam, and Zambia.⁸ Congress set PEPFAR's goals. Commonly referred to as '2, 7, 10', they are to: provide ART to two million HIV-infected people; prevent seven million new HIV infections (60 percent of those expected in the focus countries over five years); and provide care for 10 million HIV-infected people and orphans and other vulnerable children (OVC).⁹ These goals set PEPFAR's three-pronged intervention strategy of prevention, treatment, and care. By law PEPFAR's funding priorities include: 55 percent for treatment; 15 percent for palliative care; 20 percent for prevention; and 10 percent for OVC.¹⁰

U.S. government policies severely limit PEPFAR's use of effective, science-based, public health strategies to reduce HIV transmission among youth. This report discusses three major shortcomings of policies under PEPFAR and the Office of Global AIDS Coordinator (OGAC):

- 1) Ideology trumps science in PEPFAR's HIV prevention strategy for young people.
- 2) OGAC resists linking HIV prevention with reproductive health care and services.
- 3) HIV-positive adolescents receive inadequate attention as a vulnerable population.

1) Ideology Trumps Science in HIV Prevention for Youth under PEPFAR

Public health experts have criticized PEPFAR since passage of the U.S. Leadership Act because of its requirement that 33 percent of all HIV prevention dollars be spent on abstinence-until-marriage programs.¹¹ Under OGAC's ABC Guidance, youth may receive only A and B of the ABC components—(Abstinence, Be faithful, use Condoms). In regard to HIV prevention education and services, this section identifies nine specific problems with PEPFAR's youth HIV prevention strategy:

1) *PEPFAR ignores public health science regarding effective HIV prevention strategies and programs for youth.* Extensive research and global consensus support *comprehensive* HIV prevention programs, linked with reproductive health care.^{12,13,14,15,16}

2) *The abstinence-until-marriage policy rests on four unscientific assumptions.*

- ◆ *Inaccurate assumption #1:* Delivering abstinence-until-marriage programs for youth is a proven HIV prevention strategy. *The facts:* There is *no evidence* to show that abstinence-until-marriage programs are effective.^{17,18,19}
- ◆ *Inaccurate assumption #2:* Providing young people with information about condoms will confuse youth and encourage them to have sex. *The facts:* A wealth of public health research clearly demonstrates that providing young people with complete, accurate education about condoms does *not* encourage them to have sex.^{20,21,22,23}
- ◆ *Inaccurate assumption #3:* Promoting abstinence-until-marriage will increase abstinence and will also increase secondary abstinence for those who have had sex. *The facts:* After 11 years of federal funding of domestic abstinence-only-until-marriage programs, there is no evidence that abstinence-until-marriage is effective.^{24,25,26}
- ◆ *Inaccurate assumption #4:* Marriage is a protective factor against HIV. *The facts:* UNAIDS flatly states: *Marriage on its own offers no protection against HIV for young women, especially if their husband is much older.*²⁷

3) *Segmenting the ABC approach undermines its effectiveness.* In an April 2007 report, the Institute of Medicine (IOM) said, *The Committee has been unable to find evidence for the position that abstinence can stand alone.*²⁸ ...*There is little evidence to show that ABC when separated out into its components is as effective as the comprehensive approach.*²⁹

4) *PEPFAR undercuts effective, comprehensive programs.* Under OGAC's reporting requirements, comprehensive ABC programs cannot count toward the two-thirds abstinence-only earmark.³⁰ In-country staff have reported cuts to comprehensive programs in order to meet the reporting requirements of the earmark.

5) *PEPFAR creates a culture of fear around condoms.* The Government Accountability Office (GAO) said that a lack of clarity in the ABC Guidance in regard to condom activities creates a culture of fear among PEPFAR's partners.³¹ This also runs counter to language in the U.S. Leadership Act calling for "promoting the effective use of condoms."³²

6) *PEPFAR prevents young people from learning that condoms are highly effective in preventing HIV.* PEPFAR's refusal to teach young people about the benefits of condom use implies that condoms are not effective in preventing HIV infection. Yet, the Centers for Disease Control and Prevention (CDC) asserts that condoms, when used correctly and consistently, are *highly effective* in preventing HIV transmission.³³

7) *PEPFAR ignores the local context and cultural and psychosocial factors that fuel the HIV epidemic.* Factors that underlie the pandemic include culture, poverty, and high rates of unemployment among youth. The IOM found that *all* of PEPFAR's budget allocations—not just the abstinence-until-marriage earmark—have created major challenges for country teams working to develop programs tailored to the local epidemic.³⁴

8) *PEPFAR's flawed policy creates serious problems for implementing partners and U.S. government field staff.* The GAO reported: *Lack of clarity in the ABC Guidance has created challenges for a majority of focus country teams... Ten of the 15 focus country teams cited instances where elements of the Guidance were ambiguous and confusing, leading to difficulties in its interpretation and implementation.*³⁵

9) *PEPFAR exports unsuccessful U.S. domestic programs and policies.* An AB-only strategy for preventing HIV infection among young people in PEPFAR countries is much the same as the United States' abstinence-only programs. Yet, these heavily funded domestic programs have been *unsuccessful* and should not be copied in other nations. A major review of

the research concluded, *Although it has been suggested that abstinence-only education is 100 percent effective, these studies suggest that, in actual practice, efficacy may approach zero ... 'Abstinence-only' as a basis for health policy and programs should be abandoned.*³⁶

Recommendations

For Congress

- ◆ Repeal the abstinence-until-marriage funding mandate in the U.S. Leadership Act.
- ◆ Consider IOM's recommendation to remove all PEPFAR funding mandates or, at least, make all earmarks non-binding to allow country teams flexibility to meet local needs.

For OGAC

- ◆ Revise the ABC Guidance to reflect evidence-based best practices for HIV prevention among youth. Emphasize that abstinence is the only 100 percent effective method of HIV prevention so long as it is used consistently and correctly and also ensure that young people receive: 1) age appropriate, medically accurate, complete information about condoms and other contraception; and 2) access to confidential sexual health services, including condoms. (See Table 2 for suggested revisions to the Guidance.)

2) OGAC Resists Linking HIV Prevention with Reproductive Health Care and Services

Most nations agree that linking HIV prevention with reproductive health care is crucial. UNAIDS' official HIV prevention policy states, *Both HIV and sexual and reproductive health are driven by many common root causes and stronger linkages between [HIV prevention and reproductive health education and services] will result in more relevant and cost effective programs with greater impact.*³⁷ The greatest challenge to linking reproductive health and HIV prevention is OGAC's political aversion to reproductive health care—despite the fact that HIV is mostly transmitted sexually. Linkage is most critical for youth. Young people who do not perceive themselves to be at risk of HIV may seek reproductive health care (such as contraception or diagnosis and treatment of sexually transmitted infections (STIs), giving reproductive health programs the opportunity to provide HIV prevention services as well. At the same time, voluntary counseling and testing (VCT) sites can provide reproductive health services.

PEPFAR is well-positioned to link reproductive health with HIV/AIDS services. Recently, the Center for Strategic and Intelligent Studies (CSIS) reported, *There is an increasing international consensus, including within the U.S. government, about the imperative to target women and girls ... PEPFAR is well-positioned to build on this consensus and make integration of reproductive health (RH) and family planning (FP) and HIV/AIDS services a major new priority.*³⁸ The benefits of linkage for PEPFAR include: expanding the number of entry points for people needing HIV or AIDS services; increasing efficiency and cost effectiveness of programs; addressing a shortage of health care workers; and enhancing long-term, sustainable outcomes. Because youth generally view the prevention of pregnancy and HIV/STI as two sides of the same coin, integrating information and services aligns with young people's perspectives and makes services more useful and acceptable to youth.

Separate funding streams represent a great challenge for linking reproductive health and HIV/AIDS. The limited resources available for family planning make linkage difficult. In fact, it is not easy to compare funding because PEPFAR dwarfs the resources available for family planning. Many population officers at USAID missions have shifted their work entirely to activities under PEPFAR. Others face pressure when managing both accounts due to separate funding streams and different budget cycles. Few USAID missions gained additional staff to handle the increased workload and resources generated by PEPFAR. Another problem is that priority countries for USAID's Office of Population and Reproductive Health (PRH) often differ from PEPFAR's focus countries.³⁹

Recommendations

For Congress

- ◆ Increase appropriations for family planning through USAID's Office of Population and Reproductive Health. Assert the critical need to link reproductive health to PEPFAR's programs. At a minimum, maintain current funding levels.

For OGAC

- ◆ Adopt CSIS' recommendations on integrating reproductive health care with HIV/AIDS prevention and services.
 1. Offer written instructions on the importance of integrating reproductive health with HIV/AIDS services; provide guidance on managing different funding streams.
 2. Solicit successful examples of integrated services. Document successful or innovative programs and encourage the wide sharing of this information.
 3. Support evaluation. Collect information on integrated programs in order to inform the scale-up and adaptation of effective programs.
- ◆ Improve donor coordination. Recognize that linking HIV prevention and family planning is a high priority for many bilateral and multi-lateral donors.

For Country Teams

- ◆ Prioritize grants for HIV prevention for youth to organizations with expertise in both reproductive health care and HIV prevention.

3) HIV-Positive Adolescents Receive Inadequate Attention as a Vulnerable Population

There are two groups of young people living with HIV—those infected: 1) **from their mothers** (perinatally) during pregnancy, labor, and delivery or through breastfeeding; or 2) **during adolescence** through unprotected sexual intercourse or injecting drug use (IDU). The way they were infected determines the needs of each group. Youth who were infected perinatally and who survive into adolescence usually have advanced disease and are in regular contact with a health care system.⁴⁰ In contrast, young people infected after the onset of puberty generally develop symptoms and become ill more slowly than do adults.⁴¹ This second group is much harder to identify and track. They may not seek health services regularly; may not have visited any health care provider since childhood; and may have just learned their HIV status or, more likely, remain unaware of their status.

Young people living with HIV face many challenges. A meeting on strengthening the health sector's care, support, and treatment for young people living with HIV identified major challenges facing HIV-positive youth. These include: lack of information; barriers to health care; lack of psychosocial support; problems adhering to treatment; difficulty disclosing their HIV status; stigma, discrimination, and isolation; fears about consent and confidentiality; and problems moving from pediatric to adolescent or adult care.⁴² Staff may need training in order: not to discriminate against youth; to understand that parental consent may keep youth from seeking health care; to realize that young people usually lack the means to pay for services; and to cope with youth's difficulties in adhering to treatment.⁴³

PEPFAR's response includes three major problems for HIV-positive young people.

- ◆ **HIV-positive youth are invisible in OVC policies and programs.** OGAC's *OVC Guidance* overwhelmingly assumes that most orphans and vulnerable children (OVC) are HIV-negative, an incorrect assumption. There is also a myth that most OVCs are small children although nearly half of all orphans who have lost one parent and two-thirds of those who have lost both parents are aged 12 through 17.⁴⁴ As orphans grow older, they face higher risks of acquiring STIs, including HIV, than do non-orphans.⁴⁵ Yet, *OVC Guidance* does not acknowledge orphans' age or vulnerability.⁴⁶
- ◆ **Prevention for young positives is missing.** In addressing HIV-positive youth, PEPFAR pays no attention to positive prevention—strategies to increase youth's self-esteem and confidence; to support youth in protecting their own sexual health and in avoiding infecting others; and to involve HIV-positive youth in planning and implementing HIV strategies and policies.⁴⁷ Nor does PEPFAR acknowledge that reproductive health services and comprehensive life skills education are critical for positive prevention.
- ◆ **Psychosocial support systems need far more emphasis.** Psychosocial support involves issues that “impact on the daily functioning of a young person living with HIV, both at a structural and emotional level.”⁴⁸ Structural issues include housing, nutrition, food, security, and income. Emotional issues include accepting the diagnosis, disclosing one's status, isolation, stress, facing stigma and discrimination, healthy coping, and negotiating relationships in regard to one's HIV status.⁴⁹ Psychosocial supports are critical for children moving into adolescence and for adolescents recently aware of their status.

Recommendations

For Congress

- ◆ Require OGAC to improve monitoring and evaluation of programs using more precise age data.

For OGAC

- ◆ Revise the *OVC Guidance*. The *Guidance* does not adequately recognize the increased risk OVCs face for HIV/STIs. The *Guidance* does not recognize that many OVCs may be HIV-positive. It should prioritize HIV-positive youth's need for positive prevention. [See Table 5 for suggested revisions to the current *Guidance*.]
- ◆ Encourage countries to collect age-desegregated data, based on the following age ranges: 0-9, 10-14, 15-19 and 20-24.
- ◆ Solicit examples from country teams of successful programs that link prevention and treatment for youth or that integrate separate youth-focused interventions.
- ◆ Convene a technical working group on HIV-positive adolescents. From the lessons learned at the consultation, issue new guidance on HIV-positive youth's needs.
- ◆ Invest in a center of excellence regarding HIV positive-adolescents. Support research to develop science-based best practices about serving this population.

For Country Teams

- ◆ Convene in-country consultations with implementing partners and relevant stake holders to develop strategies to address HIV-positive adolescents for the next COP cycle.
- ◆ Work with national governments to support the optional course, "*One-day Orientation on Adolescents Living with HIV*," a training for first-level facility health care workers.
- ◆ Increase funding for psychosocial interventions at treatment sites, especially for peer support groups and for training peer counselors.
- ◆ Request partners to explain how they will respond to HIV-positive youth in the next COP cycle. Begin now preparing partners to expand programs to address HIV-positive youth.
- ◆ Solicit examples from implementing partners on successful interventions reaching HIV-positive adolescents. Invest in innovative HIV testing for youth by expanding program locations beyond primary care sites.

Conclusion

PEPFAR cannot succeed without targeting youth. Yet so far, PEPFAR has largely ignored the realities of young people's lives and the state of the epidemic among them. This is the time for serious reflection on PEPFAR, a time to pay special attention to youth's need for: 1) comprehensive, science-based HIV prevention education and services; 2) linkages between HIV prevention and reproductive health care; and 3) services for HIV-infected youth and for AIDS orphans. Without serious reflection and change, current policies will hinder PEPFAR from attaining its laudable goals and will leave a generation defenseless against HIV/AIDS. Advocates for Youth urges members of Congress and staff as well as OGAC, the Administration, and colleague organizations to consider seriously the recommendations in this report and to ensure that youth are not, once again, ignored by PEPFAR.

Endnotes

1. White House. *Fact Sheet: The President's Emergency Plan for AIDS Relief*; <http://www.whitehouse.gov/news/releases/2003/01/20030129-1.html>; accessed 1/8/2007.
2. Public Law 108-25, *U.S. Leadership against HIV/AIDS, Tuberculosis, and Malaria Act of 2003*; Washington, DC: Author, 2003.
3. UNICEF (2006a). *Global Statistics*; http://www.uniteforchildren.org/knowmore/knowmore_29012.htm; accessed 3/29/2007.
4. United Nations General Assembly Special Session on HIV/AIDS. *Declaration of Commitment on HIV/AIDS [A/RES/S-25-2]* New York: United Nations, 2001, paragraph 47.
5. *Ibid.* Prevention, paragraph 53.
6. *Ibid.* Reducing vulnerability, paragraph 63.
7. UNAIDS (2006). *2006 Report on the Global AIDS Epidemic*. Geneva: Author.
8. White House, *op cit.*
9. Public Law 108-25, *op cit.* § 403.
10. *Ibid.*
11. GAO (U. S. Government Accountability Office). *Global Health: Spending Requirement Presents Challenges for Allocating Prevention Funding under the President's Emergency Plan for AIDS Relief*. [GAO-06-395] Washington, DC: Author, 2006; p.2.
12. Kirby D, et al (2005). *Impact of Sex and HIV Education Programs on Sexual Behaviors of Youth in Developing and Developed Countries* [Youth Research Working Paper, no. 2] Research Triangle Park, NC: Family Health International, YouthNet Program; p. 29-34.
13. Alford S et al. *Science and Success in Developing Countries: Holistic Programs that Work to Prevent Teen Pregnancy, HIV & Sexually Transmitted Infections*. Washington, DC: Advocates for Youth, 2005; http://www.advocatesforyouth.org/publications/sciencesuccess_developing.pdf.
14. UNAIDS (1997). *Impact of HIV and Sexual Health Education on the Sexual Behaviour of Young People: a Review Update* [Best Practice Collection, Key Material] Geneva, Switzerland: Author.
15. IOM (Institute of Medicine, 2000), Committee on HIV Prevention Strategies in the United States. *No Time to Lose: Getting More from HIV Prevention*. Washington, DC: National Academy Press.
16. Speizer I et al. *The effectiveness of adolescent reproductive health interventions in developing countries: a review of the evidence*. *Journal of Adolescent Health* 2003 22: 324-348.
17. IOM, (2007), Committee for the Evaluation of the President's Emergency Plan for AIDS Relief. *PEPFAR Implementation: Progress and Promise*. Washington, DC: National Academy Press.
18. Santelli J et al. *Abstinence and abstinence-only education: a review of U.S. policies and programs*. *Journal of Adolescent Health* 2006; 38:72-81.
19. Hauser D. *Five Years of Abstinence-only-until-Marriage Education: Assessing the Impact* [Title V State Evaluations] Washington, DC: Advocates for Youth, 2004.
20. Kirby D (2001). *Emerging Answers: Research Findings on Programs to Reduce Teen Pregnancy*. Washington, DC: National Campaign to Prevent Teen Pregnancy.
21. Baldo et al. *Does Sex Education Lead to Earlier or Increased Sexual Activity in Youth?* Presented at the International Conference on AIDS, Berlin, 6-10 June, 1993. Geneva, Switzerland: WHO, 1993.
22. Alford et al, *op cit.*
23. UNAIDS (1997), *op cit.*
24. IOM (2007), *op cit.*
25. Santelli J et al, *op cit.*
26. Hauser, *op cit.*
27. UNAIDS (2006), *op cit.* p. 18.
28. IOM (2007), *op cit.* p. 80
29. *Ibid.* p. 100.
30. GAO, *op cit.* p 38.
31. *Ibid.* p. 32.
32. Public Law 108-25, *op cit.*
33. CDC (Centers for Disease Control & Prevention). *Fact Sheet for Public Health Personnel: Male Latex Condoms and Sexually Transmitted Diseases*; <http://www.cdc.gov/nchstp/od/latex.htm>; accessed 1/16/2007.
34. IOM (2007), *op cit.* p 80.
35. GAO, *op cit.*
36. Santelli et al, *op cit.*
37. UNAIDS (2005) *Intensifying HIV Prevention: UNAIDS Policy Position Paper*. Geneva: Author; p. 28.
38. Fleischman J. *Integrating Reproductive Health and HIV/AIDS Programs: Strategic Opportunities for PEPFAR: a Report of the CSIS Task Force on HIV/AIDS*. Washington, DC: CSIS, 2006, p.23.
39. Author. Interview in Washington, DC, 2/22/2007.
40. YouthNet (2005), Family Health International. *HIV-Infected Youth: Youth Need Medical, Psychological and Social Support but Programs Rarely Address Their Specific Needs*. [Youth Lens on Reproductive Health and HIV/AIDS, no. 13] Arlington, VA: Author; . <http://www.fhi.org/NR/rdonlyres/efwnk4dpo4224lmkhiyw2jm5qpnnccqwvqc236zpz7jk6qb3p6ybilfssbpvuyysmkqga55lit642ec/YL13.pdf>; accessed 2/27/2007.
41. *Ibid.*

42. WHO/UNICEF (2006). Draft for discussion. *WHO/UNICEF Global Consultation on Strengthening the Health Sector Response to Care, Support, Treatment, and Prevention for Young People Living with HIV*, 13th to 17th November 2006, Blantyre, Malawi; p. 10.
43. Bakeera-Kitaka S. *Strengthening the health sector's capacity to meet the needs of adolescents living with HIV*. Background paper prepared for WHO/UNICEF Global Consultation on Strengthening the Health Sector Response to Care, Support, Treatment, and Prevention for Young People Living with HIV, 13th to 17th November 2006, Blantyre, Malawi.
44. UNICEF (2006b). *Africa's Orphaned and Vulnerable Generations: Children Affected by AIDS*. New York: Author, 2006; p. 6.
45. *Ibid.* p. 20.
46. OGAC (2006a). *Orphans and Other Vulnerable Children Programming Guidance for United States Government In-Country Staff and Implementing Partners*. Washington, DC: Author; p. 8.
47. Bakeera-Kitaka, *op cit.*
48. WHO/UNICEF, *op cit.* p. 22.
49. *Ibid.*

