

Better Late than Never:

**HIV Prevention Among
Young Women & Girls**



hiv law project



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HIV Law Project believes that all people deserve the same rights, including the right to live with dignity and respect, the right to be treated as equal members of society, and the right to have their basic human needs fulfilled.

These fundamental rights are elusive for many people living with HIV/AIDS. Through innovative legal services and advocacy programs, HIV Law Project fights for the rights of the most underserved people living with HIV/AIDS.





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Acknowledgements

HIV Law Project would like to thank Stephanie Morain, Columbia University Mailman School of Public Health 2009, who researched and wrote this report with guidance, input and editing from Alison Yager, Esq., Project Manager of the Center for Women & HIV Advocacy at HIV Law Project. Additional edits by Cynthia Knox, Esq., Deputy Executive Director, and Michael Pankow, Development Director.

This report was made possible, in part, by funding from the Ford Foundation and Ms. Foundation for Women.

Design by Rosa Cortez.

I. Background

At the emergence of the AIDS epidemic in the United States, the disease took its heaviest toll upon homosexual males. The pattern of infection seemed so restricted to this population that early observers of the epidemic titled the new disease as “Gay-Related Immune Disorder” or GRID. Such classification promoted recognition of the particular vulnerability of gay men to the new disease, but it also cultivated a perception of AIDS as a disease restricted to insular sub-populations and posing limited threat to the general population.¹

As the epidemic spread in the 1980s, it was often called “the 4 H disease” to describe those groups chiefly impacted: homosexuals, hemophiliacs, heroin users, and Haitians. Even as women were infected, many experts were reluctant to recognize the potential for heterosexual transmission of the virus.

“The African AIDS epidemic (among heterosexuals) is devastating. But it is uniquely African. We can no more deduce transmission patterns in the United States from Africa than we can assume that because Africans suffer periodic famine, we will too.”

Michael Fumento, 1987 (author of *The Myth of Heterosexual AIDS*, 1993)

When confronted with evidence of heterosexual transmission from the rising rates of HIV/AIDS in Africa, AIDS deniers attributed such rates to “deviant” acts such as hidden homosexuality or to the “brutality” of heterosexual sex in African countries, likening such sexual acts as more akin to rape than to consensual sex as practiced in the United States.

While the legacy of GRID and 4 H is still painfully visible in the disproportionate disease burden borne along lines of sexual orientation and race today, it is also still evident in the ongoing failure to recognize the risk HIV/AIDS poses to women, particularly from heterosexual intercourse. The tendency to identify and classify individuals for testing and prevention services based on known risk activity has resulted in inadequate recognition of the growing burden of HIV/AIDS among females.

II. A Changing Epidemic

Women account for a steadily rising proportion of new AIDS diagnoses. In 1985, women comprised only 8% of new AIDS cases. (Unless otherwise stated, all statistics are for the United States.) By 2000, this number had peaked at 27% (2006 levels remained the same).² Fueling this growth in HIV/AIDS among women is a dramatic rise in infections among young women. In New York State, females accounted for 48% of 13 to 19 year olds diagnosed with HIV from 2001 to 2003.³ This tremendous increase in the proportion of HIV/AIDS cases diagnosed among young women may serve as an indication of the future trajectory of the epidemic unless aggressive prevention efforts can slow this trend.

The rising number of HIV/AIDS cases among young women demands a reassessment of fundamental assumptions about HIV/AIDS and its transmission patterns. While traditional focus has emphasized the risk for homosexual men and intravenous (IV) drug users, in 2006 a shocking 86% of females diagnosed between the ages of 13 and 19 were infected via heterosexual intercourse.⁴ Traditional risk classification systems that target homosexuals, IV drug users, or those who engage in “high risk heterosexual contact” fail to address the HIV risk for all young women. Such risk classification

systems promote the inaccurate assumption that risk can be “known.”

While many young women do not have clearly identified risk factors, they are, in fact, at risk. Many young people have had numerous sexual partners, with 18% of males in high school reporting that they have had four or more sexual partners.⁵ A sexual history, whether in the context of a casual or a long-term relationship, always carries potential risk. In essence, risk categorization which for women depends on perfect knowledge of their partners’ past and present behaviors (or possibly their HIV status at birth), is inherently flawed. Reliance on such a system too often leads women and their providers to wrongly assume no risk, when in fact the level of risk is unknown and unknowable.

The emphasis on outdated risk classification systems prevents young women from accurately assessing their risk. Even more disconcerting, such emphasis promotes the persistence of the paradigm within the medical community that females who do not participate in “high-risk” activities, are not at-risk of contracting HIV. This increasingly inaccurate construction blinds medical practitioners from the universality of HIV risk, and impedes their ability to support prevention efforts for young women and others who fall outside of the traditional “high-risk” populations. To effectively combat HIV/AIDS among women in the United States, we must address the growing disease burden upon those who fall outside the traditional risk classification model, particularly young women.

III. Composite Burdens

The highest rates of HIV transmission in young women are among those who bear the composite burdens of race, age, gender, and class — those who are already marginalized by society. African-Americans comprise only 13% of the female adult and adolescent population, yet account for 65%

of all HIV/AIDS cases in women.⁶ Further, black women are 21 times more likely to have AIDS than white women (40.4 cases per 100,000, as compared with 1.9 cases per 100,000).⁷

Several factors contribute to disproportionately high rates of HIV among racial and ethnic minorities. Individuals in minority communities tend to face more barriers in accessing health care than their white counterparts.⁸ They also receive less instruction on birth control methods before initiation of sexual activity,⁹ experience higher rates of poverty, and typically socialize in communities with higher rates of HIV.

“Race and ethnicity are not, themselves, HIV risk factors, but correlate with other more fundamental determinants of health status such as poverty, access to quality health care, health care seeking behavior, illicit drug use and living in communities with high prevalence of HIV and other sexually transmitted diseases.”

Centers for Disease Control and Prevention, *On the Front Lines: Fighting HIV/AIDS in African-American Communities*. August 1999.

Gender-related violence and coercion also place young women at risk, preventing them from negotiating safer sex practices or delaying initiation of sexual activity.¹⁰ HIV-related stigma and violence further compounds these risks, subjecting women to fear of violence upon receiving an HIV diagnosis.

IV. Why at Risk?

Young women are at risk for HIV/AIDS due to a host of biological, cultural, and socioeconomic factors.

Biologically, women are anywhere from 2 to 4 times more likely than men to contract HIV from unprotected sexual intercourse. Younger women (those under 25) are particularly susceptible to HIV infection due to incomplete development of their vaginal tract that leaves them more prone to infection than older females. Furthermore, the presence of other sexually transmitted infections (STIs) greatly compounds the risk for young women by increasing biological susceptibility to HIV.

Given the shocking estimates from the Centers for Disease Control and Prevention (CDC) that as many as 25% of adolescent females are infected with at least one STI (with estimates reaching as high as 48% among young African-American women),¹¹ the risk of HIV infection to this population may be far greater than previously recognized.

Young women are also at greater risk due to social and cultural tendencies that create unequal power dynamics between them and their male sexual partners. Women's behavior, particularly in sexual negotiation, is greatly influenced by traditional gender norms and cultural expectations. While men are commonly expected to be aggressive and confident, women are expected to be passive, even naïve. Such unequal power dynamics challenge the ability of women to protect themselves from HIV infection through negotiations for safer sex practices such as condom use, demanding fidelity, or refusing or delaying sexual activity.¹²

Because of this gender inequality, nearly 20% of young women do not know that they have "the right to refuse sexual intercourse, to ask their partner if he has been examined for an STI, or to say when

their partner is being too rough."¹³ African-American and Latina women in particular, and younger girls in general are the least likely to be aware of their sexual rights.¹⁴

This power dynamic, often resulting in the failure to use condoms, is exaggerated when young women date older men. One survey found that a quarter of sexually active girls, aged 15 to 19, were four or more years younger than their first sexual partners.¹⁵ Teenage girls with older male partners are more likely to be sexually active, and less likely to use contraceptives.¹⁶

Consistent safer sex practices such as condom use can significantly reduce the risk of transmission of HIV/AIDS. But condoms are only effective if used correctly and consistently. Only 57% of 15 to 17 year old females report using a condom every time during sexual intercourse.¹⁷ Several negative perceptions regarding condoms contribute to this problem.

Condoms are viewed as decreasing sexual pleasure, particularly for men, as well as decreasing intimacy. Furthermore, teenagers report viewing condoms, and those who request their use, with suspicion: "66 percent of teens said they would feel suspicious or worried about their partner's past, if the partner suggested using a condom; 49 percent would worry that the partner was suspicious of them; 20 percent would feel insulted."¹⁸ In other words, condoms have become nearly synonymous with infection and requesting condom use tantamount to alleging or admitting infection.

V. Rising to the Challenge: Recommendations

There are several steps that can and should be taken immediately to address the rising rate of HIV/AIDS among young women.

Routinize HIV/AIDS prevention efforts in health care settings

Current data demonstrates that, even for those adolescents lucky enough to access it, routine primary care is often a missed opportunity for HIV prevention efforts. CDC researchers found that of the 38% of women “who reported receiving contraceptive services associated with having unprotected sex (e.g., pregnancy testing or a prescription for emergency contraception), only slightly more than one-third of them (38%) received STD/HIV services.”¹⁹ In effect, healthcare providers are failing to offer necessary STD/HIV counseling, testing, or treatment to over 60% of those young, female patients who are engaging in unprotected sex.

Adolescent health care providers should make a practice of discussing sexual and reproductive health with their young patients, and should create an environment where young women feel safe and respected. Providers should discuss HIV risk reduction and endorse testing with all their patients, regardless of perceived risk. This will ensure that young women who are HIV-positive will know their status. In turn, they can take measures both to promote their own health through earlier initiation of treatment, and to protect others from future transmission risks. For young women who are not yet sexually active, a discussion of HIV and sexual health with a health care practitioner “provides an opportunity to talk about sexual readiness, delaying intercourse, and low-risk ways to explore intimacy.”²⁰

Increase access to routine preventative care

Many young women in this country do not receive regular preventative care services. Adolescents are the population least likely to be insured in this nation, hindering access to regular primary and gynecological care.²¹ Additionally, women are less likely to be covered by private insurance than their male counterparts, and are thus more likely to be dependent upon Medicaid services,²² which tend to have far greater restrictions upon sexual and reproductive health care access.²³ Ensuring access to regular primary care services is essential to the protection and promotion of the health of young women.

Regular, preventative medical care is one avenue by which young women should receive the tools and support they need to protect themselves from HIV and from other STIs which can increase their risk of acquiring HIV.

Unfortunately, many young women are not receiving regular preventative care in the form of annual physicals, routine screening, and gynecological care to promote and protect their sexual health and general well-being. As discussed earlier, one in four young women between the ages of fourteen and nineteen has a sexually transmitted infection (with rates in some subpopulations as high as 48%). Such infections, including chlamydia, HPV, herpes, and trichomoniasis, place women at a higher risk of infection by HIV/AIDS, as well as subject them to a host of other serious potential complications, including cervical cancer, ectopic pregnancy and miscarriage, and even permanent infertility, particularly if they are left untreated. Guaranteeing young women have access to regular preventative care with comprehensive sexual health screenings can help to arm them with prevention strategies to reduce the risk of transmission of HIV and other STIs, as well as reduce the rates of unwanted pregnancies.

Increase access to routine testing: mobilizing existing resources

One of the most effective, inexpensive, and empowering means to reduce the burden and transmission of HIV is to ensure individuals are aware of their HIV status. The routine offer of HIV testing can enable those infected to receive timely treatment and can help to minimize the risk of transmission to others.

Yet, only 27% of sexually active teens have ever received an HIV test. In other words, 73% of sexually active teens have never been tested for HIV. Over half of teens (52%) do not even know where to get an HIV test.²⁴ Efforts should be made to promote both access to and knowledge of HIV testing sites for adolescents. Further, testing sites must cultivate environments where adolescents feel safe and respected.

Critical elements for the delivery of youth-friendly prevention services include: providing spaces in which young people feel comfortable, staff who are experienced with adolescents, flexible hours that accommodate the demands of schoolwork and family commitments, and explicit guarantees of confidentiality to the extent allowed by law.

With effective integration efforts, existing resources can be mobilized to increase young people's access to routine testing. A broad array of programs and initiatives has been developed toward this end. Promising models come from collaborations between public health entities and the entertainment and communications industries (see below, Learning from Abroad: The eQuest Success).

Given young people's significant media consumption, these sectors are well positioned to support youth-oriented and culturally relevant prevention and testing campaigns. Additionally, they hold the power to normalize testing and to lift the stigma associated with testing and infection.

The recent **KNOW HIV/AIDS** public education campaign sponsored by CBS Corporation, Viacom, and the Kaiser Family Foundation sought to increase testing service utilization among youth, minorities, and men who have sex with men. In a multi-year initiative launched in 2003, the campaign has tackled the issue of HIV-related stigma through a variety of public service announcements, including print, outdoor, radio, television, and internet media sources to provide information on prevention and testing. Such messages were often enhanced through the use of cultural icons that resonate with the target population, such as hip-hop artists and fashion designers.²⁵ This collaboration offers an exemplary model for public education partnerships to fight the rising tide of HIV infections among youth. The campaign demonstrates the effectiveness of media partnerships in promoting prevention or testing messages.

Similarly, mass text-messaging is a strategy which has been effective in supporting a variety of public health messages, from smoking cessation to HIV testing and medication adherence. Public/private partnerships with culturally relevant celebrities and media have the potential to reach a young audience which has traditionally been peripheral to public testing campaigns.²⁶

While youth-focused messaging offered through age-appropriate means and media can decrease the stigma of testing and increase awareness, such messaging is only effective if it links youth to testing centers that are easily accessible and youth-friendly.

Learning from Abroad:

The eQuest Success

A 2005 program in Kenya demonstrates the tremendous potential for the use of culturally relevant media in HIV prevention. Funded by Vodaphone and the Elton John AIDS foundation, the program, known as eQuest, promoted awareness of HIV risk to adolescents through a nationwide text-messaging campaign.

To encourage adolescents to actively seek more information, the service texted questions on HIV/AIDS to teens around the country. Teens then could reference the special eQuest educational column in the newspaper and text back answers for a chance to win prizes. Driven by promotion featuring top musicians, the program succeeded in reaching 20,000 adolescents in only 2 months.

Family planning and reproductive health centers are an underutilized resource in the fight against HIV/AIDS in young women. While an impressive 82% of young women are receiving family planning services or STI/HIV services, only 39% are receiving both.²⁷ The failure to provide regular HIV testing and prevention services during routine gynecologic care and pregnancy prevention services represents a missed opportunity to protect the lives of young women. Improving the integration of sexual and reproductive health services would not only increase regular HIV testing, but would also enhance prevention efforts aimed at reducing HIV infection, STIs, and unwanted pregnancies through promoting regular condom use and teaching condom negotiation strategies.

Promote universal access to HIV treatment

In the United States, we have the medical capability to ensure that an HIV diagnosis is no longer a death sentence. Drugs and treatments that are presently available have

the power to make HIV/AIDS a manageable illness. However early detection of the disease and early treatment are critical to successful disease management.

Despite public efforts to ensure widespread access to treatment, many HIV-positive women are still unable to receive adequate medical treatment. This failure harms the women who go without comprehensive or top-quality treatment, but it has an additional, unanticipated impact. Our systemic inability to treat everyone in need of treatment functions as a disincentive to regular testing, since young women may be reluctant to know their status if they believe that necessary care and treatment may be inaccessible. Ensuring universal treatment of HIV/AIDS within the paradigm of chronic illness management can help overcome this disincentive to testing. Universal treatment thus promotes the health of those infected and reduces the risk of future transmission.

Unfortunately, HIV-positive young women often face many obstacles in accessing supportive treatment. In addition to the burden of lack of health insurance coverage discussed earlier, young women face particular barriers in accessing health care. HIV-positive women often report the dual barriers of provider insensitivity and lack of provider knowledge or experience in treating female HIV/AIDS patients.²⁸

Furthermore, HIV-positive women often have several competing factors or priorities that can inhibit regular treatment, including the need to provide for themselves and their families, most acutely felt by those women leading single parent households. Such competing priorities are magnified by the particular challenges faced by adolescents, including the reluctance to disclose status to family members, for whom a disclosure of HIV-positive status may also be a disclosure of sexual activity, or to friends, given the increased burden of stigma from infection and the risk of isolation from peer groups.²⁹

Promote comprehensive sex education

Comprehensive sex education has great potential to influence safer sexual behavior among youth and reduce the risk of HIV transmission. While awareness is rising of young women's risk of HIV infection, many young women still lack both the knowledge and the ability to minimize this risk. Prevention is not possible without knowledge of risk and appropriate risk-reduction strategies.

The rising rates of sexually transmitted infections among young women demonstrate that young women either do not have the information they need to properly protect themselves, or else do not have the skills, the confidence, or the motivation to implement the necessary risk-reduction strategies.

Unfortunately, recent history indicates that young women are becoming less able to protect themselves due to a failure of school systems to provide comprehensive sexuality education services. In 2006, only 38.5% of high schools provided students with information regarding proper condom use,³⁰ a decrease from 2000 when 55.1% of high schools provided this information.³¹

Young women need information regarding prevention of HIV to empower themselves to make healthy decisions: practicing abstinence, delaying sexual activity, and employing safer sex techniques can all help to reverse the growing incidence of HIV/AIDS among young women.

Further, young women must be provided not only with information, but also with the skills to put this information to use. The most effective prevention programs aim not only to increase awareness of risk, but also provide individuals with the capacity to effect behavior change. For HIV prevention programs, this means providing young women not only with access to condoms

and knowledge of their proper use, but also the skills to negotiate condom use with their partners. To achieve comprehensive sex education programs that fully address the needs of young women, we must ensure that they are empowered to act upon their knowledge. As 65% of high-school students will be sexually active by 12th grade (with more than one in five having had four or more sexual partners),³² educational programming must provide a range of prevention options to address the needs of both abstinent and sexually active young women.

Learning From Abroad:

Lessons from European Success

Rates of HIV and STIs among adolescents in the U.S. are up to six times higher than those of their counterparts in many Western European countries. U.S. teens also have higher rates of unintended pregnancies and abortions and earlier initiation of sexual activity. Such differences can be attributed to the success of several programs in Europe, including:

- Comprehensive sexual education programs
- More universal access to regular preventative care
- Easier access to sexual and reproductive health information and services
- Improved access to contraceptives
- Recognizing adolescent sexuality as a normal part of development

(See generally, "Adolescent Sexual Health in Europe and the U.S.—Why the Difference?" Advocates for Youth, October 2001).

Schools must provide young women with the full range of means to protect themselves against the rising tide of this epidemic, and the federal government and the states must ensure that schools are able to do so. Funding for abstinence-only

programming, which has been proven ineffective,³³ must be eliminated, and replaced with funds for comprehensive sexuality education.

Effective training of teachers is also essential for this goal of protection: if teachers are not well-trained, young women will not receive the information necessary to preserve their health. Again, recent trends are disturbing: while 96% of states provided funding for or offered staff development on HIV prevention to health educators in 2000, only 84% did so in 2006.³⁴ We must immediately reverse this trend of cutting resources to health educators.

Educators can play a vital role in decreasing transmission of HIV, but only if they are given the right tools to do so.

Increase access to condoms

Knowledge of HIV prevention strategies such as condom use and negotiation is vital, but young women cannot translate knowledge into effective action if condoms are not easily accessible. Nonetheless, many young women still face logistical or financial barriers to obtaining condoms because of inadequate access, high cost, or discomfort.

Purchasing condoms can be prohibitively uncomfortable for young women. More than 1 in 4 (27%) adolescent females report experiencing resistance or condemnation from clerks during attempts to purchase condoms— a rate far higher than that experienced by adolescent males (10%).³⁵ Alternative means of condom distribution are needed to ensure lack of access does not serve as a barrier to regular condom use.

One alternative distribution method with demonstrated success in reducing the social, financial, and logistical barriers of condom access for sexually active teens is the use of low- or no-cost condom availability programs in youth-friendly

settings. School-based condom availability programs have consistently been demonstrated to increase condom use among sexually active teens without increasing promiscuity or encouraging earlier initiation of sexual activity.³⁶

Increase access to and knowledge of female condoms

Increasing availability of and knowledge about female condoms can provide an additional means for young women to practice safe sex. Numerous studies have demonstrated that female condoms are an effective alternative to male condoms in preventing pregnancy and the transmission of HIV and other STIs. In a study of clients at STI clinics in the United States, women offered the female condom were three times less likely to engage in unprotected sexual acts than the control group.³⁷

As female condoms can be inserted by the female up to eight hours prior to sexual intercourse, without needing permission or cooperation from a male partner, female condoms are particularly useful for women who are unwilling or unable to negotiate with their partners regarding male condom use. This feature has contributed to an “empowerment effect” among women who receive counseling on the use of female condoms.³⁸ According to the World Health Organization, “(t)he female condom has been shown to contribute to women’s sense of empowerment, especially if supported by education and informational activities.”³⁹

Highlights from the Hearing on Abstinence-only Programs held by the U.S. House of Representatives, Committee on Oversight and Government Reform. April 23, 2008:

“Abstinence-only programs require teachers and health educators to conceal information about risk reduction measures such as condoms and contraception- or risk loss of federal funding. Misinformation about condoms is of particular concern given the high rates of sexually transmitted diseases among young people in the United States.”

Dr. John Santelli, Columbia University,
Population and Family Health Department Chair

“The U.S. has spent more than \$1.5 billion on these (abstinence-only) programs over the last ten years. This ‘decade of denial’ has left the United States with some of the worst sexual health outcomes in the developed world. One in four U.S. teen girls now has an STD and our national STD rates are exceeded only by those of Romania and the Russian Federation. Our teen birth rate is nine times that of the Netherlands, five times that of France, and nearly three times that of Canada. Teen pregnancy costs the federal government more than \$9 billion a year.”

James Wagoner, President,
Advocates for Youth

Encourage participation from the target population

HIV/AIDS prevention efforts can only be successful if they are easily understood and appreciated by the target population: young women. “The most dangerous assumption about programming for young people is that young people fit neatly into one category or another. It is critical to understand how they perceive their needs and their ability to practise protective behaviours.”⁴⁰

HIV education and services need to be developed so as to be culturally relevant -- by age, geographic location, and ethnicity-- to the target population. This requires programming to be adaptable to a variety of settings as well as flexible enough to adjust to the rapid evolution of youth culture, language, and preferences.

Health, sexuality, and prevention curricula thus must not be seen as static documents, but rather fluid guidelines that can facilitate interaction with a diverse and ever-changing population and its needs. Involving young women in the development of programming

is essential to ensuring the cultural relevance of prevention messages.

Involvement of young people through peer education programs is an effective means of influencing young peoples’ values and behaviors.⁴¹ Youth are more likely to participate in discussions about infection and are also more likely to see HIV infection and AIDS as personal dangers when information about HIV and STIs is given by a peer, than when the same information is presented by an adult.⁴² Active participation of HIV-positive young women may be particularly beneficial both to provide information to young women in an age-appropriate manner, and to offer a young adult’s real-world perspective of what it means to live with HIV/AIDS. The involvement of HIV-positive youth can assist in challenging prevailing attitudes regarding risk, in particular the commonly held notion that transmission happens to “someone else.” Finally, putting a young face on HIV will help to reduce young people’s dissociation, stigmatization and fear regarding HIV.⁴³

Involve young men

HIV/AIDS rates among young women are rising largely due to an increase in heterosexual transmission. Prevention programs targeted to reduce the incidence of HIV/AIDS in young women must not only seek to empower women, but to involve young men in the prevention process, both for their own health and for that of their partners. Efforts to involve young men should promote healthy behaviors, such as increasing condom use, as well as develop healthy attitudes, such as gender equality in sexual decision-making.⁴⁴

“Teens should know that HIV is real. And I think... no matter how many commercials you put, how many billboards you put up, how many posters, how many people come to your school and talk, they need to know that it's real and it's out there... I think my main message to another teenager, one who would be at risk or not at risk: HIV is alive, is real. If it can happen to me, it can happen to you or can happen to your friend, your BFF, your boyfriend, your girlfriend. It's alive.”

Carl, an HIV-positive teen. “A Young Man Learns to ‘Embrace’ His HIV Status”. The Washington Post, January 8, 2008.

In particular, efforts need to be made to increase access to and use of preventative care and sexual health services by young males, who currently lack the resources provided to young females by family planning and reproductive health services. While two out of three adolescent males received an annual physical exam in 2007, less than 20% received counseling or information regarding HIV and other STIs. The rates are particularly low among young men of color: while 66% of young white males received instruction on birth control and STI prevention methods before initiating sexual activity, only one-third of blacks and 45% of Hispanics received similar instruction.⁴⁵

Increase women-focused HIV research

HIV/AIDS in women often follows a different disease progression than in men. These differences impact decisions regarding initiation of treatment, drug interactions, and how to address complications. Women often experience lower viral loads than men with similar CD4 cell counts, indicating that women may need to begin treatment at viral load levels different than their male counterparts, for whom most of the treatment guidelines were initially developed.⁴⁶

Women may also experience different opportunistic infections than men and may suffer greater hormonal complications, influencing factors such as osteoporosis risk and reducing the efficacy of birth control pills.⁴⁷ Furthermore, women have been found to experience increased toxicity and stronger side effects from antiretroviral drugs than men.⁴⁸

Such differences in disease progression and drug treatment, coupled with the rise in HIV/AIDS among young women, demonstrate the need for an increase in gender-specific AIDS research and drug development. Several historical barriers, however, have served to thwart progress on this front. First, much of the early women-centered HIV research focused on transmission by women (as sex workers or through mother-to-child transmission during pregnancy and childbirth) rather than transmission to women or on gender-specific disease and treatment concerns.⁴⁹ Second, vital research was stymied by FDA regulations dating from 1977 that prevented participation in clinical trials of women of “child-bearing potential,” and thus prevented participation of the majority of women newly infected with HIV.⁵⁰

While this position of the FDA was revised in 1993 to permit the participation of women in clinical trials and to promote the need for

the study of gender-based differences in drug effects, barriers to adequate participation still exist. Such barriers negatively impact women and the body of knowledge regarding HIV drug therapy and gender-based effects. Research must be undertaken that promotes better understanding of the effects of gender upon differences in drug metabolism and disease progression and addresses the specific reproductive health concerns of HIV-positive women. Guidelines that inhibit this research hurt the health of young women.

VI. Moving Forward

The above measures, if implemented correctly, could greatly reduce the burden of HIV/AIDS upon young women. A full response to HIV/AIDS, however, cannot end merely with proximal solutions, but must address the fundamental question of why the rates of HIV among young women are increasing—particularly among young women of color. In other words, a full response must answer the question: what puts young women “at risk of risk” for HIV infection. Young women and their communities must be empowered—politically, socially, and economically—in order to fully address the epidemic. We have long known that young women who face limited economic opportunities, and who are not optimistic about their futures are more likely to initiate sexual activity at an early age, and to engage in behaviors that place them at risk for unwanted pregnancy or STIs, including HIV.⁵¹ A comprehensive strategy to combat HIV in young women must ensure that all young women have true opportunities, so they may believe that their futures are worth protecting.

VII. Summary of Recommendations

- Routinize HIV/AIDS prevention efforts for adolescents in health care settings
- Increase access to regular preventative health care for adolescents
- Increase access to routine, voluntary HIV screening for youth
- Promote universal access to HIV/AIDS treatment
- Eliminate abstinence-only education, and mandate comprehensive sexual education in schools
- Promote condom availability programs in youth-friendly settings
- Encourage participation from the target population in prevention efforts
- Involve young men in prevention efforts
- Increase women-centered HIV research

“It is time for all of us to take action to protect ourselves and our young people against HIV/AIDS. . . [W]e must educate our children about HIV prevention. They need to know that it is OK to talk about AIDS, because illness, like injustice and inequality, cannot be eliminated by remaining silent.”

Coretta Scott King

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