Critical Issues for Women and HIV:
Health Policy and the Development of a National AIDS Strategy

July 2009

African Services Committee -- New York, NY

AIDS Alabama – AL

Alliance of AIDS Services - Carolina -- Raleigh, NC

Center for HIV Law & Policy -- New York, NY and National

Community HIV/AIDS Mobilization Project (CHAMP) – New York, NY and National

Center for Health and Gender Equity (CHANGE) --National

HIV Law Project -- New York, NY

International Community of Women Living with HIV (ICW) --Washington, DC and Global

National AIDS Fund -- National

National Women and AIDS Collective (NWAC), a project of the Ms. Foundation – National

Sisterlove, Inc. -- Atlanta, GA

The U.S. Positive Women's Network (PWN) -- National

The Women's Collective -- Washington, DC

Women Organized to Respond to Life-threatening Disease (WORLD) -- Oakland, CA

Executive Summary

In April 2009, the Ford Foundation held a Women and HIV Strategic Advocacy Convening for funded organizations working on issues related to human rights, women, and HIV/AIDS. Representatives from these organizations determined a series of policy recommendations to guide the new Office of National AIDS Policy (ONAP), and related agencies in their efforts to achieve better outcomes for women living with and affected by HIV.

The following recommendations focus on reducing stigma and improving the human rights, prevention, and care and treatment needs of women living with and at risk for HIV infection. These policy directives were developed to inform the broader health care reform agenda, and the development of a National AIDS Strategy.

Through our work in the HIV/AIDS community as HIV positive women and their allies, we have determined that improvements are most needed in the areas of meaningful involvement of HIV-positive women; greater consideration of HIV-positive people's civil and human rights; health disparities in the U.S. South and rural areas; health care access; integration of sexual and reproductive health services with HIV testing, prevention and care; and HIV prevention.

HIV-positive people, and HIV-positive women in particular, must be meaningfully involved in decision making bodies at a local, state and federal level in order to assure policies and programs that are effective and grounded in the realities of people living with and vulnerable to HIV infection. Greater involvement of HIV-positive women in all levels of policy decision-making requires opportunities for capacity building in addition to elimination of barriers HIV-positive women face to meaningful involvement in governmental and community participation.

Respecting the civil and human rights of HIV-positive people is key to alleviating stigma and improving HIV/AIDS prevention and care. A growing number of states are adopting laws that criminalize HIV transmission. Not only do these policies perpetuate HIV stigma and place the onus of prevention exclusively on one partner, these laws also dangerously shift attention away from the key to HIV prevention -- insistence on safe-sex practices by both partners regardless of either person's status.

Extreme health disparities found in the U.S. South and rural areas must be addressed. Lack of medical providers, particularly HIV/AIDS specialists, targeted case management services, and housing, combined with outdated funding models have proven to be disastrous as we have watched the HIV/AIDS rates in these areas sky rocket.

Approximately 50% of people living with HIV are estimated to be out of regular care, with women and communities of color comprising a disproportionate percentage of people out of care. Health care services accessed by people living with and affected by HIV represent a microcosm of the successes and failures of our health care system. Health insurance exclusions and ratings must be eliminated, so the people who most need care can afford services. Medicaid and Medicare services need to be improved and expanded. And HIV testing must become routinized and reimbursable, so that all people are offered voluntary testing and receive information about HIV.

To best serve women, sexual and reproductive health services must be integrated with all aspects of HIV care to meet the diverse needs of women and men, regardless of their HIV status. Program guidance and funding streams must concretely integrate sexual and reproductive health services with HIV testing, prevention and care.

Because rates among women, especially women of color and young women, are on the rise, prevention efforts must prioritize evidence-based strategies that effectively reduce risk among women. Comprehensive sex education for young people of all genders is a start, as is the development of an affordable and female- controlled prevention device. Greater support should be given to organizations that work with HIV-positive women and testing and counseling must be routinized and reimbursable, so that all women, regardless of perceived risk, can easily obtain voluntary and informed HIV/AIDS testing.

The policy recommendations presented in the document were crafted within the context of our experiences as advocates and service providers, and as HIV-positive women and their allies. The women we work with face numerous structural and societal challenges in their lives that affect the health care and services available to them. This document opens the way to a formal dialogue about improving the lives of women living with and affected by HIV through increasing participation, prioritizing human rights, and improving access to and integration of health services.

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Introduction:

As the domestic HIV epidemic has become increasingly feminized, racialized, and impoverished over the past two and half decades, the development of an informed and appropriate response to the prevention and care needs of women, including transgender women, who are living with or vulnerable to HIV infection has become urgent. The vast majority of HIV-positive women in the United States are women of color who disproportionately live in poverty, care for children and families, and lack access to quality health care that adequately meets their needs.

Recent studies demonstrate pervasive stigma and bias about women living with HIV, and statistics clearly show that health care systems have woefully neglected the complex medical, economic, and societal reality of HIV-positive women.

In April 2009, The Ford Foundation convened grantees in its HIV/AIDS Human Rights portfolio who work to protect the human rights of women affected by HIV to address these issues. Out of this convening, advocacy priorities and strategies relating to women's needs under health care reform and in the development of a National AIDS Strategy were developed. A complete list of participants is included at the end of this document.

The following were identified as overarching priorities for an effective federal response to the U.S. HIV epidemic:

1) Recognition of the correlation between the fulfillment of human rights obligations and an increase in care, treatment, and support for HIV-positive women alongside a decrease in vulnerability to contracting the virus for HIV-negative women;
2) Integrated health care delivery to ensure that women living with and vulnerable to HIV infection are not lost to care and receive consistent, high quality services for sexual and reproductive health;
3) Elimination of government-reinforced stigma and government-sanctioned discrimination against people living with HIV and against women in general;
4) Health care reform to eliminate disparities based on gender, race, ethnicity, migrant status, health status, sexual orientation, geography, and income level; and
5) The meaningful involvement of people living with HIV, representative of the constituency served, in decision-making on policies affecting their communities.

The remainder of this document consists of specific policy recommendations intended to bring United States policy and practice in line with recognized international norms and standards in addressing this epidemic. These recommendations fall into the following six categories: meaningful involvement of women with HIV; human rights; southern and rural issues; health care access and reform; the integration of sexual and reproductive health services with HIV services; and HIV prevention.

We look forward to working with the Administration and with the Office of National AIDS Policy to achieve prevention and care outcomes that truly meet the needs of women living with and vulnerable to HIV infection.

Meaningful Involvement of HIV-Positive Women

Introduction

For the purposes of this document, *Meaningful Involvement of HIV-Positive Women* is defined as follows:

HIV-positive women and girls, including transgender women, representative of the constituency served and who are accountable to their constituency, are involved in all levels of policy decision-making and program design that impact their lives. Involvement of HIV-positive women includes building the capacity of positive women to participate. All of these measures should include and actively cultivate involvement by transgender women, women from the south, and women of color in order to promote and secure HIV-positive women's leadership that is reflective of the epidemic among women.

1. Increase Meaningful Involvement of Women Living with HIV on Federal Advisory Committees Related to Women Living with HIV

Background: HIV-positive women with backing and support of large institutions and constituency groups have been notably absent from federal advisory committees. Having network-based representation from the constituent communities increases transparency, accountability, and feedback mechanisms. Further, network-based representation ensures capacity building for a larger network and in turn more effective and accountable representation. When possible, representation should be achieved through established networks and other constituency-based groups whose mission includes a charge to develop leadership among their constituents, including but not limited to the U.S. Positive Women's Network (PWN), the International Community of Women Living with HIV/AIDS (ICW), the Global Network of People Living with HIV/AIDS (GNP+), and the National Association of People Living with HIV/AIDS (NAPWA).

Recommended Action: The Office of National AIDS Policy (ONAP) should require representation of HIV-positive women from networks of people living with HIV/AIDS (PLWHA) on all federal advisory committees and panels that influence policy and program design for women living with HIV/AIDS.

We request immediate representation on the following committees and councils:

- Centers for Disease Control and Prevention (CDC)/Health Resources and Services Administration (HRSA) Advisory Committee (CHAC):
- Presidential Advisory Council on HIV/AIDS (PACHA):
- The NIH Office of AIDS Research Advisory Council (OARAC):
- All panels that result from of the National AIDS Strategy:
- The Food and Drug Administration's Reproductive and Contraceptive Technologies Advisory Panel:
- Advisory groups on Health Care Reform that will be formed in the near future with focus on advising government entities and leaders; and
- Advisory groups associated with the Office of Minority Health; Office of Women's Health; White House Counsel of Members; and the State Medical Care Advisory Committees.

To further this goal, the Office of National AIDS Policy should publicly disclose membership of all federal advisory panels and advisory committees, including when membership slots open up, in order to promote transparency and maximize community involvement.

2. Correct the Lack of HIV-Positive Women Informing Programs and Practices of Organizations Serving Women Living with HIV as Well as Priorities of State Advisory Groups[i]

Background: Women living with HIV are notably absent from decision-making and management level positions even at agencies receiving large amounts of funding to serve women with HIV. Employing a strategy that includes the meaningful involvement of women living with HIV/AIDS in designing and implementing programs and policies that impact their own lives brings the approach of the United States in line with recommended international approaches to addressing HIV. According to the United Nations Joint Program on HIV/AIDS Policy Brief, the principle of greater involvement of people living with HIV and AIDS in programs enhances the quality and effectiveness of the AIDS response. [ii]

Recommended Action: Relevant provisions of the Ryan White HIV/AIDS Treatment and Modernization Act of 2006 should be amended to require that organizations that serve women living with HIV must involve HIV-positive women in the development, implementation, monitoring, and evaluation of programs that impact their lives. This involvement must be real and concrete by requiring that HIV-positive women serve as staff, board, and advisory members. This change can be mandated by amending the following provisions of the Ryan White Act of 2006:

- The definition of "Appropriate Entities" under revised section 2604(b)(2) of the Public Health Services Act, found in Section 105 of the Ryan White HIV/AIDS Treatment Modernization Act of 2006, to include that "public or non profit entities, or private for profit entities" must have HIV-positive staff and board members.

- The "minimum qualification of grantees" under Section 302(a)(1) under Title 3 of Ryan White HIV/AIDS Treatment Modernization Act of 2006 changed to require that "Eligible Entities" must have HIV-positive women on their staff and boards.

- Part D Section under revised section 2671(a) of the Public Health Services Act, found in Section 401 of the Ryan White HIV/AIDS Treatment Modernization Act of 2006, changed to state that the grants will be awarded to public and non profit entities that have active clients of their health centers on the board and staff of the organizations.

A clear precedent for these requirements exists. Federally Qualified Health Centers (FQHCs) are mandated to have 51% of active, registered clients of their health center who are representative of their health centers on their boards.

Recommended Action: Department of Health and Human Services (DHHS) can issue guidance directing organizations receiving Ryan White Act funds to staff HIV-positive women and require HIV-positive board members.

Recommended Action: DHHS can issue guidance directing states and territories receiving Ryan White Act funds to increase involvement of individuals living with HIV who reflect the epidemic in state advisory processes.

3. Expand involvement of women's HIV organizations in community planning

Background: Most women's HIV organizations in the United States are small (five or less staff) and underfunded (budgets under $200,000) and provide direct services but are not consistently or meaningfully involved in community planning processes due to understaffing and lack of capacity.

Additionally, community planning processes are not currently designed to fit the realities of most women's lives; they do not provide childcare or take into account school schedules when planning meetings.

Recommended Action: CDC and HRSA community planning guidelines should include a mandate to involve women with HIV in leadership.

Recommended Action: HRSA should release a competitive grant to promote capacity building for HIV organizations led by and for women to increase HIV+ women's involvement in community planning. This funding notice should be released no later than Summer 2010.

Human Rights

Introduction

International conventions recognize eight basic Human Rights: Civil; Political; Economic; Social; Cultural; Environmental; Developmental; and Sexual. Respect for the civil and human rights of people affected by HIV is a critical part of ending the HIV/AIDS epidemic. Government-sponsored discrimination and neglect perpetuates the stigma that fuels the HIV/AIDS pandemic. Fulfilling the government's human rights obligations to its citizens is, therefore, not only a legal obligation but also a public health necessity in the fight to stem the HIV/AIDS pandemic and to ensure the dignity of people living with HIV/AIDS.

To bring the United States in line with human rights standards around the world, an effective federal response including a National AIDS Strategy will need to make explicit the connections between health and human rights and demonstrate how a human rights framework will address the needs of women living with and at risk for HIV/AIDS. Structural and individual racism and sexism in the health care system must be addressed in order to bridge the persistent disparities in diagnosis, treatment, and outcomes for minorities of all economic levels and for low-income people. Similarly, healthcare must be provided in an ethical and culturally appropriate manner.

Federal, state and local laws and policies that criminalize, exclude, or marginalize people living with HIV/AIDS must be rejected from the bottom up and from the top down. In order for our country to meet its basic obligations to its people, it is necessary that people living with HIV/AIDS be treated with dignity and be provided the same rights and privileges as all citizens, to live and participate in society without irrational restrictions on their ability to maintain their health, livelihoods, and intimate and family relationships.

1. Take Affirmative Steps to End the Criminalization of People Living with HIV/AIDS[iii]

Background: People with HIV in the United States are subject to discrimination and exclusion to a degree that shocks most Americans. This discrimination includes travel bans on HIV-positive individuals[iv], rejection from employment due to HIV status[v], denial of child custody or adoption[vi], and refusal to license HIV-positive individuals from occupations such as barbering and home health care[vii]. At the extreme end of this disparate treatment is the criminalization of people with HIV.

More than half of the states have HIV-specific laws criminalizing sexual contact by people with HIV.[viii] Many of these laws hinge prosecution on the failure of an HIV-positive person to disclose their HIV status and obtain consent from sexual partners. Importantly, none of these laws punish the risk-taking behavior that actually drives the epidemic, namely, unprotected sex between persons who don't know their HIV status. Rather, the statutes punish only those who have taken the step of getting tested for HIV. Consequently, it is not the risk of transmission, but the fact of an HIV test, that is the central predicate to prosecution.

Recent research has increasingly raised concerns about the negative societal and health consequences related to the rise in criminal prosecutions of people living with HIV. Criminalization laws can lead to further stigmatization of people living with HIV/AIDS and a greater likelihood that people will not be tested for fear of prosecution.

Criminalization laws ignore the numerous and studied societal reasons that prevent individuals from disclosing their HIV status to sexual partners or others, including fear of domestic violence, fear of familial or partner abandonment, and community rejection. These fears are especially pertinent for

women living with HIV/AIDS.

Criminalization of HIV has a particular impact on women. Criminalization heightens stigma and discrimination faced by women when disclosing their HIV status to their partners. Women often find out their status before their partners during routine gynecological or prenatal testing. Because women often know their status first, they can be prosecuted for knowingly transmitting the virus to their partners—even in instances where women may have contracted the virus from their partners but cannot disclose their status due to fear of abuse, violence, or abandonment. Positive women are also vulnerable to prosecution for child neglect when their children contract HIV during pregnancy, childbirth, or while breastfeeding.

Criminalization of HIV transmission further marginalizes groups made vulnerable by the law including injecting drug users and sex workers and fails to take into consideration the only proven method of HIV/AIDS prevention: the acceptance of responsibility by both partners to take precautions to prevent HIV/AIDS and STD transmission. HIV transmission does not occur through a failure to disclose but through a failure of sexual partners to take precautions against transmission of HIV and STDs. Prosecutors' sledgehammer approach to the issue of HIV exposure demonstrates not only lingering stigma but also a failure to take into consideration the complexity of human relationships.

Public health officials and policy makers must make visible, concrete, credible investments in protections against HIV-related discrimination and must oppose policies and legislation that would marginalize, isolate and/or punish people with HIV and their communities. Federal incentives are needed to encourage states to approach HIV/AIDS prevention and care as a medical and public health issue and not as a criminal matter. Eliminating the criminalization of HIV/AIDS in the United States will bring our government in line with international consensus and action on this issue as articulated in the Joint United Nations Programme on HIV/AIDS Policy Brief on the Criminalization of HIV Transmission.[ix]

Recommended Action: The Administration should direct the CDC to address criminalization laws through the following measures:

- Issue a statement or publication that addresses the lack of evidence that criminal prosecutions have had a positive impact on HIV infection, transmission rates, or sexual behavior implicated in HIV transmission;

- Have the Surgeon General or appropriate medical official at CDC issue a statement that collects and sets forth facts on HIV transmission, casual contact and HIV, and the impact of ART on transmission risks posed by people living with HIV.[x]

- To ensure that these official statements can be easily accessed and used by people living with HIV and their advocates in both criminal and civil proceedings (where HIV also has been used to influence custody and other family law proceedings), direct that they be posted prominently on CDC website, as well as included in the *Morbidity and Mortality Weekly Report* (MMWR) and/or related publications, and distributed to all state Departments of Health and Attorneys General for state-wide distribution to local health departments, prosecutors, public defenders, and civil and state court judges;

- Explore incentive mechanisms, much as the CDC has done in its campaign for adoption of its 2006 HIV testing recommendations, that will encourage states to take corrective action to fix laws criminalizing HIV transmission and exposure. Incentives could include research grants that would monitor changes in testing and risk behavior following repeal of HIV

criminal laws or prevention project grants in correctional facilities in states that eliminate barriers to prisoner testing, such as the threat of prosecution for having consensual sex after diagnosis.

Recommended Action: The Administration should explore legislative incentives to reduce criminalization laws through law enforcement block grants that reward the repeal of laws that criminalize consensual sexual conduct of people who have tested positive for HIV and provide clarity that the Ryan White HIV/AIDS Treatment Modernization Act of 2006 does not require the adoption of HIV-specific criminal laws if states can certify (as all can) that their existing criminal laws are adequate to address any need to prosecute acts of intentional transmission of HIV.

Recommended Action: The Administration should further address the stigmatizing impact of criminalization by targeting a portion of prevention funding for anti-stigma training of law enforcement officials, court personnel, and prison personnel, as well as other incentive funding to reduce the irrational treatment of people with HIV in the criminal justice system.

2. Eliminate Coercive HIV Testing Requirements[xi]

Background: The health of individuals and the public demand that HIV testing programs be fully informed, consensual, voluntary, confidential or anonymous, and supported, directly or by referrals, with appropriate education, counseling, health care, mental health care, and social services.

The level of understanding of HIV in the general population is still very low, and misperceptions about HIV and AIDS and the transmission of HIV continue to fuel HIV-related stigma and discrimination. Providing all of those offered testing with culturally and linguistically appropriate information about HIV and risk-reduction strategies will help to reduce the misperceptions and related stigma. Testing without counseling about the risk of false negatives can generate a dangerously false sense of security. Most people are not aware that the greatest risk of transmission is from newly infected individuals with high viral loads who may not know that they are infected and will usually test negative in standard antibody screening. Newly-infected individuals account for nearly half of all HIV transmission, so programs must counsel those who test negative about the possibility that they could in fact be positive and at their most infectious.

Protecting human rights through an informed consent testing protocol is consistent with, and not opposed to, the public health goal of expanded HIV testing. The importance of patient knowledge, autonomy, and active participation in all aspects of HIV testing and care cannot be overstated. Many current discussions about strategies to expand testing ignore human and civil rights or treat them as barriers to expanded testing and progress in public health policy.[xii] Patients' fundamental rights to health care and informed consent are essential to engaging them in testing, prevention, and trusting relationships with primary providers.

For people to agree to engage in HIV testing and other activities within the health care system, they must feel secure that their rights to privacy and confidentiality will not be violated, that they will have access to health care when needed, that they will be able to disclose their HIV status with relative safety, and that they will be able to work and receive social services without regard to that status.

Promoting high-quality and ethical service provision is as important in HIV testing as it is in the medical management of HIV therapies and the conduct of clinical trials. The CDC maintains in its *2006 Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings* that testing must be with the knowledge of the patient, voluntary, and free from coercion (p. 8), and states that the Recommendations "…are intended to comply fully with the ethical principles

of informed consent…" (p. 13).[xiii] HIV testing programs incorporated into clinical care settings also must "ensur[e] a provider-patient relationship conducive to optimal clinical and preventive care" (p. 7 of the *Recommendations*).[xiv] The CDC *Recommendations* must be revised to ensure that all of its provisions are consistent with these basic principles and mandates.

Recommendation Action: Remove opt-out and/or mandatory HIV testing as a condition for receipt of federal Ryan White Act/CDC funding and discourage calls and incentives for mandatory newborn testing without parental consent. HIV testing programs must be tailored to different clinical settings, populations, and patient needs, such as those in dependent or abusive relationships, recent immigrants, and young women without strong systems of social support.

Recommended Action: Create incentives to encourage states to adopt local policies that mandate counseling and offering of voluntary HIV testing regardless of perceived risk. Mandatory counseling and offering of voluntary testing should be included in primary care services, including routine gynecological and sexual and reproductive health services, and other key points of entry for ongoing primary care.

These mandates will require public and private insurance plans to cover both counseling and testing as separate services to be reimbursed.

Recommended Action: Increase funding for model programs that streamline the HIV testing process while documenting informed consent, increased voluntary testing, and corresponding increased entry into care.

Recommended Action: Everyone offered testing must be educated about HIV and the significance of positive and negative test results.

Southern and Rural Issues[xv]

Introduction

Although the South accounts for only 36% of the nation's population, half of all U.S. AIDS deaths in 2005 were in the South[xvi], and more than half of all Americans with HIV lived in the region in 2006[xvii].

Nine of the 15 states with the highest HIV diagnosis rates are in the South.[xviii] Of the 20 metropolitan areas with the highest rates of AIDS cases in 2006, 16 were in the South.[xix] Approximately 45% of all new infections are in the South. Six of the ten states with the highest AIDS case rates among women are in the South, with the District of Columbia topping the list at 100 per 100,000 or 12 times the national rate for women.[xx]

1. Extension of Medicaid Coverage and Creation of Minimum Reimbursement Rates

Background: Rates of uninsured residents in the South are far higher than in other regions. While the 2004 national average of uninsured individuals was 15.7%, the uninsured rate in the South increased to 18.6% from 2004 to 2005. Further, Southern blacks are uninsured at rates that far exceed those of their white counterparts: 28.5% versus 18.5%.[xxi] Lack of insurance leads to poor health outcomes, a proposition that is especially dangerous for women living with HIV or for those at elevated risk for exposure. In 2004, 51% of uninsured women in the U.S. did not have a regular doctor, and 67% of uninsured women needed but didn't get care due to the cost.[xxii]

The dire health care situation in the South can be traced to numerous causes. High rates of poverty and high numbers of jobs without employer-sponsored insurance lead to high numbers of uninsured individuals and heavy reliance on Medicaid and Medicare. Public insurance systems struggle under the demands of federal-state matching programs in states with few resources. Finally, owing to low reimbursement rates, providers decline to accept Medicaid patients, often leaving residents, especially those in remote and rural areas, without access to care.

Recommended Action: Centers for Medicare & Medicaid services (CMS) should establish minimum provider reimbursement rates for all 50 states to ensure that reimbursement rates remain high enough to protect against the diminishing panel of doctors and service providers that accept Medicaid in some of the more impoverished states. Also, CMS should be prepared to implement the Early Treatment for HIV Act (currently H.R. 1616), expanding Medicaid eligibility criteria from people living with AIDS to include those individuals who live with HIV disease but have not been diagnosed with AIDS and increasing coverage to low-income persons with income less than $20,000 per year and families of four with incomes less than $42,000 per year or even higher, as determined by states in this optional program.

2. Expansion of Rural Case Management Services

Background: Case management consists of services that help beneficiaries gain access to needed medical, social, educational, and other services. "Targeted" case management services are those aimed specifically at special groups of Medicaid enrollees. In rural and isolated areas throughout the South, few, if any, case management services exist for people living with HIV. Those services that might exist are often geographically inaccessible. Thus, HIV-positive individuals are left without a means to learn of and connect to needed medical, social, and other services.

Women living with HIV are often heads of household or have family members or other dependants

who rely on them. Attending to their own health needs can all too easily become a secondary concern when stacked up beside the competing demands of child care and school schedules, children's medical care, provision of food for the household, frequent public assistance appointments, SSI appointments, court dates, and teacher conferences. A case manager helps a woman to ensure receipt and coordination of the services she needs, thereby improving treatment adherence and preserving her own health.

Recommended Action: The Office of National AIDS Policy should undertake an initiative to implement Medicaid Targeted Case Management programs in all states. By encouraging state Medicaid programs to expand case management services, people living with HIV would be better able to access local services.

3. Development and Retention of Local HIV Health Care Providers

Background: Southerners living with HIV often face an acute lack of health care options, a problem particularly felt by those living in rural areas where the lack of facilities is compounded by a lack of HIV expertise. In addition, people living with HIV are often unwilling or unable to receive ongoing health care due to compromised confidentiality in situations where family, friends, and acquaintances work at or utilize the health departments or rural health clinics. When care is sought at these sites, some county health departments and rural health clinics do not have the expertise to properly care for patients with HIV. Further, existing facilities and their providers too often lack adequate training in cultural competence, such that stigma and discrimination is often perpetuated by health providers themselves.

Recommended Action: Congress should amend the Public Health Services Act to require that Federally Qualified Health Clinics (FQHC) offer HIV testing and provide HIV care; at the least these facilities must provide linkages to necessary HIV screening, care, treatment, and services.

Recommended Action: The Health Resources Service Administration (HRSA) should expand the National Health Service Corps to recruit HIV specialists to serve in those areas suffering from a growing incidence of HIV and simultaneous lack of HIV expertise.

Recommended Action: The Office of National AIDS Policy should begin an initiative to promote state-level programs that allow for the establishment of independent practices for physician extenders (nurse practitioners and physician's assistants) to work in rural and underserved areas in order to expand the pool of health care resources providing services to people living with HV who need primary care.

Recommended Action: The Department of Education should create a grant or loan forgiveness-type program for capacitating Historically Black Colleges and Universities (HBCUs) in the South to develop training programs and capacitate health education programs to build expertise for students entering the public health or related fields.

4. Creation of Supportive and Transitional Housing Stock and Emergency Shelters for People Living with HIV in Rural and Underserved Areas

Background: Southern and rural areas lack adequate resources to provide proper housing assistance to people living with HIV. The Housing Opportunities for Persons with AIDS (HOPWA) funding formulary is based on cumulative AIDS cases and tends to unfairly discount the need for housing services in areas with a newer epidemic and a higher HIV to AIDS ratio, as is the case in parts of the South. (See more on this below.)

In a six-month study of adherence to HAART (Highly Active Antiretroviral Treatment) regimens, residents in long-term housing were sixteen times more likely to report good adherence to their treatment regimens than were unstably housed participants.[xxiii] Meanwhile, homeless or marginally housed women are more likely to delay treatment, are less likely to have regular access to care, are less likely to receive optimal drug therapy, and are less likely to adhere to their medications than are stably housed individuals, all characteristics that increase an individual's viral load and decrease health outcomes.[xxiv]

Providing public funds for supportive housing assistance has the potential to significantly impact the quality of life for HIV-positive women and their families. While such assistance may require larger investment up front, it has been demonstrated to be cost effective by "…substantially reduc(ing) the utilization of costly emergency and inpatient health care services."[xxv] These savings have been demonstrated by two large-scale intervention studies, the Chicago Housing for Health Partnership and the HUD/CDC Housing and Health study, both of which showed that supportive housing for persons with HIV/AIDS not only improves health outcomes but also reduces the use of expensive emergency and inpatient health care services. Such savings in costly health care services greatly exceeded the cost of housing assistance, thereby making housing assistance programs an intervention that is both effective and cost-efficient.[xxvi] Research has also shown the costs of supportive housing to be offset by decreased use of expensive public services such as emergency housing, jails, and prisons.[xxvii]

Recommended Action: The Housing and Urban Development (HUD) Office of AIDS Housing should conduct a state-by-state review of projects funded by Housing Opportunities for Persons with AIDS (HOPWA) to ensure statewide coverage in rental assistance in all 50 states. Further, the Office of National AIDS Policy should encourage a HUD initiative to create rural Continuum of Care networks that would be funded by the pro-rata share of McKinney-Vento funding for the counties that participate in the Continuum of Care. These networks should be incentivized to include HIV housing in rural Continuum of Care-funded projects.

5. Increase in Funding to Be Directed at Areas Based on Burden of Epidemic

Background: As the demographics and incidence of HIV have shifted in the United States, funding mechanisms have not adequately adjusted to provide appropriate funding streams in areas with a newer and burgeoning epidemic. In the early days of HIV in this country, additional funding, such as through the Ryan White CARE Act, was directed at urban areas where the disease was flourishing in order to build the infrastructure of systems to deliver care and services. These systems must remain intact, and the funds that support them remain essential. However, the current disease burden in rural and southern areas now demands additional funding to build similar systems of care delivery. Distribution mechanisms must be based on living HIV and AIDS cases so that funding can get to the people in need. Rather than shifting resources from urban areas to parts of the country that receive less dollars per case, a heavier percentage of new funding, as well as special initiatives, should be directed to the areas that receive less funding per case through the various existing mechanisms and through special appropriations.

Recommended Action: Congress should allow the funding to follow the epidemic and direct the majority of new funding to lesser-than areas until per capita parity is achieved with 100% "hold harmless" for current recipients of funding.

Recommended Action: The U.S. Department of Housing and Urban Development (HUD) should update funding distribution based on living HIV estimated case counts and living AIDS cases.

Recommended Action: The Centers for Disease Control and Prevention should implement rural and southern initiatives with five-year commitments.

Recommended Action: The Centers for Disease Control and Prevention should increase direct funding to community-based organizations.

6. Integration of Funding Sources to Create Partnerships among Faith-Based, Community-Based, and Public Health Service Providers

Background: With services and resources scarce, HIV-positive Southerners are hurt by the traditional division of funding allocation that divides the work of community-based, faith-based, and public health service providers. When these different sorts of service providers are supported by different funding streams, numerous challenges can arise. Services may be duplicated or collaborations not pursued due to rigid funding guidelines that define the parameters of the work, the populations to be served, and the manner in which outcomes are documented. As a result, opportunities for cross-cutting collaborations are lost. These partnerships, especially when faith-based organizations are involved, have the potential to eliminate stigma, increase inclusion, and improve access and utilization of local prevention, treatment, and care services.

Recommended Action: The Office of National AIDS Policy should initiate a process of integrating funding sources so that inefficiencies are eliminated and opportunities for integration are maximized. Special attention should be paid to the potential utility of collaborations among complementary service providers, including community-based, faith-based, and public health service providers.

Health Care Reform and Access

Introduction

Health care provided to women living with and affected by HIV/AIDS, must adhere to these guiding principles:

Availability: Health care facilities must be available to all sectors including low-income neighborhoods and rural areas; health care facilities must have health care staff sufficiently trained in HIV care and prevention; people living with pre-existing medical conditions such as HIV should not be excluded from private health insurance plans due to outright rejection of insurance services, or rated by health insurance companies on the basis of gender, health or age.

Accessibility: Health care services must be accessible to everyone without substantial bureaucratic barriers and systematic discrimination that prevent minorities and women from receiving appropriate, comprehensive, and timely care. The burden of bureaucratic navigation should not fall on those living with HIV. Health care systems and services must pro-actively address stigma and discrimination on the basis of race, ethnicity, gender identity, sexual orientation, HIV status, literacy, and language.

Acceptability: Health care must meet both ethical and culturally appropriate standards; health care providers must receive both ethical and cultural training including training in the sexual and reproductive health options available to people living with HIV, in order to provide acceptable HIV treatment and prevention methods.

Quality: The quality of care provided to all people must be of the highest standard. Health Care Reform must seek to strengthen the social contract for the most vulnerable members of our communities – in particular, people living with or at risk for HIV in poor or rural areas must be assured the same quality of care as all people in the United States.

Comprehensiveness: Holistic care services should be prioritized and integrated into systems of care for chronic disease. We must move away from a medicalized model of care to a model that accounts for the needs of the whole person and includes a meaningful investment in supportive services that keep people in care.

The below priorities will help to ensure that these principles are actualized in our health care system.

1. Improve and Mandate Health Care Provider Education in Intersecting Issues Specific to Women and HIV/AIDS

Background: When women are unable to communicate openly with their providers because they feel unsafe, judged, or misunderstood, it leads to substantially lower health outcomes and possibly fatal consequences for both women and their families. For low income women, recent immigrants and women in rural settings the consequences resulting from uninformed health care providers can be more devastating when access to, and choices in, health care providers is already severely limited.

Women living with and affected by HIV/AIDS must receive medical care in settings wherein providers are aware of, and trained in the way specific experiences affect the medical needs of women. Lack of training can lead to poor health outcomes and even fatal effects.

When working with women, providers are often insensitive or unaware of the intersection of HIV/AIDS with stigma and structural discrimination; trauma; gender identity; sexual orientation; race; mental health; substance use; and cross-cultural norms and traditions.

Additionally, providers are often not fully informed of a woman's reproductive options when living with HIV/AIDS and can transmit incorrect, harmful, and sometimes coercive information to their patients.

Recommended Action: The Department of Health and Human Services (DHHS) should fund and mandate annual trainings on the intersection of HIV/AIDS with individual and structural discrimination; trauma, gender identity, sexual orientation, race, reproductive options, cross-cultural practices, mental health, and substance use for providers at

- Ryan White Care Act Funded Clinics & Community Based Organizations (CBO);
- Medicaid Funded Clinics
- Title X & Family Planning Clinics
- Federally Qualified Health Clinics (FQHC);
- Rural Health Clinics;
- Community Health Centers;
- Migrant Health Centers;
- Health care for the Homeless Programs;
- Public Housing Primary Care Programs; and
- Other Section 330 clinics.

Utilize AIDS Education & Training Centers (AETC) and partnerships with Community Based Organizations to provide these trainings.

2. Prohibit Health Insurance exclusions and ratings based on pre-existing health conditions, gender and age

Background: Currently, private insurers may refuse or delay coverage for pre-existing conditions, or charge premiums so high that coverage is prohibitively expensive.[xxviii] Women are routinely charged more for private health insurance, and as one ages, premium costs rise. These insurer policies severely disadvantage everyone but especially women living with HIV/AIDS and limit access to the quality health care all people deserve as a right. These policies additionally prohibit people from accessing preventative care and early intervention services, and ultimately result in higher costs for expensive treatment and supportive services.

Recommended Action: The White House and CDC should issue statements and guidelines discouraging private insurance exclusion and rating policies and work with Congress to prohibit exclusions and ratings based on pre-existing health conditions, gender, or age in the new health care reform package.

3. Improve Medicaid & Medicare Services for women living with and affected by HIV/AIDS

Background: Although Medicaid and Medicare provide some services for women living with HIV/AIDS, there are many who need care but cannot fully benefit from current public insurance plans because they are ineligible due to unrealistic income-eligibility restrictions, inconsistent benefit packages from state to state, cost prohibitive out-of-pocket expenses, and waiting periods.[xxix]

Recommended Action: Provide Medicaid to all uninsured individuals with income less than

$20,000 per year and families of four with income less than $42,000 per year, and allow states to provide Medicaid coverage for persons with HIV with even higher income, as proposed in the Early Treatment for HIV Act (ETHA).

Recommended Action: Establish a comprehensive, standard Medicaid benefits package that is available in every state.

Recommended Action: Eliminate the two-year Medicare waiting period for people with disabilities.

Recommended Action: Establish a minimum provider rate to ensure qualified provider participation.

Recommended Action: Keep Medicaid and Medicare health care services and prescriptions affordable for everyone by minimizing clients' out-of-pocket costs – including fixing the Medicare Part D "donut hole" to allow ADAP costs to count towards true out-of-pocket costs.

4. Create Provider & Insurer Incentives for HIV/AIDS Testing and Counseling to Require Routine Testing for All Women Regardless of Perceived Risk

Background: Although the CDC guidelines strongly recommend that anyone who requests an HIV/AIDS test should receive one, HIV/AIDS screenings are not routinely provided by either private or public insurance plans.

Systemic barriers inhibit HIV/AIDS testing for women and other populations considered low-risk. These barriers often stem from incentives created through CDC and community based organization cooperative agreements, wherein testing providers are reimbursed at a higher rate for testing populations considered to be at elevated risk for HIV infection – including men who disclose having sex with men and individuals who disclose injection drug use. The result of this practice is that organizations federally contracted to provide testing discourage individuals at low risk due to their personal behavior to test for HIV/AIDS because it is costly. This disproportionately impacts women and others not perceived to be vulnerable to acquiring HIV infection.

Approximately eighty percent (80%) of women who test positive contracted HIV through heterosexual contact – yet heterosexual sex is considered a "low risk" behavior. This system fails to account for the real structural causes -- independent of personal behavior - of disparate HIV rates in low income communities and communities of color. The current system of targeting HIV testing resources consistently overlooks women's vulnerability to HIV infection, particularly for women of color, low-income women, women living in geographic HIV "hotspots", and women experiencing homelessness, mental health issues, and substance use. This results in women being diagnosed later in their HIV infection and experiencing worse health outcomes.

Lack of voluntary, universal screening and testing on demand, and in all medical settings perpetuates HIV-related stigma, perceptions that it only affects some communities, and the public's lack of knowledge about their own HIV/AIDS status thereby contributing to the on-going HIV/AIDS public health crisis.

Recommended Action: Through HRSA and CDC, provide guidelines and incentivize reimbursements to providers for routine HIV/AIDS testing and counseling of all clients regardless of perceived behavioral risk.

Recommended Action: Eliminate tiered CDC testing fee structure based on "high-risk" versus

"low-risk" clients and fully reimburse testing providers for all HIV/AIDS testing and counseling.

Recommended Action: Revise Current Procedural Terminology (CPT) Codes for private and Medicaid insurers to make universal informed consent and pre- and post-test HIV/AIDS counseling fully reimbursable for all providers, public and private.

Recommended Action: Urge Congress to require private insurance companies to reimburse for routine HIV/AIDS testing and counseling for all of their policy holders regardless of perceived risk.

5. Ensure a continuum of high quality health care for incarcerated and formerly incarcerated individuals

Background: Communities of color devastated by incarceration rates are similarly devastated by HIV infection – and the links between incarceration rates and HIV are inextricable. However access to appropriate health care in the prison system is patchy at best. Additionally, individuals are likely to be lost to care upon release due to lack of consistent access to quality health care, medication, and the supportive services needed to ensure adherence. These gaps in care create health hazards for the individual as well as for their sexual partners.[xxx]

Recommended Action: Create effective cross-governmental partnerships to assure a reliable continuum of high-quality confidential care, including access to appropriation medication and supportive services during the period of incarceration and upon release. Suggested public health/correctional facility transitional care partnerships may include but are not limited to partnerships between the Centers for Disease Control and Prevention (CDC), the Federal Bureau of Prisons (FBP), the Centers for Medicaid and Medicare Services (CMS), the Human Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), and Housing and Urban Development (HUD).

Recommended Action: The CDC guidelines should include recommendations on ensuring a continuum of care for incarcerated and formerly incarcerated individuals similar to CDC recommendations for condom use in prisons.

Recommended Action: Prohibit CMS from suspending services during period(s) of incarceration.

Recommended Action: Provide adequate access to routine health care, including sexual and reproductive health care, for women in county, state, federal, and immigration detention centers.

6. Improve Patient Literacy & Participation in Health Care Settings to Promote Higher Quality Health Outcomes

Background: Health care for women living with or at risk for HIV/AIDS must be modernized by promoting an emphasis on patient literacy and participation in health care services. The mirror image of health care provider education is patient education and empowerment. If women are aware of the full range of health care choices they are better equipped, when communicating with their providers, to find the care and treatment that best meets their needs.

Recommended Action: Formalize partnership between the Center for Disease Control (CDC) and CBOs to continue development of Health Indicator Programs for HIV/AIDS care.

Recommended Action: Dedicate a federal funding stream for agencies to hold trainings in patient literacy and participation in order to create materials such as "HIV/AIDS Patient Checklists," to be utilized by clients when attending doctor's appointments.

7. Educate Providers about issues of Mother to Child Transmission (MTCT) in order to decrease stigma related to HIV and reproductive health

Background: Although instances of mother to child HIV/AIDS transmissions are relatively low, there need be no instances as mother to child transmission is wholly preventable. Prevention hinges on early and consistent perinatal care by doctors properly trained in mother to child transmission protocols. Challenges for HIV positive pregnant women, or women who suspect they may be positive, arise when they have received incorrect or incomplete information regarding pregnancy and HIV. Faulty information may cause women to avoid perinatal doctor's visits for fear of being judged, involuntarily tested for HIV, or coerced to terminate their pregnancy. Incomplete education of doctors can lead to just these results, which violate the rights and dignity of HIV positive women.

Recommended Action: The Centers for Disease Control guidelines should recommend and help to fund

- voluntary HIV testing with written, informed consent and pre- and post-test counseling for all pregnant women in the first and third trimester, regardless of perceived risk;
- voluntary HIV testing with written, informed consent and pre- and post-test counseling for women planning pregnancies regardless of perceived risk;
- include incentives in future funding for MTCT programs that require documentation of pre- and post- test counseling of pregnant women and informed consent;
- training and education requirements for gynecologists, obstetricians, midwives, and other pre- and post-natal service providers in HIV/AIDS care for women pre- and post-pregnancy.

Integration of Sexual and Reproductive Health and HIV Care

Introduction

One important shortcoming of the current response to the HIV epidemic is the failure to fully develop programs and collaborations that reflect the interconnection between sexual and reproductive health (SRH) needs and vulnerability to HIV. Although there is broad consensus on the importance of better integration of HIV and reproductive health services,[xxxi] current public health funding silos and program guidance outright discourage integrated health care delivery models. This disjointed approach simply does not work for women. If we are to address the needs of women more effectively, it is critical that we coordinate and integrate sexual and reproductive health services with all aspects of HIV care—across all prevention, diagnosis, treatment, and care programs—to meet the diverse needs of women and men, regardless of their HIV status.

This requires that federal policies and programs explicitly acknowledge and protect the right of individuals living with HIV to choose procreation and related family planning services; and concretize that right through real access to associated medical and social services. Thus, people living with HIV, and serodiscordant couples, have a right to a full range of reproductive options allowing them to choose when and how many children they will have, and the right to parent them, and to have access to alternative conception methods such as artificial insemination, sperm washing, and invitro fertilization.

A central component of all such services must be the recognition and protection of the rights of women to make informed decisions for themselves and their infants at every phase of diagnosis and treatment. For this right to be a reality, those who staff SRH and HIV services must be adequately trained to provide integrated services and referrals with compassion and respect for the sexual and reproductive health needs and human rights of all individuals, and to fully discuss the nature and meaning of HIV and the importance of diagnosis and care as part of sexual health.

1. Modernize Public Health Programs to Support Care Coordination and Integrated Service Delivery

Background: Traditionally, public health funding silos have created barriers for integrated service delivery in health care settings throughout the country. There has been a damaging lack of coordination among agencies focused on HIV, STI, and women's health services, and program guidance has prevented health care integration as a result. For instance, the Centers for Medicare and Medicaid Services (CMS) limits access to HIV/STI services for women receiving care through Medicaid family planning expansions.

Recommended Action: The White House should direct HHS agencies to review public health program guidance and encourage integration of HIV, STI, and reproductive health services where appropriate.

For instance:

- The Centers on Medicare and Medicaid (CMS) should reverse policies that limit HIV/STI services for Medicaid family planning expansion patients.
- HHS and the CDC should revise guidelines for federally-funded HIV/AIDS, STI, and women's health programs to ensure that integration is encouraged and that guidance is in

place indicating which SRH, HIV, and STI services should be provided, and how they should be provided (either by direct service or referral).

- HIV/AIDS and STI programs should allow the purchase of contraceptives. For instance, contraception should be included in ADAPs since it is directly related to the treatment regimens of HIV-positive women.
- The Administration should ensure the provision of comprehensive, integrated and voluntary SRH and HIV prevention and treatment services for women who are incarcerated or recently released, female sex workers, immigrants, and other marginalized populations

Recommended Action: Congress should amend existing legislation and proposed legislation related to HIV/AIDS and reproductive health to encourage integration at the point of care.

For instance:

- The Ryan White Care Act should be updated to support integration. Ryan White requires that part A, B, and C grantees devote 75% of their funds for "core medical services." (Secs. 105, 201, 301) Those services are specifically defined in the legislation, and should be amended to include sexual and reproductive health services including, but not limited to, the following:
    - nondirective, nonjudgmental and confidential counseling about reproductive options;
    - voluntary contraceptive services, including emergency contraception;
    - safe pregnancy and delivery services;
    - prevention, diagnosis and treatment of STIs other than HIV;
    - referral for abortion services;
    - screening with relevant responses for intimate partner violence and sexual coercion, and provision of post-exposure prophylaxis (PEP) and emergency contraception.
- Ryan White currently requires part C grantees (sec. 305) to provide pre- and post-test counseling for HIV testing and sets out what must be included in those counseling sessions (post-test is required for both positive and negative results). Grantees should also be required to provide nondirective, nonjudgmental and confidential counseling related to sexual and reproductive health.
- Ryan White, Part D, focuses on care for women, infants, children, and youth. In section 401, related to additional services, sexual and reproductive health services should be made available for both women and adolescents, including LGBT youth.
- Under Part D of Ryan White, OB/GYN care, including labor and delivery care, for HIV positive women should be covered, especially for undocumented women who can receive continuum of care despite MEDICAID regulations in a state.
- The Violence Against Women Act (VAWA) should be updated to include provisions that encourage sexual and reproductive health and HIV/AIDS service providers to offer screening with relevant responses for intimate partner violence and sexual coercion, and provision of post-exposure prophylaxis (PEP) and emergency contraception.

HIV Prevention

Introduction

Women in the U.S. are increasingly affected by HIV, with the proportion of HIV/AIDS cases diagnosed in women tripling from 8% in 1985 to 26% in 2007.[xxxii] The vast majority (80%) of women who are infected with HIV are infected via heterosexual sex with a male partner. Black and Latina women are disproportionately affected by the epidemic, comprising 80% of new female AIDS diagnoses.[xxxiii] The proportion of young women infected with HIV is on the rise, making prevention for women even that much more of a priority for the U.S.[xxxiv]

We recommend the following actions be taken to address the HIV prevention needs of women (including transgender women):

1. Prioritize and support comprehensive, age appropriate sexuality education.[xxxv]

Background: There is no evidence that abstinence-only education delays sexual debut among youth yet research indicates that abstinence-only programs may reduce levels of contraceptive use. Meanwhile, studies show that comprehensive sexuality education does delay the onset of sexual activity among teens, reduces the number of sexual partners, and increases levels of contraceptive use. Women need quality education about their bodies and sexuality in order to make empowered, informed decisions about their health and wellness, including their sexual health and sexual activities.

Recommended Action: Eliminate all funding for the Community-Based Abstinence Education (CBAE) Program and the Title V Abstinence Education Program.

Recommended Action: Fund age-appropriate, comprehensive, and evidence-based risk-reduction sexuality education programs, including HIV-prevention interventions that discuss abstinence, contraception, male and female condom skills, and healthy relationships. Sexuality education programs must also address the social context of sexual and reproductive health and include content on gender roles and gender equity. Sexual education should not be limited to school-aged populations – it needs to be targeted to all women, throughout their lifespan.

2. Prioritize and support a variety of women-centered research strategies to address HIV transmission among women.[xxxvi]

Background: Disturbingly, women are disproportionately underrepresented in biomedical research trials. Considered difficult to enroll and retain in trials due to psychosocial characteristics or biological/reproductive complexities – or considered by researchers and policymakers to be a lower priority population than men – women pay the ultimate price with their lives as they are unable to access the latest prevention science.

Without adequate representation in trials, researchers are unable to draw conclusions about sex differences or the efficacy of interventions for women, and interventions that are developed and disseminated to the public may be unavailable to women because they were not included in the original research. Inclusion of women in research and an emphasis on developing women-specific research trials addresses this problem and indicates that women are a highly-prioritized population in HIV prevention research.

Current evidence-based interventions for HIV-positive populations are largely focused on increasing

condom use and improving condom skills. An important development occurred in March 2009, when the FDA approved a second generation female condom product that will become available for the public and private sectors in late 2009. Female condoms are the only existing, safe and effective prevention method designed for women to initiate. Despite their critical role, they have been underfunded and not made accessible. Studies have shown that female condoms are often used when one or both partners refuse to use a male condom, and that female condom promotion and use increases the total number of protected sex acts.

While increasing and improving condom use is an important and essential prevention strategy, in most situations condoms are a male-controlled prevention method. While interventions can work with women to increase their assertiveness and ability to negotiate condom use with a male partner, the success of these strategies ultimately lies with the consent of both partners. .

We need to develop messages and curricula that include prevention activities that women can enact themselves, independent of their male partner. For example, interventions could target: preventing mother-to-child transmission, improving adherence to treatment regimens, increasing gender and racial/ethnic pride, and emphasizing the women-specific benefits of behavioral change (e.g., preventing STIs). Successful interventions should also address the broader social context of women's lives that affect health and behavior, such as stigma, discrimination, poverty, gender-based violence, xenophobia, and homophobia.

Recommended Action: Advocate that biomedical research funding be directed toward female-controlled prevention methods, including antiretrovirals, new female condom products, and vaginal and rectal microbicides, and include women in pre-exposure prophylaxis research.

Recommended Action: Advocate for behavioral research on women-specific HIV prevention interventions, including interventions for HIV positive women.

Recommended Action: Increase funding for procurement, distribution and programming for female condoms.

3. Invest in the creation and implementation of evidence-based HIV prevention interventions targeting men who have sex with women with the goal of preventing male-to-female HIV transmission via heterosexual sex.[xxxvii]

Background: The majority of women are infected with HIV through sex with a male partner. Prevention interventions aimed at preventing HIV transmission to women have focused on women themselves as the primary target for behavioral modification, ignoring the fact that the male partner is 50% of the heterosexual dyad and failing to adequately address the complex relational realities that drive male-female relationship (power, economics, children, dependence, etc.).

There are few rigorously-evaluated, evidence-based HIV prevention interventions that specifically target heterosexual men. In the CDC's Compendium of Evidence-Based HIV Prevention Interventions, only four of the 11 interventions that target heterosexual men (exclusively or in combination with women) were evaluated since 2000. Three of the more timely interventions target small subsets of the heterosexual male population (men about to be released from prison, STD clinic patients, men in outpatient psychiatric clinics) and one is implemented with male youth and their fathers. While these populations are at-risk and important targets for HIV prevention efforts, we must make an effort to create and support the implementation and evaluation of a broad range of HIV prevention interventions in a variety of venues that target men who have sex with women in a variety of venues.

Recommended Action: Interventions should target men who have sex with women and men who have sex with both men and women, including men who are HIV-positive as well as men whose HIV status is negative or unknown. Interventions with men must move beyond focusing on just the man as an individual and instead address issues of gender roles and gender power and men's roles as partners of women.

4. Invest in building the capacity of community-based organizations that work primarily with women.

Background: Gender disparities have clearly played a huge role in the ever-growing HIV epidemic among women and girls across the globe. These disparities have also played a role in the HIV prevention and care landscape for women in the United States. There are very few HIV organizations that are specifically focused on the unique needs of women and those that do exist are often poorly resourced thus, a) restricting their ability to provide a comprehensive array of HIV prevention and support services, and b) inhibiting them from moving beyond their direct, local work with women in order to weigh in on important policy issues. This has created a dynamic whereby policy at the national level is informed without an adequate representation of women thus negating the role that gender plays in the vulnerability of HIV infection.

Providing women-led and women-focused HIV organizations with capacity building tools will result in a better informed process of developing, implementing and evaluating prevention strategies in the United States. In the United States, this often manifests as a power imbalance between traditionally male-led organizations and those that specialize in serving women. Until this imbalance is addressed the quality of community input and partnership with government bodies will be flawed and women will continue to be at increased risk of contracting HIV. It is time to empower these organizations to gain equal footing and capacity to serve a population in need and to weigh in on critical prevention issues.

Recommended Action: We are aware that there is a significant commitment to capacity-building activities within the CDC. Within the current CBA announcement, a minimum of one selected organization must have the capacity to address needs of women-focused organizations. If there is no applicant that meets this criterion, money should be kept out of the pool to ensure that an organization be identified that can provide assistance to women-focused organizations. In the future program announcements must explicitly call for CBA providers that have core competence in capacity-building activities for women-focused organizations.

5. Enhance current surveillance outcomes by revising CDC's HIV/AIDS surveillance categories to more accurately reflect the epidemic in women.

Background: Most women infected with HIV are infected via their male partner, but women are often unaware of their male partners' behavioral risk factors. Under the current hierarchical surveillance categories, women who present with no knowledge of their male partners risk factors are coded as "no identified risk."

When reporting HIV/AIDS statistics, the CDC distributes the "no identified risk" individuals into the other risk categories based on pre-determined formulas, aiming to approximate the true distribution of HIV infection among risk populations. However, this system is imperfect and especially unfair to women (who are more likely than men to fall into the "no identified risk" category), as it may result in skewed surveillance statistics. Since funding and treatment and prevention priorities are tied to surveillance data, inadequate data collection means that treatment and prevention resources could be wrongly prioritized and/or distributed.

The adoption of the "presumed heterosexual" category will capture women who would traditionally fall into a non-identified risk category and therefore be missed in surveillance data. The adoption of this category would also improve resource allocation to support prevention planning efforts that better meet women's needs.[xxxviii]

Recommended Action: Include the "presumed heterosexual" category among the existing risk transmission categories in order to capture women who report no other known risk factors and are being classified as "No Identified Risk" in the current surveillance system.

6. HIV prevention for women must be comprehensive and consist of a continuum of strategies, including structural interventions that address social determinants that increase women's risk of HIV.

Background: Prevention must address social determinants, such as poverty, stigma, discrimination, gender-based violence, xenophobia, and homophobia, that are primary drivers of the epidemic. Prevention efforts must also take into account that prevention of HIV transmission – for both negative and positive women – is inextricably linked to access to information, testing, care, and support. Top public health officials and community activists agree -- we need a paradigm shift in HIV prevention research and policy to inform and improve our practices if we are to turn back the tide of HIV transmission. Poverty is not only an overriding driver of HIV/AIDS in the United States. It is also a vital issue to be addressed in federal, state and local policies in a time of increased acknowledgement of economic inequity and fiscal crisis.

Recommended Action: The National AIDS Strategy should develop a cross-agency strategy on addressing the social determinants of women's HIV risk, including poverty, and acknowledge that this requires participation beyond HHS.

Recommended Action: The CDC's National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention needs to clarify the structure of their Social Determinants Framework and timetable for developing the Framework, and clarify how it will impact the work of currently funded providers and address specific determinants of vulnerability in women.

Conclusion

When HIV/AIDS policies, whether national or local, do not address the specific needs of women affected by HIV/AIDS, they risk not only furthering the stigma and systemic discrimination faced by women but actually exacerbating the epidemic itself. With many of our towns, cities and states facing an epidemic that is hitting women, and especially women of color hard we cannot risk ignoring the needs of women, nor can we implement policies that will further alienate already disenfranchised groups.

It is imperative to use a human rights framework in the development of health care reform, including a National AIDS Strategy that will bring about a successful HIV/AIDS treatment and prevention plan for our nation. Such a framework takes into account, and seeks to alleviate, the intersecting issues surrounding HIV/AIDS treatment and prevention that perpetuate health disparities.

We have seen what years of disjointed and competing policies have created. But we hope to enter a new era with the Obama Administration, wherein the principles and recommendations provided above can serve as a guide in this period of great change. Taking women's rights and dignity into account throughout this process will prove beneficial not only for women and their families but for the nation as a whole.

Women and HIV Strategic Advocacy Grantee Convening

Participants' and Organizational Profile

***AFRICAN SERVICES COMMITTEE**, founded in 1981, is a non-profit organization based in Harlem and is dedicated to improving the health and self-sufficiency of the African community in New York City. African Services provides health, housing, legal, educational and social services to over 10,000 newcomers each year. Expanding HIV prevention and access to AIDS treatment and care is central to our mission. African Services has taken this work from Harlem to the frontlines of the global epidemic and now operates four HIV testing and care clinics in Ethiopia. African Services is committed to challenging stigma and discrimination at all levels and supporting individuals, families and communities most impacted by AIDS.*

Amanda Lugg
Community Advocate
Amanda Lugg began working at African Services Committee in 2000 as the AIDS Housing Coordinator. For the past five years as the Community Advocate, Amanda has worked to integrate direct service with immigrant mobilization and advocacy to address issues of immigration, access to healthcare, and the global AIDS pandemic at the local, national and international level. Amanda is also the Project Coordinator for the Independent Living Skills program which is an integrated health education and self-sufficiency program for HIV positive clients as well as being the Program Manager for African Services' social network-based recruitment strategy for rapid HIV testing.

Prior to joining African Services in 2000, Amanda began her work in HIV/AIDS as the Volunteer Manager with God's Love We Deliver and as a Community Organizer at Gay Men's Health Crises.
Amanda is also an active member and Board Treasurer of Health GAP (Global Access Project), a U.S. based organization dedicated to eliminating barriers to global access to affordable life-sustaining medicines for people living with HIV/AIDS.

***AIDS ALABAMA** was incorporated as a nonprofit organization in 1986, and our mission is to help people with HIV/AIDS live healthy, independent lives and to prevent the spread of HIV. Over the past 22 years, AIDS Alabama has grown to be the largest AIDS-service organization in the state. Our HIV prevention education efforts reach more people than any other organization in the state, and **we are the only agency in Alabama that focuses on providing housing to low-income individuals and families affected by HIV/AIDS.** At AIDS Alabama, we believe that housing is not only a basic need of life, but for those who are HIV-positive, housing is healthcare. Last year, AIDS Alabama provided over 81,000 nights of safe and affordable housing to homeless and near-homeless Alabamians living with HIV/AIDS. In addition, the agency provided vital supportive services to our consumers, including rental and utility assistance, transportation, insurance continuation, and vocational and life skills training. AIDS Alabama also provided essential HIV prevention education information to over 60,000 persons statewide. We have over 15 years of experience providing permanent and transitional housing and managing federal, state and local grants.*

Kathie M. Hiers
Chief Executive Officer
Kathie M. Hiers is the Chief Executive Officer of AIDS Alabama, a nonprofit organization that provides housing and services to low-income persons with HIV/AIDS as well as education, outreach, and testing. AIDS Alabama provides grants to the state's other nine AIDS Service Organizations and several clinics to ensure that services reach all 67 counties of the state. Additionally AIDS Alabama provides leadership for state and national advocacy.

Kathie has served locally as Co-Chair of the local Ryan White Consortium, as well as a two-year term as President of Birmingham's local Continuum of Care for homeless services. Kathie serves as convener of the Governor of Alabama's HIV Commission for Children, Youth, and Adults and the Alabama Legislative Workgroup, as well as on many other groups. Kathie educates legislators on the state's HIV/AIDS issues, promoting state investment in the HIV/AIDS portfolio. She and her staff implement an annual Media Day in the state's Capitol in which hundreds of HIV-positive persons, advocates, and policy makers gather to highlight the extreme need for resources to fight the HIV epidemic in Alabama. Kathie has been called upon for guidance in the development of state advocacy networks in Florida, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee.

Nationally, Kathie served as Co-Chair for the Southern AIDS Coalition (SAC) from 2004 through early 2009. She currently serves as Treasurer on the board of directors for the National AIDS Housing Coalition (NAHC), as Vice President of the Community Access National Network (CANN), and as an elected member of the Convening Group of the Federal AIDS Policy Partnership (FAPP). Kathie also serves on the board of the National Association of People with AIDS (NAPWA) as an at-large member of the Executive Committee.

Several national periodicals, including HIV Plus, Poz, The Washington Blade, The Houston Blade, Positive Populations, Mother Jones, the Progressive, Marie Claire, Congressional Quarterly, and Southern Voice, have published interviews with Kathie. Her work in Alabama has also been featured in Jacob Levenson's book, The Secret Epidemic: The Story of AIDS and Black America. Kathie co-authored the Southern States Manifesto: Update 2008, which was featured as the headline story on MSNBC in July 2008, as well as in nationwide media.

Kathie is frequently called upon to speak on AIDS housing, advocacy, and service issues. She has been a featured speaker for many press conferences and Congressional Briefings on the Ryan White Act, for Housing Opportunities for Persons with AIDS program, and on health disparities, as well as for the Southern AIDS Coalition. In 2006 Kathie appeared on a national webcast for the Southern AIDS Coalition that drew thousands of viewers. In 2008 she was featured at a Congressional Briefing in support of a National AIDS Strategy.

***ALLIANCE OF AIDS SERVICES-CAROLINA** provides a variety of support services to those affected with or effected by, HIV/AIDS in Wake, Durham and Orange counties with direct services such as providing transportation to medical appointments, providing housing and skilled nursing services. We serve the Triangle community through education and prevention programs and advocacy for those afflicted with and affected by HIV/AIDS. The Alliance mission is to serve people living with HIV/AIDS, their loved ones, caregivers and communities at large, through compassionate and non-judgmental care, prevention, education and advocacy.*

Jacquelyn Clymore
Executive Director
Jacquelyn Clymore is the Executive Director of the Alliance of AIDS Services-Carolina a $2.1 million ASO in Raleigh, NC. She has served in that position for five years, and prior to that worked as Director of Programs and Director of Client Services since 1990. Jacquelyn serves on the Board and as Treasurer of the Southern AIDS Coalition, helping to represent the issues of HIV positive southerners in North Carolina to the wider national audience. She holds a BA from Vassar College and an MS in Rehabilitation Counseling Psychology from the University of North Carolina at Chapel Hill.

***CENTER FOR HEALTH AND GENDER EQUITY (CHANGE)** was founded in 1994 to promote accountability of U.S. international*

policies to the sexual and reproductive health and rights agenda fought for by advocates for women's rights for several decades. Our niche was then and remains today to promote accountability by examining laws, funding streams, policies and program guidance set by the U.S. Administration and Congress; follow the funding and policy down to the ground in other countries; report on our findings as to whether and how U.S. policy is supporting or undermining our primary goals; and disseminate recommendations on needed changes in policy and program. We work within and across the intrinsically related areas of HIV and AIDS, sexual and reproductive health and family planning, and gender-based violence. Since our founding, we have grown in international recognition and legitimacy and have established contacts with advocacy movements within the U.S. and throughout the globe.

Serra Sippel
Executive Director
Serra Sippel is Executive Director of the Center for Health and Gender Equity (CHANGE), a nongovernmental organization that seeks to ensure that U.S. international policies and programs promote sexual and reproductive health and human rights for women and girls worldwide. Prior to joining CHANGE, she was International Program Director at Catholics for Choice where she worked collaboratively with women's rights activists around the world to secure and promote women's rights and sexual and reproductive health globally. She has also supported women's rights through her work at a homeless shelter for women with children in Texas and on behalf of incarcerated women in the state of Indiana. Serra holds a master's degree in religion. She has written extensively and spoken at conferences in the United States and internationally on sexual and reproductive health and rights.

CENTER FOR HIV LAW AND POLICY (CHLP) *is a national legal and policy resource and strategy center for people with HIV and their advocates. CHLP works to reduce the impact of HIV on vulnerable and marginalized communities and to secure the human rights of people affected by HIV. We support and increase the advocacy power and HIV expertise of attorneys, community members, and service providers, and advance policy initiatives that are grounded in and uphold social justice, science, and the public health. We do this by providing high-quality legal and policy materials through an accessible web-based resource bank; cultivating interdisciplinary support networks of experts, activists, and professionals; and coordinating a strategic leadership hub to track and advance advocacy on critical HIV legal, health, and human rights issues.*

Launched in January 2005, the Center for HIV Law and Policy remains the only national HIV legal and policy resource bank and strategy center, created to support, expand, and highlight the work of HIV advocates across the country. The Center takes a collaborative approach to the persistent problems of HIV discrimination and the shortage of trained advocates, providing resources, trainings, and strategic assistance at no cost while allowing local advocates to use their knowledge of local conditions to the best advantage. We are dedicated to supporting and expanding the advocacy capacity of other HIV advocates, particularly those who work on behalf of underserved and marginalized people with HIV/AIDS, and to securing local advocates' participation in the creation of national models and guidelines to ensure they reflect the on-the-ground reality of affected communities and those who are in the trenches on their behalf.

The Center for HIV Law and Policy is a national legal and policy resource and strategy that works to reduce the impact of HIV on vulnerable and marginalized communities and to secure the human rights of people affected by HIV. We increase the advocacy power of advocates, and community members, and advance policy initiatives that are grounded in and uphold social justice, science and the public health. We do this by providing an accessible web-based resource bank; leadership and analysis on key policy issues; and direct back-up to advocates on initiatives through our interdisciplinary support networks of experts, activists, and high-quality resources.

Catherine Hanssens
Executive Director

Catherine Hanssens, Executive Director and founder of the Center for HIV Law and Policy, has been working on HIV legal and policy issues since 1984. She previously was AIDS Project Director at Lambda Legal, where she led the development of Lambda's national HIV litigation and policy work; an attorney with the AIDS Law Project of Pennsylvania , where she created a multi-site, clinic-based project offering direct legal assistance to women with HIV; and, as a lawyer at the New Jersey Department of the Public Advocate, successfully litigated cases dealing with involuntary HIV testing, state-wide segregation and mistreatment of prisoners with HIV, and the right of incarcerated women to adequate prenatal care and funded elective abortions. She also was Director of the Women and AIDS Clinic at Rutgers University Law School-Newark.

Margo Kaplan
Staff Attorney

Margo Kaplan, Staff Attorney, is a graduate of New York University School of Law and the Kennedy School of Government at Harvard University. Before joining CHLP, she was a Staff Attorney Fellow with the American Civil Liberties Union. Margo also assisted with the research and drafting of the sixth edition of Professor Derrick Bell's text, Race, Racism, and American Law. Previously, she clerked for the Honorable Judge Julio M. Fuentes in the Third Circuit and the Honorable Judge John G. Koeltl in the Southern District of New York. She has worked for numerous human rights organizations, including the Center for Economic and Social Rights, the International Center for Transitional Justice, and the Carr Center for Human Rights. Margo is also a published author on the use of international law and cooperation to address human rights violations and end conflict. She is a former Teaching Fellow on the subject of international trade at Harvard University and a former Junior Fellow at the Center for International Studies for New York University School of Law.

***COMMUNITY HIV/AIDS MOBILIZATION PROJECT** (CHAMP) is a vibrant national initiative founded in 2003 by Julie Davids and other AIDS activists. Our mission is to fight HIV/AIDS by building a powerful community-based movement bridging HIV/AIDS, human rights, and struggles for social and economic justice. In an era of persistently high HIV rates and policies forged under concerted attacks on prevention efforts, CHAMP mobilizes people living with HIV, community activists, researchers, academics and policy advocates in our country, and links them with allies nationally and around the world. We unite across communities facing high rates of HIV, through community organizing, strategy development, media efforts, and training in popular education, history, critical thinking, and data analysis. CHAMP is arming a new generation of leaders with the tools and resources to challenge and change HIV/AIDS prevention policies; to attack the root causes of the epidemic such as poverty, homophobia, sexism and racism; and to sustain and expand our movements for social justice.*

CHAMP is dedicated to HIV prevention justice, understanding that the persistence and spread of the epidemic is rooted in social, economic and racial injustice. HIV prevention requires much more than "condoms onto bodies." Amplifying the voices of underserved and high-risk populations, we unite across constituencies for the development and distribution of a broad, effective range of HIV prevention options and programs, and for policies that address the inequality, bias and discrimination that are at the heart of the epidemic.

Vanessa Brocato, JD
Executive Director

Vanessa Brocato, JD, is the first hired Executive Director at CHAMP. She began doing HIV and AIDS work as a Stop AIDS Chicago trained peer educator in high school, then continued as president of her college LGBTQ organization in Peoria, Illinois. After graduating with a degree

in Women's Studies from Bradley University, she earned a law degree from Georgetown University Law Center, where she received the human rights award for her graduating class. Since then, she has advocated at the local, national, and international levels for HIV prevention as a public health and human rights imperative.

Vanessa is a founding member of the Caucus for Evidence-Based Prevention and facilitated working groups on vulnerable populations for the International AIDS Conference (IAC) held in Toronto in 2006. In 2008, she served as a contributing editor to the Caucus's daily newsletter and CHAMP's community blog AIDS2008.com at the IAC in Mexico City. In 2007, she served as a key member of the coordinating team for the international Women Deliver conference and advocacy campaign launched in London. Working with advocates worldwide, she helped to facilitate the involvement of HIV positive women, harm reduction advocates, women who have experienced imprisonment, and young people into this pivotal global event on maternal health and sexual and reproductive rights.

Her publications include Understanding Religious and Political Opposition to Reproductive Health and Rights: a Resource Guide; "Violence Against Women and HIV/AIDS" an information manual published for the Ark, Ghana; Profitable Proposals: Explaining and Addressing the Mail-Order Bride Industry through International Human Rights Law in the San Diego International Law Journal; and National Human Rights Commissions in Voices of African Women: Women's Rights in Ghana, Uganda, and Tanzania. Prior to joining CHAMP, Vanessa worked as the Assistant Director for Prevention Policy at Gay Men's Health Crisis (GMHC). She has also served in various capacities at amfAR, the Foundation for AIDS Research; Family Care International; Housing Works; the Sexuality Information & Education Council of the U.S. (SIECUS); the Whitman-Walker HIV/AIDS Clinic, Legal Services; and the Women's Law and Public Policy Fellowship Program.

Julie Davids
Director, Policy and Mobilizations
Julie Davids is Director for Policy and Mobilizations at the Community HIV/AIDS Mobilization Project (CHAMP), after serving five years as the group's founding Executive Director. Currently, working alongside other staff, she coordinates research advocacy activities and strategic communications and assists with fundraising, program planning and movement building. She learned the ropes of hell-raising from the leaders of ACT UP Philadelphia in the first-wave HIV/AIDS direct action protest movement, and stuck around for the next 14 years. During that time, she worked on campaigns for needle exchange, health care access, research issues, and the rights of people of all genders, and served as a community advocate in the AIDS Clinical Trials Group (ACTG). She helped to start Project TEACH (Treatment Education Activists Combating HIV), which provides activist and leadership training for people living with HIV at Philadelphia FIGHT.

She was the first community organizer for Health GAP, an activist group dedicated to eliminating barriers to access to HIV/AIDS treatment around the world. She founded CHAMP in 2003 after a year-long Charles H. Revson fellowship at Columbia University, where she developed an analysis of the history and future of HIV/AIDS as a social struggle tied to economic, racial and human rights. She is the co-chair of the Federal AIDS Policy Partnership (FAPP) and is on the steering committees of the Caucus for Evidence-Based Prevention and the International Rectal Microbicides Advocates. Currently, she is the board co-chair for the Providence Youth and Student Movement (PrYSM), a non-profit Southeast Asian youth-led organization whose vision is to end all forms of violence, whether they come from the self, the community, or from institutions and systems.

***HIV LAW PROJECT** remains the only legal agency providing comprehensive legal services exclusively to low-income people living with HIV/AIDS in New York City. HIV Law Project handles nearly 1,000 cases each year addressing a range of critical legal needs for positive people, including housing advocacy and eviction prevention,*

[redacted]

immigration services, and benefits issues. In addition to its renowned direct legal services program, HIV Law Project partners with positive women through its Center for Women & HIV Advocacy to advance public policies that are responsive to their needs and enhance their lives as women living with HIV. Informed by 20 years of experience on the front lines of HIV services, HIV Law Project monitors national policy as it impacts women with HIV, engages in education campaigns and produces policy reports on a range of domestic HIV health and human rights issues. HIV Law Project targets its resources to traditionally underserved populations, particularly women and their families; people of color; undocumented and recent immigrants; members of the LGBT community; and the homeless.

Tracy L. Welsh, Esq.
Executive Director

Tracy L. Welsh has over 15 years of legal and advocacy experience working with low-income people living with HIV/AIDS. Having worked as a front line staff attorney in Manhattan and the Bronx for many years, Ms. Welsh assumed leadership of the HIV Advocacy Project at Queens Legal Services in 1998. In 2002, she joined HIV Law Project as Executive Director. As Executive Director, Ms. Welsh has stabilized the agency and subsequently led it through its first branding and strategic planning process. Building on the agency's programmatic successes, Ms. Welsh has fought to preserve government funding for HIV legal services in New York City as well as diversify HIV Law Project's own funding base through increasing private donor initiatives. Ms. Welsh is actively involved in HIV Law Project's policy and advocacy work, and a passionate advocate for social justice for low-income people and traditionally disenfranchised communities. She works along side a team of exceptionally talented and committed professionals (managers, attorneys, community organizer) who, together, seek to realize HIV Law Project's mission and core values. Ms. Welsh holds a Juris Doctorate from CUNY School of Law and a Masters in Public Policy and Public Administration from Columbia University.

Hadiyah Charles
Community Organizer

Hadiyah Charles is the community organizer for HIV Law Project's Center for Women and HIV Advocacy and has over 10 years of experience working with people infected and affected by HIV/AIDS. As an advocate and grassroots activist, Ms. Charles has worked closely with women living with HIV/AIDS, their families, and their communities. Through her work at the Center, Ms. Charles has spearheaded a number of important initiatives, including intensive advocacy and media trainings for Center women, community outreach and education workshops on issues relevant to women living with HIV/AIDS, and a robust campaign to bring comprehensive sex education into New York schools. Ms. Charles is committed personally and professionally to fighting the injustices faced by women living with HIV/AIDS. In addition to her professional responsibilities, Ms. Charles is an active member in her Brooklyn community as well as communities in the Bronx and Manhattan.

Alison Yager, Esq.
Project Manager

Alison Yager is the Project Manager for HIV Law Project's Center for Women and HIV Advocacy and has been advocating on behalf of women, children and families for over thirteen years.
Ms. Yager began her career as an activist at the Children's Defense Fund - New York where she focused on child health issues. She subsequently spent a year in Mexico working with indigenous women who were struggling for civil rights issues, and safety in their homes. During law school she represented homeless and runaway youth in Los Angeles. Since graduating from law school in 2001, Ms. Yager provided legal services first to young people at The Door's Legal Service Center in Manhattan, then represented young survivors of dating violence at Break the Cycle- New York, and has been a Staff Attorney at HIV Law Project since 2006.
She has served as Project Manager of CWHA since September 2007. Ms. Yager is responsible for producing policy reports, monitoring significant policy issues, tracking proposed legislation, and responding to emerging issues through outreach to media, and to allies. Finally, she oversees the Law TAP classes (now in English and Spanish), a "know your rights"

program, and the Advocacy Institute, a new advocacy training program, both for HIV-positive women.

***INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV/AIDS** (ICW) is the only global network run by and for HIV positive women including young women. It was founded in 1992 due to a desperate lack of support, information and services available to women living with HIV, and the need HIV positive women felt to influence policy development. The founding members were a group of 56 HIV positive women from around the world attending the 8th International Conference on AIDS held in Amsterdam in July 1992.*

*ICW is an international network run by and for HIV positive women that promotes all our voices and advocates for changes that improve our lives. ICW's vision is a world where all HIV positive women have a **respected and meaningful involvement** at all political levels; local, national, regional, and international, where decisions that affect our lives are being made; full **access to care and treatment**; and enjoy **full rights**, particularly sexual, reproductive, legal, financial and general health rights; irrespective of our culture, age, religion, sexuality, social or economic status/class and race.*

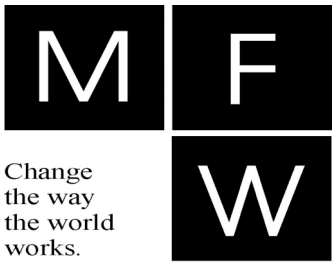
ICW exists to promote the voices and improve the situation of HIV positive women throughout the world. It aims specifically to raise awareness of HIV positive women issues and promote effective action to address them; empower women living with HIV/AIDS to address and promote change on issues of importance to HIV positive women's lives; reduce the isolation of women living with HIV/AIDS and overcome the stigma of HIV/AIDS; and romote the human rights of women living with HIV/AIDS globally.

Aziza Ahmed
Women's Law and Public Policy Fellow
Aziza graduated from Emory University with a Bachelor of Arts in Women's Studies. She then went to Johannesburg, South Africa, where she worked with the Planned Parenthood Association of South Africa (PPASA), organizing sexual and reproductive health education for adolescents and sex workers. Aziza later attended the Harvard School of Public Health (HSPH) and received a Masters of Science in Population and International Health. Her master's thesis focused on children engaging in transactional sex in Jamaica and their increased vulnerability to HIV/AIDS. After graduation, Aziza worked as a consultant in Barbados with the United Nations Development Fund for Women (UNIFEM), the United Nations Children's Fund (UNICEF), and Development Alternatives With Women in a New Era (DAWN). She subsequently began her law degree program at the University of California, Berkeley. She spent her first summer with Breakthrough, a human rights organization in India, where she co-wrote a curriculum on sexual rights in India. She spent her second summer working with the International Women's Health Coalition mainly on issues related to UN General Assembly Special Session on HIV/AIDS five-year review. Aziza is a Georgetown Fellow supported by the Ford Foundation.

***M·A·C AIDS FUND**, established in 1994 by M·A·C Cosmetics, supports men, women and children affected by HIV/AIDS globally. Introducing its first VIVA GLAM lipstick that same year, M·A·C decided that every cent of the selling price of the VIVA GLAM lipsticks would go to the M·A·C AIDS Fund. With a total of six shades of Viva Glam lipstick and two shades of Viva Glam lipglass now sold worldwide, and through the annual Kids Helping Kids Card Program, M·A·C Cosmetics has provided over $135 million (US) to date for the M·A·C AIDS Fund. The M·A·C AIDS Fund is the heart and soul of the company*

- with its employees giving their time, energy and talent to help those affected by HIV/AIDS worldwide.

Nancy Mahon, Executive Director of MAC AIDS Fund & Senior Vice President, M·A·C Cosmetics
Diana Echevarria, Executive Director, North American Programs



MS. FOUNDATION FOR WOMEN *has supported grassroots organizations across the United States to sustain the voice and vision of women who are leading change in their communities—particularly low income women, young women, and women of color. More than a grantmaker, the Ms. Foundation connects organizations with training, networking, and other resources. We leverage women's power by connecting powerful and effective local organizations to the national level to help build and sustain national movements.*

The Ms. Foundation for Women supports the efforts of women and girls to govern their own lives and influence the world around them. Through its leadership, expertise, and financial support, the Foundation champions an equitable society by effecting change in public consciousness, law, philanthropy, and social policy. Our work is guided by our vision of a just and safe world where power and possibility are not limited by gender, race, class, sexual orientation, disability, or age. We believe that equity and inclusion are the cornerstones of a true democracy in which the worth and dignity of every person are valued.

Desiree Flores
Program Officer, Health
Desiree Flores, Program Officer, Health, oversees grantmaking and programmatic work for the Ms. Foundation's Reproductive Rights Coalition and Organizing Fund, Women and AIDS Fund, and the New Partners, New Initiatives Fund that supports work around sexuality education. Before joining the Ms. Foundation for Women in 2001, Ms. Flores was a Fellow with the Congressional Hispanic Caucus Institute Fellowship Program in Washington, D.C. (Fall 1999-Summer 2000) where she honed her skills in advocacy, grantmaking, and federal policy work. During this time, she worked in the Dance division of the National Endowment for the Arts and in the Immigrant Women Program at the NOW Legal Defense and Education Fund. Ms. Flores is currently a board member of the Funders Concerned About AIDS and a member of the National Network of Grantmakers, National Coalition to Support Sexuality Education, New Leadership Networking Initiative, Pro-Choice Public Education Project steering committee and the Funders Network on Population, Reproductive Health and Rights. She holds a bachelor's degree in dance and Chicana/o Studies from UCLA (1989), where she was active in campus organizing and projects using art as social activism.

Rona Taylor
Organizer, National Women and AIDS Collective
Rona Taylor, an ardent women's health advocate, is currently the Board President of The Women's HIV Collaborative housed at the Ms. Foundation for Women: it's the only network that advocates for HIV/AIDS organizations that are led by, and serve, women. Her other involvements in HIV/AIDS work include participating in the Centers for Disease Control's (CDC) External Peer Review process and serving as the Community Advisory Board Liaison of the NYU Adult and Pediatric AIDS Clinical Trials Unit. She has also been a member of the East New York/Brownsville HIV CARE Network and Brooklyn Outreach Worker's Network. Prior to her work at the Ms. Foundation, she was the Program Coordinator for the African American Capacity Building Initiative (AACBI) and the National Technical Assistance Provider for Syringe Exchange Programs at the Harm Reduction Coalition.

NATIONAL AIDS FUND *was founded in 1988 to reduce the incidence and impact of HIV/AIDS by promoting leadership and generating resources for effective community responses to the epidemic. Through its unique expanding network of Community Partnerships, NAF supports over 400 grassroots organizations annually which in turn provide HIV prevention, care and support services to underserved individuals and populations most impacted by HIV/AIDS including communities of color, youth and women.*

The National AIDS Fund connects national and local funders, scientists, and community based organizations. With its Partnerships, it invests more than $8 million annually in HIV/AIDS grant making to agencies nationwide, and has the ability and responsibility to lead discussions on the most effective strategies for preventing HIV. Grants provide care and services and work to prevent new infections through education and advocacy. The National AIDS Fund Community Partnerships use the leverage of national Challenge Grants to raise support locally, and make community-level decisions about how and where funds should be spent. Together with our Community Partnerships, the NAF has raised and invested over $150 million since 1988 for the fight against HIV/AIDS in the United States.

Kandy Ferree, M.C.P.
President & CEO

Kandy Ferree, M.C.P. is a leader in health philanthropy and currently serves as the President and CEO of the National AIDS Fund (NAF) and adjunct faculty in the areas of Gerontology and Sociology at Messiah College. The National AIDS Fund is the 6th largest private funder of domestic HIV/AIDS programs in the United States. Over the past 20 years NAF has raised and invested over $150M in HIV prevention and care through its Challenge Grants program alone. Ms. Ferree is credited with an organizational turn-around at the National AIDS Fund – rebuilding and diversifying the Board of Trustees and staff and using her relationship building and fundraising skills to grow the organization's annual budget from $3.5M in 2001 to over $10M in 2009. Ms. Ferree began her career in New York City where she worked in HIV/AIDS direct services. She also served as Program Director for HIV/AIDS and housing programs in south central Pennsylvania before entering the non-profit consulting arena working on corporate diversity training and minority employee recruitment and retention strategies.

Prior to joining the National AIDS Fund staff in 1999, Ms. Ferree was the Program Officer at the Foundation for Enhancing Communities – a community foundation in Harrisburg, Pennsylvania. In this capacity she was responsible for managing all donor advised and discretionary grantmaking as well as scholarships. She was also responsible for four special initiatives and served as the Program Officer liaison for three regional community foundation affiliates. Ms. Ferree holds a Bachelors degree in Family Studies with a minor in Gerontology from Messiah College and a Masters degree in Community Psychology from the Pennsylvania State University. Her professional interests include building strategic philanthropic relationships with corporations, foundations and individuals to address public health issues. Her research interests include identifying the social determinants of sexual onset and HIV risk among adolescent girls and using that information to create prevention interventions; the translation of evidence-based HIV prevention programs into broad community application; the impact of societal attitudes and norms on the aging process and the self concept of women; and finding ways to build bridges across public and private funding silos as well as between academic institutions and community-based organizations.

Suzanne Kinsky
Program Officer

Suzanne Kinsky has worked in the HIV/AIDS field for eight years. Prior to coming to the National AIDS Fund to manage the Women's Initiative, she worked for the Maryland AIDS Administration where she managed various aspects of the statewide Counseling, Testing, and Referral Program and conducted program evaluation for HIV prevention interventions targeting at-risk adults. Suzanne was also the Women's Services Director at Our Place in Washington, DC, a non-profit serving incarcerated and recently-released women. In addition, she spent two years working as a Program Coordinator with the Washington AIDS Partnership. Suzanne holds a Master of Public Health degree from the Johns Hopkins Bloomberg School of Public Health and a Bachelor's degree in Sociology from Cornell University.

NO/AIDS TASK FORCE, *founded in 1983, is one of the oldest and largest AIDS Service Organizations in the Gulf South. We have been providing, hope, dignity and care to men, women and families affected by HIV and AIDS for over 25 years. NO/AIDS Task Force mission is to reduce the spread of HIV infection, provide services, advocate empowerment, safeguard the rights and dignity of HIV-affected individuals, and provide for an enlightened public.*

Gina Brown
Homeless Case Manager
Gina Brown is a single mother of two children diagnosed with HIV positive in 1994 while pregnant with her youngest child (whom is negative thanks to AZT). Gina believes to have contracted the disease from my former boyfriend, who is currently deceased. She started working in the field of HIV/AIDS in 2002 and currently employment title is Homeless Case Manager for the NO/AIDS Task Force, which has been a rewarding experience working with the homeless population of both men and women. In addition to this Gina is also a student at Southern University at New Orleans enrolled in the undergrad Social Work program, with an expected graduation date of May 2011.

PLANNED PARENTHOOD FEDERATION OF AMERICA *is the nation's leading sexual and reproductive health care advocate and provider. Planned Parenthood affiliates operate nearly 880 health centers nationwide, providing medical services and sexuality education for millions of women, men, and teenagers each year. Planned Parenthood also works with allies worldwide to ensure that all women and men have the right and the means to meet their sexual and reproductive health care needs.*

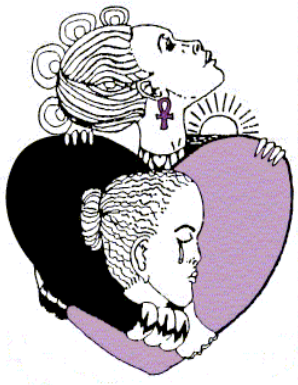
Emily Stewart
Policy Analyst
Emily Stewart is a Policy Analyst for Planned Parenthood Federation of America (PPFA) in Washington, DC. In this capacity, she analyzes policy and regulatory initiatives that impact women's access to reproductive health care services and works closely with Planned Parenthood affiliates on health care finance policy issues that directly affect patients' ability to access care. Immediately prior to joining PPFA, Ms. Stewart served as a policy analyst for the Health Privacy Project, where her work focused on examining federal and state health privacy laws and regulations, public health surveillance systems, and health information technology initiatives.

SISTERHOOD MOBILIZED FOR AIDS/HIV RESEARCH AND TREATMENT (SMART) *was founded to provide treatment education and support for all women living with HIV/AIDS in order to increase their self-confidence and self-esteem. SMART University is our core Treatment and Prevention Education Program founded in 1998 by a group of women living with and affected by HIV/AIDS in East Harlem. SMART University welcomes all women living with or affected by HIV/AIDS who are interested in getting control of their lives; willing to listen and be heard; and interested in learning how to better their health in order to live longer and healthier lives. These interactive classes are taught by experienced health care and legal professionals, activists and advocates. SMART's mission is to spread vital treatment and prevention information for women in a safe and supportive environment. As women go through the SMART University journey together, they gain the necessary tools to "take charge" of their lives to stay mentally and physically healthy.*

Susan Rodriguez, Founding Director

Christina Rodriguez, SMART Youth Coordinator

SISTERLOVE*, Inc., founded in 1989, is the oldest nonprofit in the State of Georgia dedicated specifically to the education, prevention, advocacy and support needs of women at risk for or living with HIV infection and AIDS. We are a reproductive justice organization, with a gendered lens on HIV/AIDS. Dázon Dixon Diallo, SisterLove's founder and current Chief Executive Officer, was moved to create an organization to address the needs of Black women when she realized that the looming AIDS epidemic among women was not a priority of the feminist health movement of which she was an active participant. At the time, there were no local services available to women, yet dozens of newly diagnosed Black women with AIDS were desperate for help.*



A local group of Black women self-help advocates decided the work of SisterLove was a critical need based on the undeniable fact that African American women have been disproportionately represented among women with sexually transmitted infections for decades and would most likely come to represent those most affected by HIV. They decided that Black women would take the lead in responding to the needs of other Black women, as well as themselves. Unfortunately, the women were right. The incidence of HIV among African American women and women of African descent exceeds that of any other ethnic group of women in the United States. SisterLove's history of service and advocacy includes providing prevention and health education for women at risk for HIV and other reproductive health challenges, providing leadership development and capacity building among HIV-positive women to become leaders and representatives of their communities, and advocating on behalf of women most affected by the lack of national and international attention paid to actions and attitudes which threaten women's sexual and reproductive health and rights.

Dázon Dixon Diallo
Founder & President

Dázon Dixon Diallo is Founder and President of SisterLove, Incorporated, the first and largest women's AIDS organization in the southeastern United States. She also serves as an adjunct faculty member in women's health at Morehouse School of Medicine and Spelman College, and is a recipient of the 2004 Ford Foundation's Leadership for Change Award. Ms. Diallo currently chairs the Fulton County Title I HIV/AIDS Services Planning Council and the Community Advisory Board of the HOPE Clinic, Emory University's HIV Vaccine and

Microbicides Research Center. She hosts a weekly radio program focused on black women, "Sistas' Time," on WRFG 89.3FM and www.wrfg.org in Atlanta, and has coordinated delegations of African-American women to Brazil, China, Egypt, Jamaica, South Africa, Senegal, and Uganda. She recently opened a SisterLove program office in Mpumalanga, a rural South African province near Johannesburg. Ms. Diallo holds a master's degree in public health from the University of Alabama at Birmingham and a bachelor's degree from Spelman College in Atlanta, Georgia. She teaches leadership and advocacy in the MIPH course.

***THE WOMEN'S COLLECTIVE (TWC)** mission is to meet the self-defined needs of women, girls and their families living with or at-risk for HIV/AIDS, reducing barriers to care and strengthening their network of support and services. As a Washington DC-based nonprofit organization led by women with HIV and their allies/advocates, TWC works to fulfill its mission by providing services that are peer-led, woman and girl-focused, family-centered, and culturally appropriate; a safe, non-judgmental environment for all women, girls and families; a voice for women, girls and their families who are living with or at-risk for HIV/AIDS through advocacy at the local, national, and international levels; and creating partnerships among service providers, governmental, non-governmental and private entities.*

Our services are divided between three programs: 1.) HIV care management for women ages 18+ and families living with HIV/AIDS, 2.) HIV prevention for women, girls and families at risk for HIV/AIDS, and 3.) Policy & Advocacy to address the needs and issues of women and girls locally and nationally. TWC implements core programs such as: family-centered case management services; peer outreach; comprehensive risk counseling services; HIV counseling, testing and referral services (CTR); primary and secondary prevention skills building groups; peer-based support groups; and fosters a national policy advocacy network led by women living with HIV, among other services.

Patricia Nalls
Founder & Executive Director

Patricia Nalls is the mother of two children—Alana, age 29 and Shawn, age 25—and she is a community AIDS activist, locally and nationally, for the rights of women, girls and their families living with and at risk for HIV/AIDS. She was diagnosed with AIDS in 1986, after the death of her husband and three year-old daughters. Patricia has since been a long-time activist for women in the Washington, DC community. After years of frustration at not finding appropriate support for women, girls and their families she founded The Women's Collective, an AIDS service organization (ASO) dedicated to empowering women living with and at risk for HIV/AIDS, with special emphasis on women of color. The Women's Collective provides Care, Prevention and Advocacy services in a and most importantly gives women, girls and their families the hope they need to live healthy lives. Under her leadership, what began as a support group in her home is now an organization with a staff of twenty six employees. The Women's Collective program model has been shared with women activists from Africa, Ukraine, Guyana, Spain, Canada and Brazil among others as well as around the USA.

Patricia served as a consultant on a Health Resources and Services Administration (HRSA) Special Project of National Significance (SPNS) that focused on bringing women living with HIV/AIDS to the policy table where decisions were being made about their very lives. She has organized dozens of community focus groups, speak outs, and information sharing meetings, as well as assisted with the publication of various research and policy documents designed to target Policy makers to assist them in better understanding the needs of women. She has successfully advocated for women, girls and families at all levels including policy forums and with the Ryan White Title I Planning Council where she has made a difference In breaking down many of the barriers women face in accessing services. She also sat on several other committees, including, the PWA Committee, the District of Columbia's Mayor's task force on AIDS, Co-Chair of a committee that looked at Medicaid waiver for DC. She also speaks on

Capitol Hill to address issues that women living with HIV/AIDS face in the fight against the disease.

Patricia has been featured in many media venues on a variety of critical issues facing women. She appeared in Essence magazine; People magazine, Newsweek the Washington Post; Little India; and on several National and local television interviews. Patricia was the recipient of several awards including: The Courage Award; The Linowes Leadership Award from the Community Foundation; Caribbean People's International Award; The WJLA Channel 7 Tribute to Working Women Award. Pat also received the National Association of People with AIDS (NAPWA) Certificate of Recognition of efforts on behalf of women living with HIV/AIDS in DC and the National Association for the Advancement of Colored People (NAACP) Youth Council of DC's Outstanding Leadership Award. She also was recognized as a Hero in the Struggle, an honor of the Black AIDS Institute among other honorees such as Coretta Scott King and Dr. M. Jocelyn Elders and the prestigious Gloria Award from the Ms. Foundation. The Women's Collective was also featured on Transformation Nation a television show that feature people doing outstanding work to change lives in their community.

Brook Kelly
Women's Law & Public Policy Fellow

Brook Kelly is the Women's Law & Public Policy Fellow at the Women's Collective in Washington DC. She works with a local and national network of women living with HIV/AIDS, and in coalition and partnership with likeminded organizations and universities to bring attention and give voice to the particular concerns of women living with and a risk for HIV/AIDS through the combined efforts of grassroots organizing, and policy and legislative reform. Currently, she is developing a report in partnership with the Women's International Human Rights Clinic at Georgetown University Law Center on the human right implications for women living with and at risk for HIV/AIDS in the District of Columbia. In partnership with the Harrison Institute for Public Law, she is developing a report on the impact of doctor-patient relationships in the treatment and prevention of HIV/AIDS for women.

As a recent graduate of Georgetown University Law Center Brook spent the previous year clerking for the Honorable Ronald L. Ellis in the United States District Court of the Southern District of New York. She has experience in the field of women's rights law and policy, specifically reproductive health and justice. During law school she worked for the California Women's Law Center and the ACLU Reproductive Freedom Project organizing grassroots, local and state policy initiatives, as well as federal impact litigation. Additionally she worked with the Georgetown Women's International Human Rights Clinic in Swaziland on a fact finding mission and co-wrote a human rights report and proposed legislation on the property rights of Swazi women living with HIV/AIDS.

WOMEN ORGANIZED TO RESPOND TO LIFE-THREATENING DISEASES (WORLD), *founded in 1991, was registered as a charitable organization in 1994. WORLD works to support and educate women living with HIV, and to inspire them to advocate for themselves and one another. It does this through a variety of peer led HIV education, training and advocacy projects. WORLD serves women living with HIV throughout the U.S. and has published a newsletter with an international readership for the last 17 years. It has been recognized as a national leader in developing and promoting leadership and advocacy among HIV positive women.*

WORLD is a diverse community of women living with HIV/AIDS and their supporters whose mission is to provide support and information to women with HIV/AIDS and their loved ones; educate and inspire women with HIV/AIDS to advocate for themselves, one another and their communities; and promote public awareness of women's HIV/AIDS issues and a compassionate response for all people with HIV/AIDS

Cynthia Carey-Grant
Executive Director

Cynthia Carey-Grant is the incoming Executive Director at Women Organized to Respond to Life-threatening Disease (WORLD) as of June 1, 2009. She returns to the arena of women's health advocacy after working for several years in the philanthropic sector. Cynthia brings over 25 years of women's health leadership and advocacy experience to her new role.

Prior to this appointment, Ms. Carey-Grant served in leadership roles in several prominent women's health organizations. Among these were Planned Parenthood Federation of America as Western Regional Field Manager in the Public Policy Division where she was responsible for the management of PPFA public affairs assistance through the implementation of strategies at the local level and as it relates to the development of affiliate and state office public affairs work. Cynthia served as Project Manager for Women's Health with The Permanente Medical Group where she worked to advance women's health within Kaiser Permanente. The Women's Health -KP initiative received national recognition for leadership in improving health service to women in northern California. She was also the Executive Director and then Board Chair of the California Abortion and Reproductive Rights Action League where she distinguished herself through work in local, national and international reproductive health initiatives. In 1993, Cynthia led CARAL as it expanded its mission from a focus on abortion rights to including the full range of reproductive choices for all women. Under her leadership, CARAL received the Outstanding Grassroots Organizing award from NARAL. Additional volunteer leadership includes Chair of the Board of the Bay Area Black Women's Health Project and Board Chair of Californians for Justice (CFJ) formed in 1995 to work against passage of the anti-affirmative action initiative proposition 209.

Cynthia's expertise and passion is in developing relationships with culturally diverse community based women's health advocates and organizations, legislators and the media to improve access to affordable quality health care for women. She has committed her life work to improving the status of women, people of color, and the empowerment of the politically disenfranchised. One of her most cherished dreams is to help build a multi-cultural, international woman's health and reproductive justice movement. Cynthia is a proud family member of three living generations of feminist, pro-choice African/Native American women. Cynthia has three healthy adult children and two grandchildren.

Naina Khanna
Director, Policy and Community Organizing, WORLD
Coordinator, U.S. Positive Women's Network

Naina Khanna is the Director of Policy and Community Organizing at Women Organized to Respond to Life-threatening Disease (WORLD) in Oakland, California. Naina serves on the leadership team of the National Women and AIDS Collective (NWAC), the first national policy coalition led by and for women living with and affected by HIV. Naina also serves on the coordinating committee for a National AIDS Strategy and on the women's task force of the California HIV Prevention Planning Group. Also at WORLD, Naina is Coordinator of the newly launched U.S. Positive Women's Network (PWN), a membership body of individual HIV positive women, inclusive of transgender women, that advocates for policies and programs at local, state and national levels that are reflective of HIV positive women's needs. She has spoken nationally and internationally about the critical role HIV positive women play in developing policies and programs that will meet women's needs and help end the epidemic

overall. Prior to joining WORLD, Naina co-founded and served as national field director for the League of Young Voters, a progressive national youth voter engagement project.

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[xiv] *Id.*
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