



NATIONAL ASSOCIATION OF PEOPLE WITH AIDS WRITTEN TESTIMONY ON DOMESTIC HIV PREVENTION

COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM CONGRESSIONAL HEARING ON DOMESTIC HIV PREVENTION

September 16, 2008

Committee Chairman Waxman, Ranking Member Davis, Congresswoman Holmes-Norton, Congressman VanHollen, and the entire Oversight Committee, thank you for your demonstrated leadership and the opportunity to speak with you about the state of HIV prevention in the United States of America.

As the trusted and representative voice of the greater than one million persons living with HIV/AIDS in America, I say with great confidence that we know our status and that has enabled us to save lives. HIV continues to disproportionately affect gay and bisexual men, women and men of color, and individuals challenged by poverty, incarceration, and mental illness. It is NAPWA's belief as well as many in the AIDS community that HIV is exacerbated by social marginalization with effects that manifest in individual health challenges.

For this reason, from our view HIV prevention can only succeed through access to and dissemination of evidence-based information and education, protected and voluntary HIV testing and screening services; expanded access to healthcare, treatment, and support services; and efforts to reduce stigma and increased support for sero-status disclosure, as well as by addressing structural/systemic/economic barriers that continue to perpetuate HIV vulnerability among the most marginalized groups of Americans.

This is the basis of support for the call for a National AIDS Strategy that is coordinated, evidence-based, outcome-driven and inclusive of people living with HIV/AIDS. The principles of the National AIDS strategy, as well as the over 300 organizations and 1000 individuals that have endorsed it, can be found online at www.nationalaidsstrategy.org. As we are in the midst of an election year, it is critical to those living with and concerned about HIV/AIDS in this country that those who are in or seeking political office once again prioritize HIV/AIDS through their support of the establishment and implementation of a National AIDS Strategy. To this end it is critical for people living with HIV/AIDS to share their lived experiences to inform development and implementation of a national AIDS strategy.

Evidence-based Information & Education

The Centers for Disease Control updated its annual HIV incidence estimate reporting that HIV infections have been as much as forty percent higher for the past fifteen years. This information does not indicate that prevention doesn't work, but that it is not reaching the amount of people that need it. Dr. David Holtgrave of Johns Hopkins University and Julie Scofield of the National Alliance of State and Territorial AIDS Directors (NASTAD) in the *Baltimore Sun*, August 31, 2008 articulated the community consensus that we must scale up HIV prevention in this country to an annual investment of \$1.3 billion – this commitment will bring resources closer to pace with prevention and surveillance need and efforts.

Over the past eight years we've seen an emphasis on prevention interventions that are not science-based. The administration has pushed abstinence-only-until-marriage education and refused to remove the ban on federal funding for syringe exchange programs. These kinds of short-sighted policies have real consequences for people's lives. Max Siegel, now employed by AIDS Alliance for Women, Youth, and Families was inadequately prepared to make informed decisions about his own sexual health as a result of ideologically based abstinence-only-until-marriage programs. Max Siegel is now HIV-positive and sharing



his experience to address the unintended consequences of failing to provide comprehensive sex education. At the same time the Centers for Disease Control also released information articulating that while HIV infections decreased slightly among women, women between the ages of pregnancy and sexually transmitted diseases – indicators of HIV risk—revealed increased susceptibility.

Human sexuality is a right! Evidence proves that risk reduction strategies reduce HIV infections. It is imperative that we don't sacrifice lives and waste already constrained resources on programs that have been proven to be ineffective. Verified by the testimony from the Centers for Disease Control, more people have been acquiring HIV than we previously thought.

Support HIV Diagnosis & Quality Healthcare and Treatment

Dr. Holtgrave provided research detailing that among persons living with HIV -- people like us—members of the National Association of People with AIDS -- 95% are making decisions about their health and behavior that aren't contributing to the spread of HIV. We mentioned earlier that we know our status and that has empowered us to save lives. Sixteen years ago, the National Association of People with AIDS (NAPWA) launched National HIV Testing Day because we believe that taking an HIV test makes it possible for us to protect ourselves and those we love. This supports the evidence from researchers that people who are aware of their HIV status make adjustments to their behavior that are vital to their health and advance HIV prevention goals. However, a positive HIV diagnosis is life altering and decisions to test must be made accessible in a safe, voluntary, and confidential manner. While NAPWA supports increased and targeted HIV screening to bring important health information to vulnerable populations, we strongly believe there is an obligation to link those HIV-positive individuals to high-quality care, treatment, and support services.

Highly Active Anti-retroviral Treatment (HAART), also known as “the drug cocktail” first came onto the scene in 1996. The availability of which has drastically reduced individual progression to AIDS as well as deaths. Despite documented evidence in a 2004 AIDS journal which indicates that HIV therapies reduce infectiousness by 60%, approximately half of people living with HIV that are eligible for HAART are not receiving it. NAPWA in partnership with the Treatment Access Expansion Project is seeking the passage of the Early Treatment for HIV Act (ETHA) (S.860; H.R.3326), the bill has been deadlocked in Congress for more than a decade. Access to quality and comprehensive healthcare and treatment should be a guaranteed right for American people, not an earned privilege. In many areas of the country, low-income pre-disabled people with HIV remain ineligible for Medicaid until they develop AIDS. Medicare Part D beneficiaries suffer from limited formulary access due to cost-sharing challenges. Ryan White recipients continue to attempt to piecemeal their care in a system that is supported by discretionary funds, and hold onto hope with each reauthorization that they will continue to be able to access life-saving care and treatment.

Numerous influential sources have made the connection between access and adherence to treatment and reduced HIV infectivity. However the Kaiser Family Foundation continues to report that 45-55% percent of those with HIV are still not in care, inclusive of the 24% - 27% of those that are not presently aware of their status. This is a central principle to any effort to increase routine HIV testing efforts. It is our view that any effort to diagnose HIV must be paired with a guarantee of access to HIV/AIDS care, treatment, and support for individual ability to manage the complexity of the disease.

Within this context we must address the absent resources and diminishing workforce to treat persons that are diagnosed. As experienced HIV clinicians and other healthcare providers retire and move on to other specialties, newly trained and rotating specialists have been moving into other more lucrative specialties



or using their talents and abilities to address the global pandemic. The Health Resources and Services Administration has begun to address this growing disparity, however the implications go beyond HRSA's purview and require a comprehensive approach to find solutions. This raises many concerns for those living with HIV as well as those who are newly diagnosed with HIV, who are revealing increased needs to respond to a complex chronic illness. These individual must be provided with appropriate and effective tools and information to increase their ability to prevent new infections.

Greg Millet, a researcher for the Centers for Disease Control completed an analysis of African-American men who have sex with men (MSM) which showed that unknown HIV seropositivity -- in addition to the lack of access to antiretroviral care among African-American men who know that they are positive – is so high that there is a much higher prevalence rate of men who are viremic in the population, which we in the community call “viral load”. In the context of men whose sexual access is limited by race, and whose sexual networks have such a high community viral load, even modest levels of sexual risk-taking can result in very high transmission rates; even though the men are doing the best they can to be sexually safe.

Aggressive research and treatment advances have helped more people live with HIV/AIDS than ever before. This only occurred as a result of the concerted demands of people living with and concerned about AIDS. The benefits of this research have extended beyond HIV/AIDS into the treatment of other infections and diseases of concern. Information acquired about infectivity learned from the experience of HAART since 1996 also begs for more research into more available people-centered risk reduction methods to slow the spread of HIV. The global environment has been much more aggressive in researching and applying new HIV prevention technologies such as pre-exposure prophylaxis, microbicides, vaccines, the effects of treatment adherence on transmitting HIV, and more. We must allocate resources to the Centers for Disease Control and Prevention to continue to do the requisite research and work on the ground as well as to the National Institutes of Health to identify new research opportunities that will further expand the toolkit of prevention strategies.

In turn, NAPWA offers its trusted voice and reach into the community toward informing additional research and prevention efforts for people living with HIV/AIDS. Prevention with positives serves to increase and sustain individual sense of ability and control on the part of the person living with HIV to protect their individual health and the health of those they love. Prevention with positives can be most successful by engaging and educating PLWHA in self care and prevention; and support them in navigating disclosure, relationships, insurance/access, and other factors of daily living (housing, employment, non-HIV medical needs, mental health, addictions treatment, etc). Without these basic services and support, which every American has a right to, more people will die.

Reduction of HIV-Related Stigma and Increased Support for Sero-status Disclosure

Stigma and discrimination continue to serve as the most pronounced impediment before resources and access to care and prevention efforts in this country. Anecdotal information from members in the community continues to reveal that persons with HIV/AIDS are finding additional barriers to accessing care on the basis of their HIV-positive sero-status alone. At a recent meeting of people living with HIV/AIDS in Atlanta, GA, an anonymous participant stated, “I was refused treatment at my local clinic though they wouldn't tell me it was because I have HIV, the next nearest clinic to me is forty-five minutes away. How am I supposed to get there? I don't have a car, and I have a job!” The result of continued occurrences of this prejudicial treatment further perpetuates stigma and has a negative impact on self-disclosure, as well as threatens efforts to get others to screen for HIV if they perceive this is how they will be treated.



Regan Hoffmann, Editor-in-Chief of POZ magazine shares why she felt it was important to disclose to the world in the April 2006 issue of POZ magazine. She states, “Why now? Because there’s a real need for positive people to be visible—AIDS needs to be in the spotlight again.” Regan is responding to the complacency that has become pervasive in the community with regard to the treatment of people with AIDS as well as HIV prevention. She goes on to state, “AIDS is a preventable disease, yet last year there were more than 40,000 new infections in the U.S., including higher numbers of women and people of color than ever before. Not to mention that the stigma surrounding the disease, even after a quarter-century of education efforts, is still so severe that many with HIV feel they have to live in shame and secrecy.” We now know that HIV incidence has been estimated 40% higher than previously thought.

Perceptions of stigma have been shown to be directly proportionate to willingness to be open about one’s HIV status. NAPWA invites more leadership from all sectors of American society and life to increase the visibility of and oppose stigmatizing or negative language toward people living with HIV/AIDS, especially within the communities/individuals that are most disproportionately impacted by the disease. The critical issue of AIDS in America must be a political priority in the U.S. Like our economy, national security, and universal healthcare, HIV/AIDS remains a life and death issue for more than 1 million people in the U.S. Strong national leadership is required to make progress decreasing new HIV infections and improve the quality of life for people living with HIV/AIDS in the U.S.

Ignorance and misunderstanding remains about the plausible infection routes for HIV. People with HIV/AIDS report being denied dental care and have experienced providers wearing three pairs of gloves to provide treatment. Mary from Ohio reports, “She had so many pairs of gloves on, she could barely move her fingers! They seemed to get more in the way than anything else. That was the most painful dental visit I have ever had.” More needs to be understood about how individuals interpret an HIV-positive diagnosis, and how stigma and discrimination must be addressed to increase engagement in HIV prevention education and testing.

Addressing Structural/Systemic/Economic Barriers

A recent report released by the Black AIDS Institute has helped us understand that if we adjusted our view of AIDS in this country to look at its impact on the Black community, the devastation would be greater than that of 7 of the 15 President’s Emergency Plan for AIDS Relief funded countries.

NAPWA supports HIV prevention activities that are culturally and gender specific. The Centers for Disease Control and Prevention understanding that more thoughtful and coordinated efforts are needed launched the Heightened National Response to the HIV/AIDS epidemic in African American communities. NAPWA supports similar community mobilization strategies for all communities disproportionately impacted by this disease. In this manner, NAPWA will launch the first National Gay Men’s HIV/AIDS Awareness Day on September 27, 2008 in Raleigh, North Carolina. The day will seek to accomplish increased awareness about the needs of gay men for HIV/AIDS prevention, care, and treatment, forums to strategize effective responses to the epidemic in this community, and social marketing campaigns that promote evidence-based and de-stigmatizing strategies and messages.

NAPWA seeks appropriate resources to provide capacity building assistance (CBA) in the form of technical assistance and skills building trainings to women-led or women-serving community based organizations (CBOs). The purpose of this CBA is to: 1) increase the effectiveness and sustainability of these CBOs in providing culturally competent, gender specific HIV prevention services and 2) strengthen partnerships between these CBOs and HIV positive women. Such a partnership is essential to reaching, encouraging, and supporting women access the continuum of HIV services beginning with HIV testing.



The global community has already begun to address how criminalization of HIV transmission exacerbates rather than promotes an effective and medically sound means of stopping the spread of HIV. Stigmatization has no preventative effects! It is extremely destructive to people already living with HIV and discourages others from disclosing their status or getting tested. Further, these cases undermine the efforts of public health advocates who have worked tirelessly over the years to educate the public about HIV.

Targeted HIV screening is sound public health and proven efficacious for maximizing resources. These well-intended efforts have at times resulted in missed opportunities for diagnosis and prevention and treatment intervention. Yvette Ogletree of San Marcos, CA reports going to doctor several times complaining of persistent illness. In spite of evidence immune suppression and a recently deceased husband, her doctor refused to test her for HIV on the grounds that she wasn't at risk because she was married. When Yvette was finally tested for HIV, she was diagnosed with AIDS, having 4 CD4 cells (the white blood cells that HIV inhabits to replicate and perpetuate its existence) and meningitis. This occurrence should never happen. The cost is individual life! Undiagnosed HIV results in AIDS and death.

PLWHA rights: I think we need to state unequivocally that PLWHA are partners to achieving HIV prevention goals but policies and laws that perpetuate stigma and discrimination and/or threaten confidentiality (forced testing; criminal transmission; immigration ban; onerous and invasive record keeping, etc) hurt efforts to engage PLWHA in prevention activities. Finally the lack of broad social marketing about HIV/AIDS that includes people openly living with HIV contributes to more ignorance and misinformation about all of us who are living with HIV/AIDS and adds to stigma.

The National Association of People with AIDS (NAPWA) continues to act as a conduit for people with HIV/AIDS to provide meaningful input in all issues affecting our lives. Such input is especially needed at the highest levels of political and public life. We urge both political parties to make a response to HIV/AIDS a central component of their plans for the nation.

- Development, implementation, and bipartisan support for a National AIDS Strategy to bring a much more *coordinated, evidence-based* and *results-oriented* approach to addressing HIV prevention and treatment in our country, inclusive of persons living with HIV/AIDS.
- Increased federal appropriations for domestic HIV prevention programs
- Federal leadership to address stigmatizing policies and increase visibility of persons living with HIV/AIDS
- Ensuring affordable to access comprehensive and quality care, treatment, and support services
- Increased support and funding for innovative biomedical and behavioral research initiatives

To be blunt our present course of action wastes valuable resources and most importantly costs the lives of American people.