NAPWA Testifies Before Congress

On September 16, Frank J. Oldham Jr., president and CEO of the National Association of People with AIDS (NAPWA), spoke before the House Committee on Oversight and Government Reform on the state of HIV/AIDS in America.

September 24, 2008 By Frank J. Oldham Jr.

Committee Chairman Waxman, Ranking Member Davis, Congresswoman Holmes-Norton, Congressman Van Hollen 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 1 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 health care, treatment and support services; and efforts to reduce stigma and increased support for sero-status disclosure, as well as by addressing structural, systemic and economic barriers that continue to perpetuate HIV vulnerability among the most marginalized groups of Americans.

This is the basis of support for our communities’ 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 more than 300 organizations and 1,000 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. It is critical to our success that people living with HIV/AIDS be invited meaningfully and equally to share their lived experiences toward informing the development and implementation of a National AIDS Strategy.

Evidence-based Information & Education

With the benefit of new technologies to identify when HIV was acquired, the Centers for Disease Control and Prevention updated its annual HIV incidence estimate reporting that HIV infections have been as much as 40 percent higher for the past 15 years. This information does not indicate that HIV prevention doesn't work, but that it is not reaching the amount of people that it needs to. 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. We understand that increasing prevention resources to meet need will not happen immediately. NAPWA, in coalition with the AIDS community, urges that prevention appropriations to the Centers for Disease Control and prevention be increased by $200 million in FY [Fiscal Year] 2009 to respond specifically to domestic resource needs.

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 resulting from heterosexual contact decreased slightly, young women revealed increased susceptibility to sexually transmitted diseases and higher numbers of early pregnancy—indicators of HIV risk.

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 by employing programs that have been proven to be ineffective.

Support HIV Diagnosis & Quality Health Care and Treatment

Dr. Holtgrave reports there is upcoming researching indicating that 95 percent of people like us—members of the National Association of People with AIDS—who are aware of our HIV status, are making decisions about our health and behavior that **are not** 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 opt-out 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 percent, 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 health care 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 to 55 percent of those with HIV are still not in care, inclusive of the 24 to 27 percent of those that are not presently aware of their status. This must be considered for any effort to increase routine HIV testing efforts. We must invest in opportunities to understand why many individuals are not testing for HIV, and respond with effective strategy that will help them learn their status. 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.

To guarantee access to care, we must address the absent resources and diminishing workforce to treat persons that are diagnosed. As experienced HIV clinicians and other health care 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 (HRSA) 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, revealing increased needs to respond to an exceedingly 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 (NIH), Substance Abuse and Mental Health Agencies (SAMHSA), and the Office of Minority Health (OMH) to identify new research opportunities that will further expand the toolkit of comprehensive 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 Serostatus 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 serostatus alone. At a recent meeting of people living with HIV/AIDS in Atlanta, Georgia, 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 45 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 Hofmann, 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 as 40 percent 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 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 health care, 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 remain 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 seven 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's access to 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, prevention and treatment intervention. Yvette Ogletree of San Marcos, California, reports going to a doctor several times complaining of persistent illness. In spite of evidence of 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 four CD4 cells (the white blood cells that HIV inhabits to replicate and perpetuate its existence) and meningitis. This result complicates which treatments are available to respond to the disease in addition to impeding prevention opportunities caused by an absent timely diagnosis. This occurrence should never happen. The cost is individual life! Undiagnosed HIV results in AIDS and death.

PLWHA have rights! Our lives have value. I think we need to state unequivocally that PLWHA are partners to achieving HIV prevention goals. However, 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 access to 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.
