



Moving toward Positive Health, Dignity and Prevention (PHDP)



A briefing paper written by the U.S. PLHIV Caucus

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US PLHIV CAUCUS

United States People Living with HIV Caucus

Description

The US PLHIV Caucus is a group of organizations, coalitions, networks, client groups, and individuals who principally advocate for people with HIV in the U.S. Organizational members of the Caucus have board majorities and leadership comprised primarily of people living with HIV.

Charge

By organizing ourselves as a Caucus, we have a greater opportunity to:

1. *National HIV/AIDS Strategy (NHAS)*: Provide leadership and consultation to federal government regarding its NHAS Federal Implementation Plan. This activity will take the form of annual consultations between PLHIV Caucus and the Office of National AIDS Policy (ONAP) on national HIV/AIDS issues and any related/tangential issues, e.g. health care reform.
2. *HIV Service Implementation*: Provide leadership and consultation to federal advisory and decision-making bodies, particularly with regard to “Prevention for Positives” campaigns and other program designs.
3. *2012 International AIDS Conference*: Serve as the organizing body for the US efforts to assist and support LIVING 2012 by 1) coordinating our input with the Global Network of People with HIV (GNP+) and the Conference Coordinating Committee of the IAS to assure that the perspectives and priorities of HIV positive people living in the host country are appropriately incorporated into all conference planning; 2) having a unified voice as we participate in planning pre-conference and conference sessions specifically for positive conference attendees; and, 3) serving as a welcoming body for other PLWH/A organizations and individuals attending IAS.

U.S. PLHIV Caucus Membership List (in formation)

- 20/20 Leading Women’s Society
- Campaign to End AIDS (C2EA)
- Communities Advocating Emergency AIDS Relief (CAEAR) Coalition, People Living with HIV/AIDS Caucus
- Global Network of People Living with HIV/AIDS – North America (GNP+ NA)
- International Community of Women Living with HIV/AIDS – North America (ICW-NA)
- Michigan Positive Action Coalition (MIPOZ)
- National Association of People with AIDS (NAPWA)
- Ohio AIDS Coalition
- Positive Iowans Taking Charge (PITCH)
- Positive Leaders Uplifting Sisters (PLUS)
- U.S. Positive Women’s Network

EXECUTIVE SUMMARY

This paper introduces various approaches to engaging people living with HIV in initiatives to prevent the forward transmission of HIV. The Positive Health, Dignity and Prevention approach that emerged from consultations convened by the Global Network of People with HIV (GNP+) and UNAIDS is built on a human rights framework and has been adopted by most European and many African governments. The approach evolving in the U.S. (through CDC statements and, most recently, the National HIV/AIDS Strategy) has been somewhat more epidemiologically focused. While it acknowledges the damaging effects of stigma, it places little emphasis on the synergy between protecting human rights and generating trust and authentic engagement with people living with HIV (PLHIV) in communities most heavily burdened by HIV.

Research on the efficacy of using ARVs to reduce viral load in the bodies of people living with HIV and, thus, their likelihood of transmitting it to someone else are reviewed here, as is the status of U.S. efforts (such as the TLC+ initiative and the proposed 12 Cities project) to implement programming that utilizes this approach, among other strategies. The diverse roles that PLHIV are uniquely qualified to play in making such strategies successful are then reviewed.

This paper details the various ways in which PLHIV leadership and active involvement can contribute to:

- promoting regular HIV testing,
- supporting treatment adherence and retention in care,
- working to resolve poverty-related, Institutional, political and cultural barriers to testing, adherence, and retention in care that are largely endemic in marginalized communities and
- introducing potential innovations in prevention created by people living with HIV for people living with HIV.

Finally, it discussed the extent to which test and treat strategies rely on people's willingness to be HIV tested repeatedly, adhere to prescribed drug regimens, and modify their behaviors over long periods of time. Such cooperation is best generated by programs with highly visible PLHIV leadership and the authentic support of target communities. Thus, government willingness to invite and invest in such engagement at every level has the potential to achieve prevention programming that works both pragmatically -- by tapping the expertise of PLHIV in target communities to tailor them appropriately -- and ideologically -- by showing the respect, mutuality and trust that is most likely to motivate cooperation among participants.

PREAMBLE

Recent research has shown the potential efficacy of using ARVs both to improve health outcomes and prolong life among those of us living with HIV or AIDS and to prevent HIV transmission to our sexual partners. These findings raise urgent questions about how we provide HIV prevention education to our communities and shape initiatives such as Test, Treat, Suppress and TLC+ (Testing, Linkage-to-Care plus Treatment). They also elicit vital questions about our rights – in terms of reproductive and sexual decision-making, our access to reproductive and sexual health care, and the right to be free from the threats posed to us by criminal statutes that single out and unfairly burden people living with HIV.

Our future success will depend on significant system reforms that ensure our unfettered access to the high quality health care and support services we need to manage living our lives with HIV. Further, social justice reforms must create more equity in our collective personal responsibilities for, protection of, and acceptance of our own sexuality. Encouraging news from biomedical research presents the HIV and public health communities, as well as society with an opportunity to do the following:

1. Rebuild and restore dignity and humanity among people living with HIV or AIDS

The research clearly demonstrates that the vast majority of us who are living with HIV adopt behaviors that will prevent onward transmission of HIV. However, HIV prevention messages far too often result in severe social isolation and stigmatization of people living with, or at increased vulnerability to, HIV. Early on, four risk groups shouldered much of the HIV-related stigma (homosexuals, hemophiliacs, Haitians, and heroin-users). The homophobia and xenophobia caused by this branding is heavily felt to this day by gay, lesbian, bisexual, and transgender individuals and the communities where they live. Additionally, HIV reinforces the destructive attitudes of racism, sexism and prejudices against people of color, women, drug users, sex workers, and poor people in general. Contradictory societal messages encouraged people to protect themselves from becoming infected both by using condoms and by avoiding people living with HIV. Instead of achieving the desired result of more consistent condom use, this contradiction fostered the rejection of those of us who are living with HIV. The public health community has to empower us to make informed decisions about our sexuality -- whether we have HIV or not – that do not result in stigmatization of individuals who choose to delay treatment.

2. Re-engage people living with HIV in outreach and linkage activities

Thirty years of fighting HIV in the United States has taught us some valuable lessons. Key among them is that the people indigenous to any given community have the most access to, and influence over, other members of that community. We are more than just our personal stories or conduits for recruitment into research trials and programs. The primary role for community members in HIV prevention is to reinforce desirable behaviors and discourage undesirable behavior. If we are to succeed, future efforts must fully respect the experience and authority that we have as community stakeholders by ensuring that we have a seat at the table at every level of decision-making.

3. Challenge our current understanding of PLHIV

Our experiences of vulnerability to, and living with, HIV or AIDS are varied and complex. In the absence of a cure, biomedical strategies alone cannot end the domestic HIV epidemic. HIV prevention, retention in care, and treatment adherence goals must be channeled through greater understanding of our lived and contextualized experiences, as well as those of our sexual partners. We can increase early HIV diagnosis, disclosure, and safer sex practices by connecting those goals with improved sexual health and a high quality life full of worth and dignity. Connecting public health goals to psychosocial benefits and improved social determinants can help to ease the anxiety and trauma caused by a life-altering diagnosis and help us mentally and emotionally construct a world where we can actually LIVE with HIV.

The Affordable Care Act, National HIV/AIDS Strategy, the National Prevention Strategy and Opening Doors Federal Strategic Plan to Prevent and End Homelessness offer unprecedented opportunities to reorganize our domestic response to HIV. But system enhancements and reforms that expand eligibility will fail unless we are engaged respectfully both in efforts to improve our individual health, and simultaneously in efforts to save our communities.

INTRODUCTION AND SOME HISTORY

In 2009, the Global Network of People with HIV (GNP+) and UNAIDS convened a consultation in Tunisia that was attended by people from twenty-eight countries and six continents. The meeting's agenda was shaped by a seven-month consultative process that occurred globally and the Living 2008 Summit that was convened at the 2008 International AIDS Conference by the Living Partnership, and staffed by GNP+. The fifty participants at the 2009 consultation represented "people living with HIV (PLHIV) networks, development agencies, civil society organisations, country implementers, multilateral and UN agencies, and donor agencies"¹. Over half were also people living with HIV.

The consultation sought to explore the difficulties experienced with 'positive prevention' approaches, including many donor-led interventions that participants saw as focusing "almost entirely on preventing the onward transmission of HIV – which should not be the sole aim of any 'positive prevention' programme"². They rejected the 'positive prevention' or "prevention for positives" as terms suggesting the responsibility for preventing onward transmission of HIV rested entirely with the person living with HIV.

Historically, such efforts have focused solely on changing the behavior of people living with HIV. Anuar Luna from the Mexican Network of People Living with HIV expressed the view that "'positive prevention' denoted activity imposed upon people living with HIV."³ Consultation participants agreed that prevention must, instead, be defined as a responsibility shared by both partners, regardless of their HIV status,

The Consultation resulted in the design of Positive Health, Dignity and Prevention (PHDP) – an approach that is based in a human rights framework and includes both legal protections from discrimination for PLHIV and "access to HIV treatment, care and support services, and by doing so contributes to the health and wellbeing of their partners, families and communities"⁴. The essential components of PHDP (a term now adopted by many African and most European countries) include "health promotion; treatment access; sexual and reproductive health and rights; prevention of transmission of HIV and other sexually transmitted infections (STIs); protection of human rights, including stigma and discrimination reduction; gender equality; social and economic support; and the empowerment of people living with HIV"⁵.

The CDC first focused on this area of HIV prevention in 2003, when they announced "Advancing HIV Prevention (AHP): New Strategies for a Changing Epidemic", an initiative designed to increase "uptake of and access to HIV testing and "prevent[ing] new infections by working with persons diagnosed with HIV and their partners, and further decreas[ing] perinatal HIV transmission."⁶

¹ Global Network of People Living with HIV, UNAIDS. *Positive Health, Dignity and Prevention. Technical Consultation Report*. 2009. Executive Summary.

² Ibid.

³ Ibid, page 11.

⁴ Ibid, Introduction.

⁵ Ibid.

⁶ CDC. *Advancing HIV Prevention: New Strategies for a Changing Epidemic – United States, 2003. MMWR 2003; 52: 329-332.*

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Moving Toward Positive Health, Dignity and Prevention

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Many local, state and national PLWH/A organizations provided guidance and consultation on how the CDC could partner with the HIV community in order to successfully implement AHP.

Unfortunately, this effort was conducted after the fact as AHP had already been released without contributory involvement of PLHIV and other important stakeholders. As a result, states struggled to implement the CDC guidance and the importance of involving PLHIV in HIV prevention efforts was undermined.

The approach articulated in 2010 in the U.S.' new National HIV/AIDS Strategy (NHAS) lies somewhere between the wholistic, human rights-based view of PHDP and the narrower, epidemiologically-focused view articulated by the CDC in 2003. The NHAS emphasizes the importance of people knowing their HIV status and assuring that those who are HIV-positive are linked to care and services including drug treatment, family planning, housing, and mental health services that may contribute to reducing their risk of transmitting HIV. It further recommends connecting PLHIV with partner notification assistance and access to "behavioral and biomedical interventions that have been shown to sustainably reduce the probability of transmitting HIV to others and reduce acquisition of other sexually transmitted diseases."⁷

The NHAS also addresses the crucial issue of adherence in acknowledging that, "“Being linked to care is not enough.... There is also a need for ongoing support to maintain the necessary high levels of adherence to antiretroviral treatment.”"⁸

The NHAS approach diverges somewhat from the PHDP approach, however, on the subject of human rights and anti-discrimination protections for people living with HIV. It acknowledges the importance of "lessening stigma and discrimination"⁹. But, with regard to laws in place in 35 U.S. states and territories that specifically criminalize HIV exposure and/or transmission, the NIH simply notes that, "In some cases, it may be appropriate for legislators to reconsider whether existing laws continue to further the public interest and public health. In many instances, the continued existence and enforcement of these types of laws run counter to scientific evidence about routes of HIV transmission and may undermine the public health goals of promoting HIV screening and treatment"¹⁰.

Such laws, of course, are not at all unique to the U.S. UNAIDS reported in 2008 that over half (84 of the 136) of the countries reporting data had laws and regulations in place that "present obstacles to effective prevention, treatment, care and support for vulnerable populations."¹¹

In response to this, the PHDP consultation participants called decisively for "protective laws to ensure non-discrimination, reduce stigma, and change harmful gender norms"¹², adding that the discriminatory actions needing to be addressed include not only criminalization of HIV

⁷ The Office of National AIDS Policy. The National HIV/AIDS Strategy for the United States. July 2010. Page 16. Available at www.WhiteHouse.gov/ONAP

⁸ Ibid, page 24.

⁹ Ibid, page 32.

¹⁰ Ibid, pages 36-37.

¹¹ UNAIDS, *2008 Report on the Global AIDS Epidemic*. 2008. UNAIDS. Available at www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp

¹² Global Network of People Living with HIV, UNAIDS. *Positive Health, Dignity and Prevention: Technical Consultation Report*. 2009. Page 14.

transmission or exposure but also immigration and residency restrictions, and mandatory HIV testing, as is imposed on incarcerated people, sex workers, and drug users in some places. The PDPH report calls explicitly for “[c]reating better linkages between local level experts, people living with HIV networks, civil society, and multilateral and UN agencies to obtain more data on specific laws and their impact”¹³ and for countries to implement measures, “[m]itigating the impact of a non-supportive legal and policy environment (e.g. on people whose behaviours or status is criminalized [by] criminal HIV transmission laws)”¹⁴.

This paper does not focus on the human rights arguments favoring the PHPD approach, since that case is already made well in the Consultation report. Instead, it focuses, on the pragmatic advantages of using an approach that

- supports the HIV prevention needs of positive people,
- is defined and led by PLHIV, themselves, and
- consciously and explicitly recognizes as counter-productive any further exacerbation of the stigma and discrimination that we already experience.

One example of this pragmatic advantage can be seen in the choices available for responding to the increasing prevalence of syphilis and other STIs among HIV positive individuals. To address this important public health issue effectively, local and state public health systems need HIV positive individuals working with them in leadership positions. Traditional STI control approaches have been top-down, relying on institutionally-directed case finding, testing, partner notification, and imposed, impersonal public health advice. The epidemiological data show that these tactics are not working well.

A strategy that combines public health expertise with highly visible and vocal PLHIV leadership and community guidance can produce a patient-engagement model focused on the individual benefits of avoiding HIV/STI co-infection and the community benefits of working to prevent STIs from serving as a gateway for HIV transmission. This model better reflects the goals of chronic disease care. It also builds patient knowledge and empowerment which, in turn, promotes informed decision-making about physical and sexual health concerns overall.

A member of the Poz Prevention Working Group, part of the Ontario Gay Men’s Sexual Health Alliance, noted in 2009 that “We [PLHIV] care about HIV infections and our communities, but in the absence of health and social policy, society defaults to criminal law and stigma. But when we replace shame with empowerment, we can make conscious decisions.”¹⁵

¹³ Ibid. Page 15.

¹⁴ Ibid. Page 24.

¹⁵ Hoe, D. *Policy from PLHIV perspective: the story drives the policy*. Technical consultation presentation, Hammamet, Tunisia. April 28, 2009, Available at http://www.gnpplus.net/images/stories/PHDP/presentations/05_david_hoe.pdf

WHAT DOES THE “PREVENTION REVOLUTION” HAVE TO DO WITH THIS?

The HIV “Prevention Revolution” is a 2010 catch phrase for the confluence of promising technological advances in biomedical prevention (microbicides, PrEP, and “treatment for prevention”) and the growing consensus that “combination prevention” is the way forward. It envisions these biomedical tools (as they become available) being used in tandem with behavioural and structural prevention interventions in an effort to optimize the overall effectiveness of all of these these partially effective modalities.

The American Foundation for AIDS Research (amfAR) recently reported that “[e]xpansion of preventive interventions could potentially avert more than half of the HIV infections projected to occur by 2015 and could save \$24 billion in AIDS treatment costs globally”.¹⁶ Even so, it is drastically underfunded. Only 3% of the domestic FY 2011 HIV/AIDS budget is allocated to domestic HIV prevention¹⁷.

This paucity of resources clashes with the emergence of exciting new data on how anti-retroviral drugs (ARVs) could help to prevent onward transmission of HIV. This clash further fuels debate about the proper role of people living with HIV in designing and implementing prevention efforts. ARV-based prevention research that is now (wholly or partially) enrolling people living with HIV in the U.S. as study participants includes studies on the following¹⁸:

“Treatment for Prevention”

The HPTN 052 trial is widely regarded as a “game-changer” in terms of the opportunities for HIV prevention offered by this approach. It showed that viral suppression resulting from adherence to ARV treatment by an HIV positive sexual partner could reduce HIV transmission risk to an HIV negative partner by as much as 96%. These data suggest that this prevention strategy offers the greatest hope, by far, of curtailing HIV spread.

“Treatment for Prevention” is the idea that routine HIV testing combined with immediate, yet voluntary initiation of ARV treatment to those testing positive (regardless of their stage of HIV infection) would lower the amount of virus in body of the positive person, thus reducing the probability that she or he would transmit HIV to another person.

Since the HPTN 052 data were released in May, 2011 interest has been escalating in looking at the population level effect of offering HIV testing and treatment as widely as possible in a community. Further study is needed of factors that could impede the success of “treatment for prevention”, including its efficacy outside of monogamous relationships and the possibility that it may generate widespread resistance to the most commonly used ARVs if those adopting early treatment do not adhere to medication schedules.

¹⁶ American Foundation for AIDS Research. Accelerating the Prevention Revolution: A Roadmap. *Issues Brief*. March 2011. Available at http://www.amfar.org/uploadedFiles/In_the_Community/Publications/IB%20HIV%20Prevention%200311.pdf?n=3836

¹⁷ Ibid.

¹⁸ AIDS Vaccine Advocacy Coalition. Treatment as Prevention Studies Table. *Px Wire*. Vol. 4, No. 2. April-June 2010. Available at <http://www.avac.org/ht/d/sp/i/346/pid/346>

Treatment and Linkage to Care PLUS (TLC +)

TLC+ expands on the “test and treat” idea by facilitating regular HIV testing and linking those who test positive not only to medical care but also social services and supports promptly and on an on-going basis. By making these connections efficient and working to retain people in care over time, TLC+ proposes to encourage people to start ARV therapy when they feel ready to (although it neither promotes nor discourages or excludes immediate treatment upon diagnosis). It also promotes treatment adherence once they start, counsels participants on preventing transmission, and ensures that they receive the ancillary supportive services they need to maintain a regular medical regimen and preventive behaviors.

A U.S. pilot study of TLC+ is underway in the Bronx and Washington DC. It will enroll 22,000 participants and is expected to produce results in 2013.

START: Strategic Timing of Antiretroviral Treatment

The START study, enrolling 4000 men and women living with HIV, will look at how early initiation of ARV treatment among asymptomatic people with HIV (participants with CD4 levels above 500/mm³) affects HIV disease progression and the rate of acquiring other serious, non-HIV diseases. While this study does not address prevention per se, an NIH press release states that it will, “also examine HIV transmission risk behaviors, treatment adherence, drug resistance, health care utilization and the cost of care”¹⁹. Participants are being enrolled in 30 countries (including the U.S.) and results are expected in 2015.

The U.S. Department of Health and Human Services (DHHS) is also initiating the “12 Cities” project as part of its implementation of the NHAS. This project will involve comprehensive HIV/AIDS planning and will work to create fully integrated, cross-agency responses to HIV in the twelve U.S. jurisdictions in which HIV prevalence rates are highest²⁰.

The 12 Cities initiative is focused on treatment, as well as prevention and is regarded by DHHS as a Continuous Quality Improvement effort to build coordination and enhance the efficiency of service provision. It focuses on “neighborhoods with a high community viral load” because these are, “also places where uninfected individuals are at greater risk for acquiring HIV than neighborhoods or other localities with a comparatively lower viral load. Innovative solutions such as reducing community viral load may help reduce the number of new HIV infections in specific communities that may, in turn, reduce disparities in HIV infection”²¹.

Thus, the 12 Cities initiative and the TLC+ study are related in that both propose to improve treatment access, enhance medical outcomes, and reduce onward transmission of the virus by taking a more thorough and holistic approach to provision of services to people living with HIV.

¹⁹ National Institutes of Health. NIH Study Examines Best Time for Healthy HIV-infected People to Begin Antiretrovirals. [press release]. 7 March 2011. U.S. Department of Health and Human Services. Available at <http://www.nih.gov/news/health/mar2011/niaid-07.htm>

²⁰ National Institutes of Health. NIH and D.C. Department of Health Team up to Combat District’s HIV/AIDS Epidemic. [press release], 12 January, 2010. U.S. Department of Health and Human Services. Available at <http://www.nih.gov/news/health/jan2010/niaid-12.htm>

²¹ Ibid

WHAT ROLES DO PLHIV PLAY IN USING THIS RESEARCH?

Findings from the above-described research, while much needed, raise some daunting, overarching questions. How can we apply what is learned in an environment in which HIV testing and treatment realities fall so far short of optimal levels? And how do we do this in the context of an economic down-turn that makes access to enough funding to sustain current services unlikely, much less resources for massive new testing and treatment programs.

Other challenging situations factors include:

- CDC estimates that at least one fifth (21%) of all Americans who are HIV positive do not know that they have the virus.²²
- Of those who do know, only about half are receiving regular medical care.²³
- Of those who are receiving care, 25%-44% are “lost to follow-up in many settings”.²⁴
- Most of those receiving care (80%) should be on ARV therapy but one quarter of that number do not get the ARVs they need²⁵ because of financial problems. Gardner et al note, “few studies have assessed the extent to which financial barriers impede access to HIV care in the United States.”²⁶ But it is worth noting what happened in San Francisco when this barrier was removed by implementing universal access to ARVs for all who needed them. The city’s surveillance data now show “decreasing rates of new HIV infections that correlate with ART expansion and lower community viral load”²⁷.

Given the statistics listed above, it is not surprising that nationally:

- Less than one fifth (19%) of all HIV-positive individuals in the US have an undetectable viral load²⁸ and
- 15% of new HIV infections in the U.S. are the result of transmission of drug-resistant HIV from one person to another²⁹ (a situation usually related to inconsistent use of ARVs, whether due to adherence problems or inconsistent access). This significantly reduces, but doesn’t eliminate, options available to individuals to treat their HIV. For these persons, adherence to their prescribed ARV treatment regimen is critical, given that few options are available to them if their regimen should stop working.

²² CDC. HIV prevalence estimates—United States, 2006. *MMWR*. 2008; 57: 1073-1076.

²³ Gardner EM, McLees MP, Steiner JF, et al. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clinical Infectious Diseases* 2011;52(6):793-800.

²⁴ Ibid

²⁵ Ibid

²⁶ Ibid

²⁷ Charlebois, ED, Das, M, Porco TC, et al. The effect of expanded antiretroviral treatment strategies on the HIV epidemic among men who have sex with men in San Francisco. *Clinical Infectious Diseases* 2011;52 (April 15):1046-1049.

²⁸ Ibid

²⁹ Ibid

Since we will have to do more with less in order to implement the NHAS goal in a time of economic and political constraints, we must look closely at what efforts can further support

- regular HIV testing,
- PLHIV willingness to enter into health care and remain in care, and
- their commitment to ongoing adherence to an ARV regimen, when prescribed.

While numerous factors affecting these three areas have been identified. The following is a discussion of the areas in which PLHIV are uniquely positioned to provide guidance, assist with the conceptual development and implementation of interventions, and otherwise advocate for close adherence to the principles of Positive Health, Dignity and Prevention.

Promoting regular HIV testing

Fear, mistrust of health care systems, and denial of HIV risk keep people from getting tested. As the NHAS points out, “[e]ncouraging more individuals to disclose their HIV status directly lessens the stigma associated with HIV”³⁰

Engaging PLHIV in HIV testing promotion and prevention efforts targeted to other HIV positive people both reduces stigma and gives these messages more potency. The effectiveness of this strategy has also been well proven. When HIV testing was introduced 26 years ago, PLHIV were instrumental in the establishment and operation of the first HIV test sites. Public health departments collaborated with us because it was apparent that the communities at highest risk would not access HIV counselling and testing unless it was promoted and provided by their peers. These efforts were highly successful but inconsistently funded, and they receded as AIDS services became increasingly “professionalized” in the 1990s.

The NHAS specifies that prevention efforts should be targeted most intensively to areas where the epidemic is most concentrated. It also acknowledges that these are the communities in which distrust of the government and medical establishments may be highest. It follows logically that anything perceived as mass, coerced, or mandatory HIV testing will only increase such fears and testing/treatment avoidance behaviors. Human rights-based strategies are the only ones likely to make people want to be tested.

This is where attention to the Positive Health, Dignity and Prevention approach becomes a matter of sheer pragmatism. Most of the people charged to date under laws that criminalize HIV exposure and/or transmission were/are living in poor communities and/or people who are incarcerated. The incentive to be tested for HIV is necessarily dampened by publicity about cases in which PLHIV are charged with knowingly infecting another person.

The people most keenly aware of the risk of being wrongfully charged under these laws may likely avoid HIV testing and may choose not to seek medical care at all rather than risk being

³⁰ The Office of National AIDS Policy. The National HIV/AIDS Strategy for the United States. July 2010. Page 36. Available at www.WhiteHouse.gov/ONAP

confronted with “opt out” testing and the stigma associated with declining to be tested. Such avoidance directly undermines NHAS goals. Thus, laws that specifically criminalize people living with HIV carry the risk of being counter-productive to public health promotion and HIV prevention, as well as to human rights.

The involvement of PLHIV as uniquely qualified and credible messengers for HIV testing and treatment promotion is one important step we can take to support “test and treat” strategies. But it will be undermined if NHAS implementers do not also, simultaneously, take stronger steps toward mitigating the impact of laws criminalizing HIV exposure and transmission.

Supporting adherence and retention in care

Gardner and his colleagues identify the four main barriers to successful ARV treatment as “delay or failure to initiate therapy, lack of persistence with therapy, poor adherence to therapy, and viral resistance to antiretroviral medication”³¹ As noted above, the fourth factor results from one or more of the first three – either on the part of either the non-adherent individual or the partner from whom the drug-resistant virus was transmitted.

Factors that can contribute to promoting treatment adherence and retaining people in care include:

- Case management and outreach³²
- Peer support, which can occur in groups, through individual mentoring, via peer-to-peer workshops and other activities, in the context of community education sessions, etc.³³
- Community engagement processes that bring people living with HIV together with other local stakeholders and health providers to raise community awareness and counteract stigma, identify service gaps, and address social barriers to care and adherence³⁴
- Identification and resolution of structural barriers to adherence and retention. Kagee and colleagues divide these barriers into three categories:
 1. poverty-related barriers: including competing demands on individual/family budgets for housing, transportation to care, adequate food, insurance co-payments, etc.;
 2. institutional barriers: including inaccessible or inadequate health care delivery, insufficient access to mental health or addiction services, insufficient access to

³¹ Gardner EM, McLees MP, Steiner JF, et al. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clinical Infectious Diseases* 2011;52(6):793-800.

³² Bradford JB. The promise of outreach for engaging and retaining out-of-care persons in HIV medical care. *AIDS Patient Care STDS* 2007;21(Suppl 1):S85-91.

³³ Harlem Adherence to Treatment Study, Harlem Hospital. *Peer Support for HIV Treatment Adherence: A Manual for Program Managers and Supervisors of Peer Workers*. 2003. Available at [http://www.peernyc.org/Assets/web_docs/Peer%20Adherence%20Support%20Manual%20\(HIV\).pdf](http://www.peernyc.org/Assets/web_docs/Peer%20Adherence%20Support%20Manual%20(HIV).pdf)

³⁴ Samuels, F, Simbaya, J, Sarna, A, et al. Engaging communities in supporting HIV prevention and adherence to antiretroviral therapy in Zambia. *Horizons Research Summary*. 2008. Available at http://www.popcouncil.org/pdfs/horizons/Zambia_ARVAdherenceSum.pdf

accessible information in one's own language, etc.

3. political and cultural barriers: including stigmatizing behavior by providers, family, friends, and/or community members, and “traditional beliefs about HIV and AIDS, poor health literacy and gender inequalities”³⁵.

Traditionally, PLHIV have been engaged primarily in prevention programming as providers of peer-based individual and group support. As the Harlem Adherence to Treatment Study noted, “[t]he growing range of peer titles reflects their varied function, and includes: peer educator, peer counselor, peer advisor, community health worker, lay health worker and buddy”³⁶.

Meeting the enhanced adherence and retention challenges associated with implementing new test and treat strategies (including TLC+), however, will require recognition that PLHIV expertise and talents can and should be more broadly engaged.

Who has greater life experience with the structural barriers identified above – and is more likely to understand what is required to overcome them -- than HIV positive people living in the target areas being addressed? Who is a more effective community educator and liaison between PLHIV organizations and other community stakeholders than a PLHIV who has the training and skills to negotiate strategies for resolving social barriers?

This is, again, an area where history demonstrates our ability to take on these roles. In the 1980s and 1990s, in large and small communities all over the country, PLHIV created peer-based buddy systems to deliver adherence support. We helped each other navigate complex and unresponsive social and medical service delivery systems by compiling and sharing our individual learning and offering guidance to newly diagnosed people. But the systems we created were usually either unfunded or drastically under-funded. They fell into disuse when Ryan White Care Act funding and other resource streams mandated the hiring of people with appropriate professional degrees to take on these responsibilities, rather than integrating those with professional skills into the existing networks of community expertise that has evolved by that time.

This synthesis can still be achieved, however, by making funding decisions that prioritize the re-energization of service delivery systems that fully integrate and respect peer-based approaches. With appropriate, preparatory capacity-building, PLHIV can be recruited in target communities who are well qualified to participate in designing, as the NHAS puts it, “[h]ealth care services that are respectful of and responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients”³⁷.

Our commitment to engage in this way, however, must be matched this time with the resources

³⁵ Kagee, A, Remien, RH, Berkman, A, et al., Structural barriers to ART adherence in Southern Africa: Challenges and potential ways forward. *Global Public Health* 2010 May 26:1-15.

³⁶ Harlem Adherence to Treatment Study, Harlem Hospital. *Peer Support for HIV Treatment Adherence: A Manual for Program Managers and Supervisors of Peer Workers*. 2003. Available at [http://www.peernyc.org/Assets/web_docs/Peer%20Adherence%20Support%20Manual%20\(HIV\).pdf](http://www.peernyc.org/Assets/web_docs/Peer%20Adherence%20Support%20Manual%20(HIV).pdf)

³⁷ The Office of National AIDS Policy. *The National HIV/AIDS Strategy for the United States*. July 2010. Page 26. Available at www.WhiteHouse.gov/ONAP

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we need to train ourselves and adequately fund the programs in which we are involved. We also need to be integrated from the outset in developing the monitoring and evaluation tools that will be used to assess systems that we collaboratively design and administer. We will view the level of federal and state investment in this approach as indicative of the public sector's real commitment to such collaboration.

The NHAS notes that “care providers should be culturally competent and able to clearly and effectively communicate to help their patients understand the benefits of following treatment plans”³⁸ Who is better prepared than PLHIV from the local community to train and guide HIV-related medical and social service delivery professionals in creating and implementing systems that effectively support adherence and retention in care?

³⁸ The Office of National AIDS Policy. The National HIV/AIDS Strategy for the United States. July 2010. Page 26-27. Available at www.WhiteHouse.gov/ONAP

INNOVATIONS IN PREVENTION CREATED BY PEOPLE LIVING WITH HIV

For decades, people living with HIV have, of necessity, created their own strategies for protecting their own health and that of their partners. Some of them already have been assessed as medically efficacious and others have not. But all of them deserve consideration, to determine which ones reduce risk sufficiently to warrant their inclusion among the range of harm reduction strategies that are being promoted.

Using condoms to prevent HIV transmission

In the early 1980s, before HIV even had a name, the first AIDS organizations began vigorously promoting the use of condoms to reduce risk. Their approaches to this were denounced in some circles until the medical community came to consensus in support of any form of condom promotion that worked. In 1988, Senator Jesse Helms (who, on television, advocated quarantining people with HIV) introduced a federal budget amendment prohibiting use of tax dollars for AIDS prevention materials that “promote or encourage homosexuality”. To illustrate the need for his amendment, he showed the Senators a comic book produced by the Gay Men’s Health Crisis to promote condom use. This historic example is an instructive reminder of how harm reduction strategies that seem risky and politically unpalatable at one time can be accepted as a cornerstone of prevention subsequently.

Achieving pregnancy while preventing risk to an HIV negative partner

Many women living with HIV share the common, human desire to have children and raise a family with their partners. Although resources have been devoted to develop “sperm washing” procedures to enable HIV positive men to impregnate their HIV negative female partners without risk, little research has been done on how HIV positive women can best become pregnant by a negative male partner while protecting him as fully as possible from HIV risk.

Since its inception in 1992, the International Community of Women Living with HIV/AIDS has been calling for further research in this area³⁹, and has collected information about the strategies that its members have developed for themselves. These include alternative insemination, in which semen is inserted into the vagina or cervix by a medical provider using sterile equipment or – more commonly – by the woman, herself, via a tube (such as a turkey baster or some comparable tool). Semen can also be inserted via a diaphragm or cervical cap. Some positive woman reduce their partner’s risk by having unprotected sex only immediately after ovulation, thus maximizing the chances of conception while reducing the number of times the negative partner is exposed.⁴⁰

Women with access to ARVs, of course, can now substantially reduce risk by using treatment to render themselves virtually non-infectious. Given that regular ARV access is not available to most of the HIV positive women in the world, however, further research is still needed to find

³⁹ International Community of Women Living with HIV/AIDS (ICW), 2002. *Positive Women: Voices and Choices – Zimbabwe Report*. 2002. Available at <http://www.icw.org/icw/files/VoicesChoices.pdf>.

⁴⁰ Forbes, A. Microbicide Development: Positive Women’s Concerns, *BETA*. 2009). Available at http://www.sfaf.org/hiv-info/hot-topics/beta/beta_2009_wintspr_women.pdf

risk reduction strategies that can be responsibly recommended when women do not have ARVs or do not want to use them. One possibility is the development of non-contraceptive microbicides, another research priority in which women living with HIV have expressed strong interest⁴¹.

Sero-sorting and strategic positioning among MSM

HIV positive men who have sex with men (MSM) have experimented with non-condom strategies for reducing risk of HIV transmission to their partners. These include withdrawal before ejaculation and negotiated safety (in which partners make mutual decisions about what sexual activities they will engage in and with whom). Two more strategies that have provoked some scientific discussion are sero-sorting and selective positioning.

In sero-sorting, men selectively chose to have unprotected sex only with men whose sero-status matches their own. In strategic positioning, sero-discordant pairs agree that the HIV positive partner will be receptive so that the negative partner is not exposed to HIV positive semen.

Both of these strategies still involve some risk. In the case of sero-sorting, there is the possibility that one may not know, or may not be honest about, his HIV status. When both partners are positive, re-infection with other viral strains may cause medical complications for one or both partners within the first year of diagnosis. In the case of selective positioning, the insertive partner may still be exposed to HIV in the receptive partner's rectum or mouth.

A few studies have been done documenting the prevalence of strategic positioning and sero-sorting behaviors^{42,43,44}. But very little has been done to determine the extent (if at all) to which these two strategies reduce transmission risk. One study showed sero-sorting as associated with a moderate reduction in transmission risk⁴⁵. No significant data are currently available, however, on the impact that strategic positioning is having on HIV transmission rates.

Viewed in the context of harm reduction, it is important to know the extent to which these practices are protective and to make this information publicly available in a balanced way. As U.S. researchers on this topic have noted, "[m]essages need to be carefully constructed so that men receive accurate information regarding the relative risk of various sexual risk practices, while at the same time making clear that 'lower risk' does not equal 'low risk' or 'no risk'."⁴⁶

⁴¹ Ibid.

⁴² Pebody R. UK Gay Men's Sex Survey: new data on age, strategic positioning, condom failure and HIV testing. *NAM Aidsmap.com*. 6 January 2011. Available at <http://www.aidsmap.com/UK-Gay-Mens-Sex-Survey-new-data-on-age-strategic-positioning-condom-failure-and-HIV-testing/page/1600593/>

⁴³ Balthasar H, Jeannin A, Locicero S, et al. Intentional risk reduction practices of men in Switzerland who have anal intercourse with casual male partners. *JAIDS* 2010; 54 (5): 542-547.

⁴⁴ Parsons, JT, Schrimshaw, EW, Wolitski, RJ, et al. Sexual harm reduction practices of HIV-seropositive gay and bisexual men: Serosorting, strategic positioning, and withdrawal before ejaculation. *AIDS* 2005,19():S13-S25.

⁴⁵ Philip SS, Yu X, Donnell D, Vittinghoff E, Buchbinder S. Serosorting is associated with a decreased risk of HIV seroconversion in the EXPLORE Study Cohort. *PLoS ONE* 2010; 5 (9): e12662.

⁴⁶ Ibid

Re-engineering Couples Counseling

It is important to note that PLHIV have pivotal roles to play in adapting existing prevention strategies to heighten and or extend their effectiveness.

Recent research, for example, has documented demand among American MSM for Couples Voluntary Counseling and Testing (CVCT) services⁴⁷. First implemented among heterosexual couples in Africa, CVCT has been shown to help sero-discordant couples reduce their transmission risk by talking together in the presence of a testing counselor about behavior changes. The Atlanta-based researchers reported that, in the focus groups they convened, “CVCT was seen as a sign of commitment within a relationship and was reported to be more appropriate for men in longer-term relationships.”⁴⁸.

They further noted, however, that CVCT will certainly not be appropriate for all couples and that the African model would need to be adapted for use among American populations.

Their focus group participants speculated, for example, that many MSM might avoid CVCT if they feared that that, during the session, they would be required to disclose sexual encounters they were having outside of the partnership. They said that counselors must be trained to focus on developing agreements around safer sex practices to be used within the relationship and “recognize the variations in couple’s needs that may occur with relationship duration and type of relationship”⁴⁹. PLHIV who have experience in MSM relationships can bring vital perspectives to developing training curricula that meet these specific needs.

Cancer Screening Outreach

Cervical cancer is an AIDS-defining illness for women, making access to user-friendly, affordable cancer screening services vital to women living with HIV. As Jaisre and colleagues observed, “[a] high recurrence rate of CIN [carcinoma in situ] after standard treatment has been noted in HIV-infected women” and “[o]nce cervical cancer develops in HIV positive women, the disease may be aggressive and less responsive to treatment”⁵⁰.

In the U.S, however, an estimated 23% of women living with HIV have not had a pap smear in the last year. USAID’s Maternal and Child Health Program has developed a “single visit approach” that is being rolled out in Mozambique and South Africa. The “single visit” strategy combines screening with immediate treatment of pre-cancerous lesions, if necessary and integrates both of these services into the other care provided at HIV care and treatment clinics⁵¹. In this approach, screening is combined with immediate treatment of pre-cancerous lesions, if necessary. This opportunity to obtain these single visit services is promoted by HIV

⁴⁷ Stephenson R, Sullivan PS, Salazar LR, et al. Attitudes towards couples-based HIV testing among MSM in three US cities. *AIDS and Behavior* 2011; 15: S80–S87.

⁴⁸ Ibid

⁴⁹ Ibid

⁵⁰ Jaisri A, Bhaskaran S, Kumar P. Human Immunodeficiency Virus and carcinoma cervix. *American Medical Journal* 2010; 1 (2): 133-135.

⁵¹ USAID Maternal and Child Health Integrated Program. *Cervical Cancer Prevention for Women Living with HIV*. USAID. Downloaded on 8 April 2011. Available online at <http://www.mchip.net/node/140>

positive health educators talking to other HIV positive women in their communities⁵².

In the U.S., the AIDS Education and Training Centers (AETCs) provide training to HIV care providers on screening and treating HIV positive women's increased cancer risk⁵³. But the need to communicate the importance of accessing these services to women living with HIV is urgent. As discussed above, women living with HIV are likely the messengers best positioned to carry this essential prevention message within their communities and work to reverse this serious gap in prevention services.

High rates of anal cancer are also occurring among young men with HIV as a result of human papilloma virus (HPV) infection. These rates have increased throughout the last 30 years despite the advent of effective therapies for HIV. Due to the widespread lack of effective screening services, these cancers are often first detected when they are already at an advanced stage. Routine access to cancer screening services for HIV positive MSM is needed, as is HPV screening for all MSM.

⁵² Oster A, Sullivan P, Blair J. Prevalence of cervical cancer screening among HIV+ women in the United States, 2000 to 2004. 2009.16th Conference on Retroviruses and Opportunistic Infections. Abstract 975.

⁵³ Armas L, Coffey S, Fry R. et al. *Cervical Cancer Screening in HIV-Infected Women: Pap Smears and Pelvic Examination*. 2007. [powerpoint presentation]. AETC Women's Health and Wellness Workgroup; Cervical Cancer Screening Subgroup. Available at <http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-345>

CONCLUSION

Preventing onward transmission of HIV through strategies such as test and treat or TLC+ isn't simply a matter of getting drugs into bodies. The effectiveness of such initiatives depends on people's willingness to be HIV tested repeatedly, their adherence to prescribed drug regimens, and their commitment to modifying their behaviors and staying continuously engaged and cooperative over long periods of time (if not indefinitely).

This requires individual motivation, which is most effectively sustained when there is broad-based community buy-in and trust in an endeavour. This trust is best inspired when leaders and peers within the target communities, themselves, are seen to be fully invested in the initiative and are actively communicating its value.

This trust cannot be generated, and is not justified, by programming that fails to recognize medical benefit to the person living with HIV as the primary goal of ARV-based treatment, and limiting forward transmission of HIV as a decidedly secondary benefit.

Every person with HIV, regardless of his or her individual medical need for ARVs, should be counseled about how treatment can reduce infectiousness and provide greater confidence in one's ability to protect one's partners. But the decision as to when, and if, to start treatment must be made by the person with HIV and it must be an informed decision. Informed consent is not just the absence of coercion and it does not simply consist of advising patients that they have the option to refuse therapy or start "when they are ready". Informed consent means that patients are fully informed of the science, including the ambiguity about when it is in their best medical interest to start treatment, as well as how the public health objective of reducing HIV transmission by reducing community viral is motivating public health interest in starting people with HIV in ARV treatment regardless of their individual medical need.

Individual commitment to ARV therapy takes time. Barriers to adherence (whether structural, psychological, or social) must be successfully addressed and people need the resources and opportunity to become knowledgeable about the available treatment options so that they can make fully informed decisions. We uphold both the right to early, voluntary, frequent HIV testing and the right of HIV positive individuals not to receive ARV treatment unless and until they give their fully informed consent to do so. No strategy that seeks to advance HIV prevention by compromising these human rights in any way can succeed for the simple reason that it generates non-adherence generally, as well as active resistance from those of us in this Caucus.

Many people living with HIV in the U.S. are well positioned and well prepared to serve as leaders in their communities and to do their part to take ARV-based prevention initiatives of all types forward. But, to do so, they must be respected, hired, trained, and brought into leadership and decision-making positions. They must have clear and forceful roles within prevention planning, and to be recognized as the subjects – not just the objects – of prevention efforts.

As shown above, PLHIV input, expertise and leadership is needed in all aspects of this process ranging from setting the research agenda and coming up with formative research designs, to program conceptualization, design and budgeting, to provider training and monitoring, to

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community education, to the strategic integration of prevention services into other areas of care provision, to ethical and policy analysis and problem-solving, to service delivery and evaluation.

In short, the only way to prevent the onward transmission of HIV successfully, cost-effectively, and over the long term (i.e. in the current environment) will be for the government to fully partner with, and involve, a broad cross-section of people living with HIV. Since this type of prevention is all about what people living with HIV do with their own bodies, no other approach can be expected to succeed.

As Helen Epstein concludes in her book, *The Invisible Cure*, “[s]ocial mobilization is actually quite hard to program. It is a spirit that flourished when people come together to face a common threat. It is not something that can be packaged and paid for and then shipped around the world”⁵⁴.

⁵⁴ Epstein H. *The Invisible Cure: Why We Are Losing the Fight Against AIDS in Africa*. New York: Picador. May 2008.