



*A VISION OF  
THOUGHTFUL  
CHANGE*

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 **FLOWERS**  
HERITAGE FOUNDATION

*AIDS does not discriminate, Mitchell Doyle (2006)*

*“America’s cities and mayors must join together to utilize all resources to end the epidemic of HIV and AIDS in the United States. We must all remember HIV is 100% preventable and mayors across the country must play a leadership role in ending the epidemic.”*

*–Ronald V. Dellums, Mayor, Oakland, California.*

## PRELUDE TO A VISION

In the face of almost daily discussions and the never-ending publication of reports in the United States about the domestic HIV/AIDS crisis, the question must be posed: what possible use might there be for yet another? The California-based Flowers Heritage Foundation-sponsored “Think Tank on HIV/AIDS” brought together an unusual group of experts and consumers of HIV/AIDS programs, services, and policy makers and sought to answer the question anew. As the facilitator of this Think Tank ‘conversation’ and as a participant in a host of “national” discussions about HIV/AIDS, I found the Think Tank to be significantly different in tone and in scope from others that I have attended.

As a conversation, it succeeded in blending the realities of the local, neighborhood-specific nature of HIV/AIDS with the recognition that this collection of local epidemics has created a national problem that consumes billions of dollars every year in attempted solutions. The tension between these two poles was especially evident, as national policy experts and a number of participants who had worked within national governmental agencies tried to find common ground with participants who were intensely engaged in local HIV prevention, care, treatment and social service efforts.

This report summarizes the complex series of exchanges which took place over the two days of the Think Tank between the national and the local epidemics; the federal and the state responses; and the domestic and the global discourse.

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## *A VISION OF THOUGHTFUL CHANGE*

### INTRODUCTION

A vision of Sylester Flowers, R. Ph., his son Eric and daughter-in-law Hillary, The Flowers Heritage Foundation is a nonprofit organization dedicated to providing solutions for public health issues affecting underserved populations and improving the lives of the most fragile among us. On June 6 and 7, 2008, The Flowers Heritage Foundation joined other national efforts to develop strategies for confronting the HIV/AIDS pandemic as it enters its third decade by convening a meeting - "Think Tank on HIV/AIDS." Our goal was to examine, assess and evaluate current 'on the ground' efforts to: prevent and interrupt HIV transmission; identify and reduce risk of transmission; identify and diagnose HIV infection; assess access to prevention education, care and HIV treatment services; and evaluate and monitor the outcomes.

The City of Oakland, California, provided an important backdrop for the conversation. Mayor and former Congressman Ronald Dellums was one of the meeting hosts and *Get Screened Oakland*, a public-private partnership in public health that was created to increase levels of HIV testing and HIV/AIDS awareness in Oakland, provided important technical support. Representing Mayor Dellums was the director of *Get Screened Oakland*, Dr. Marsha Martin, who provided significant focus for the discussions that occurred during the two-day meeting. Also participating as co-hosts and Think Tank co-conveners were Dr. Gregory Edwards, Executive Director, Flowers Heritage Foundation and Sylester Flowers, founder and former Chief Executive Officer, Ramsell Corporation, the largest provider of pharmacy benefits management services for the federally financed AIDS Drugs Assistance Program.

Dr. Robert Fullilove of The Mailman School of Public Health, Columbia University, served as the Think Tank facilitator. Participants represented a broad cross section of advocates, public health officials, policy analysts, agency directors, health care providers, academics, and individuals representing communities that have been particularly affected by the epidemic. Among the participants were: staff from local health departments in Philadelphia, Houston, Los Angeles, San Francisco, Alameda County (Oakland); local AIDS Service Organizations in Los Angeles, Oakland, and San Francisco; national advocacy organizations, including the American Bar Association, and the Urban Coalition of HIV/AIDS Prevention Services; local client specific organizations serving women, Native Americans, Latinos, African Americans; community social service agencies; representatives from the media and entertainment sectors and persons living with HIV/AIDS.

The Think Tank was presented as a "conversation about the direction of the current US HIV/AIDS epidemic", and followed a semi-structured format that closely resembled a

focus group. On the first day of the meeting, a series of very general questions and observations were placed before the participants. Over the course of two days, each participant was encouraged to respond to the question(s) or to the comments made by other Think Tank members. On the second day, participants were divided into two groups that were asked to generate recommendations that would improve both the national and local response to the HIV/AIDS crisis. This report summarizes the key recommendations that have particular salience for the ongoing discussion of the future of HIV/AIDS in the United States.

## LOCATION, LOCATION, LOCATION

Oakland has a significant HIV epidemic in its African American and Latino populations. As a number of Think Tank participants noted, Oakland presents one of the significant paradoxes in the domestic AIDS crisis: it is minutes away from yet another epidemic epicenter, San Francisco, but the natures of the prevention, treatment, and social interventions directed at the crises differ dramatically in each city. As noted in the June 2008 POZ Magazine article about the Bay Area, “Though a mere eight miles separate the two cities, the gulf between their AIDS epidemics is massive. The juxtaposition perfectly illustrates the disease’s shifting national economic and racial profile – and how economics and race can determine AIDS funding, care and attention.” (Scott, 2008)

More than any other region in the United States, the San Francisco epidemic fueled primarily by gay white men and non-gay men who have sex with men stands in sharp contrast to the largely African American and Latino epidemics fueled by men who have sex with men in Oakland. San Francisco, a historically activist ‘gay defined community’ has a comparatively well-financed organizational and governmental infrastructure for combating HIV/AIDS. In Oakland, as in many US cities with a large community of under-resourced people of color, HIV competes with other health disparities – and other social and economic issues – for limited local, state and federal funds. And as a result, Oakland has a not so well-financed HIV infrastructure, as energies are, by necessity diffused. Yet, as dissimilar as some of the local responses to HIV/AIDS may be, Think Tank participants agreed that HIV prevention and care strategies were not keeping up with demand. And some agencies on the local level were out of step with today’s HIV epidemic trends and needs.

As noted in the sections that follow, there was significant agreement between the observations, conclusions, and recommendations made by Think Tank participants and those made in other reports published by national AIDS organizations. However, the local issues at the heart of the Oakland/San Francisco divide and echoed by participants from Philadelphia, Houston, and Los Angeles and in Indian Country also informed this conversation and provided an added dimension to the deliberations of Think Tank participants.

## THE INVITATION

This Think Tank opportunity gathered those on the cutting edge of new thought in HIV. The Flowers Heritage Foundation was well positioned to bring together a seasoned group of leaders to review, discuss, and develop a new road map and to chart a new course.

Think Tank topics evolved around the following:

**Reaching**—Approaches to outreach and early intervention;

**Screening**—Efforts to identify individuals currently infected and at risk;

**Linking**—Referring and assuring HIV+ persons are connected to HIV clinical care and on-going community support;

**Serving**—Featuring exemplary efforts in providing HIV programs to a diverse population of HIV-positive persons;

**Crossing-cutting issues in the US HIV Epidemic**—Bridging the gaps; and

**Commentary: Next steps** — Where do we go from here?

## A LOCAL EPIDEMIC WITH NATIONAL IMPLICATIONS

The invitation to the Think Tank provided the participants with a brief overview of current and re-occurring issues that confront implementation of effective HIV/AIDS responses on a local, state and national level. Think Tank participants were asked to bring their experience, expertise and curiosity to the Think Tank. The Think Tank was to be guided by “thinking differently” not by reference to a particular report, policy document, or position paper. Nonetheless, there was universal agreement with the idea that, to quote Dr. Marsha Martin, “the US response to HIV/AIDS is broken. I think we need to discern what is actually working and have the humility to acknowledge that which doesn’t work in the context of today’s realities. HIV is outgrowing our existing local and state service system infrastructure. It is not working.”

Participants agreed that existing HIV prevention, care and treatment resources are ill-equipped to address today’s realities: HIV disease has out-paced our capacity to address it. Statistics from the Centers for Disease Control and its HIV/AIDS surveillance reports provide extensive support for these assertions. One of the most powerful indicators of the degree to which the system is “broken” is revealed in a comparison of the CDC’s goals for HIV prevention for the nation that were set in 2000 and surveillance data reported for 2005. The CDC’s program, Advancing HIV Prevention and its Strategic Plan, set as its national goal for the year 2005 the reduction of incident HIV infections by

50 percent, from 40,000 new cases per year to 20,000 by 2005. With the number of new cases stagnant at 40,000 annually, the CDC has missed its goal by a very wide mark.\*

There was a consensus among participants that in most communities today, we do not know where the epidemic truly is. Gone are the days of a population-specific, geographically defined epidemic. As HIV/AIDS moves into the third decade, the domestic response has only reached 10-20% of the community with HIV education and awareness--even less with testing and early identification. Think Tank participant, Nell, a church-going African American grandmother of 14 and great-grandmother of four, reaffirmed this reality and gave the national epidemic a local face. She received her HIV diagnosis in 2004 following a late-in-life second marriage. She did not know she could get HIV or that HIV could happen to her.

Think Tank participants discussed how and who will reach the remaining 80-90%, like Nell. Whose responsibility is it? Recognizing the need for a national response, the CDC has recommended making testing for HIV a routine component of health care. The World Health Organization followed suit by announcing the Provider Initiated Testing and Counseling initiative on 2007. So, why isn't this national/global response working for people like Nell?

Many Think Tank participants agreed with the frequently cited observation that the HIV/AIDS epidemic is now being confronted by a fragmented system of advocacy, program development and funding. Worse, the domestic AIDS community has retreated into silos and bunkers that are separate and distinct, and often at odds with one another, and even at war - fighting over funding and the ever present sense of 'entitlement.'

Dr. Judy Auerbach of the San Francisco AIDS Foundation stated: "One of the things I think has resulted from the silos is that it's diffused a sense of community, and we keep arguing with each other about who owns the epidemic. The lack of trust is related to this confused sense of ownership - you can't do something because you're not me and you're not one of mine."

Moreover, Dr. Auerbach observed, one concrete result of a system dominated by silos and the bunker mentality is that there is no national leadership providing clear direction for our efforts to confront the AIDS crisis. What we have instead, she suggested, is a process in which individuals and their communities must fight to be included in the national conversation and must battle even harder not to be excluded. "How," she concluded, "do we re-grant permission for people to take leadership on this issue?"

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\*In an oft-cited article by Holtgrave and Pinkerton (2003), the authors attempted to assess the progress toward this goal. They examined CDC's HIV/AIDS spending for fiscal year 2002. Their conclusion, published well before 2005, was that "It does appear a real possibility that the national HIV prevention goal might not be met by 2005." The authors concluded after a cost-benefit analysis that - in crude terms - the reason for this failure was that the necessary investment of prevention resources was simply not being made (Holtgrave and Pinkerton, 2003).

Mario Perez, Los Angeles County Office of AIDS recounted efforts to invite new players to the table, only to be disappointed at the increasingly high 'no show' rate. After an 18 month African American consultation process designed to encourage new partnerships and commitments, none have been forthcoming.

Melvin Harrison, Navaho AIDS Project, talked of the invisibility—not only being left out of the rooms, but very often being the only one invited, to represent all native people—which is not possible—so he often does not participate. On the reservation, tribal leaders are reluctant to acknowledge the HIV/AIDS epidemic. Think Tank participants agreed that if natural local leadership was not forthcoming—steps needed to be taken to go out and find new players, new partners, those not so entrenched in business as usual.

A number of participants, most notably Dr. Joe O'Neill, former White House AIDS Czar and HIV/AIDS Bureau Chief, pointed out that the President's Emergency Plan for AIDS Relief (PEPFAR) approach is one in which the US routinely requires participating nations to create nation coordinating bodies and directors to assure the efficient distribution of programs and services. "If we can demand it of international partners," a Think Tank participant observed, "we can certainly demand it of ourselves."

Leadership, however, cannot simply be decree via executive fiat. Much of the leadership that exists is highly local and has its origins in the communities that are affected most by the epidemic. Think Tank participants addressed the need for local, culturally competent responses to the national crisis.

Michael Milsop, a social worker with the Philadelphia Community Prevention Planning Process talked about the involvement of 'the community' in making decisions about developing a sound funding allocation prioritization process with transparency, with funding going to where the epidemic is and how the prioritization process has fostered local leadership. The City of Philadelphia's Prevention Planning Process utilizes a non-profit agency which keeps the business and decision-making arms length removed from the government and it helps to foster leadership and maintain community buy-in. In that respect, many comparisons with the Civil Rights Movement have been made and efforts to tie the AIDS epidemic to many issues that are affecting the health and welfare of poor communities of color.

Echoing the need to articulate an agenda distinct from the "communities of color" agenda - which is often a 'buzz phrase for African American HIV'- Angel Fabian, Prevention Education Manager at La Clinica de la Raza reminded Think Tank participants that the Latino community has many cultural issues, language needs, immigration/citizenship challenges, and strong familial structures that necessitate establishing a separate HIV/AIDS agenda. Guillermo Chacon, one of the architects of the National Latino

AIDS Action Agenda went further, pointing out the need to identify issues and leadership within the Latino community and once fully vetted by the community to come back together with the African American HIV/AIDS community to build a powerful coalition. Recognizing the need to meet to discuss differences and commonalities, Guillermo challenged Think Tank participants to work locally to establish opportunities to discuss the sensitive issues between African Americans and Latinos.

Naina Khanna of Women Organizing and Responding to Life-threatening Diseases (WORLD), Coordinator of the National Positive Women's Network and co-founder of the League of Young Voters also raised the issue of the need for new leadership and new leadership styles. Recognizing that she was one of the youngest Think Tank members - Ms. Khanna reminded Think Tank participants that young people are approaching HIV/AIDS from very different perspectives and their ideas and experiences must be considered in any local response to HIV. She also challenged all Think Tank attendees on making sure the voice and experiences of positive persons was always in the mix.

Advancing another perspective, Shelley Hayes, Chair, American Bar Association's AIDS Coordinating Committee, suggested that we might re-frame HIV/AIDS prevention and treatment as a civil rights issue for which the power of the courts might be utilized to advance a variety of agendas, as was the case in the early days of the Civil Rights Movement. For example, legal strategies might be used to assure that each community affected by HIV has equal access to all the necessary resources to assure that the prevention and treatment of HIV infection. The characterizing of HIV/AIDS as a civil rights issue might, therefore, provide the means to implement structural changes in the manner in which resources are distributed to communities and, in so doing, reduce the divisive consequences of an AIDS discourse conducted from various silos.

But the larger issues of structural interventions must include more than the legal system can provide. Thus, the Think Tank participants grappled with the issue of how to create and implement structural-level changes, changes that seek to address the particular problems created by racism, sexism, homophobia, and a generalized stigma of persons living with AIDS on a state and local level.

Dr. Gregory Edwards, Think Tank co-convener, reminded the participants that foundations, such as the one he directs are interested in understanding today's realities in HIV/AIDS, as well as suggested interventions. Dr. Edwards suggested the problem was not one of available funding but, rather, one of evidenced-based, successful interventions. Foundations will fund sound solutions to problems they understand and are brought to their attention. To that, several of the Think Tank participants echoed the need to fund 'home grown' interventions -interventions that community agencies know work. All Think Tank participants agreed that the federally financed behavioral intervention strategies, "DEBIs" or diffusion of evidence-based interventions, has limited the creation, implementation and evaluation of locally developed interventions.

## STRUCTURAL INTERVENTIONS TO ADDRESS LOCAL NEEDS

The recognition that poverty, racism, homophobia, sexism, and race/class segregation are drivers of the HIV/AIDS epidemic in the US has increased calls for structural interventions that are designed to combat these factors and in so doing prevent new HIV infections. Think Tank participants were divided on how to respond to calls for structural interventions.

Marsha Martin noted “I struggle with the issue of the socio-political, cultural, behavioral, phenomenological causes of HIV and the clinical public health realities of HIV. Both require interventions. The problem is, what I’m experiencing on the ground with the social HIV phenomenon is that there are no real interventions. As a public health worker, I need people to get tested, to get treatment, and to have ongoing medical services. I get funds for the medical HIV. I don’t get funds for the social HIV. The money I have says, ‘Find and treat.’ My money comes with marching orders.”

However, as some participants pointed out, going to the core of many of these structural issues requires a focus on the social determinants of health such as housing, education, employment and the impact of our criminal justice system. The immediate manifestation of these issues in the lives of patients often requires concrete interventions that improve housing, increase the provision of educational services, reduce the numbers of drug users who are incarcerated for victimless crimes, and provide job training. Rather than a social movement to combat such social and economic woes, participants envision a service delivery system in which the risks associated with these structural issues are minimized.

Think Tank participants agreed that the local, neighborhood character of HIV/AIDS would ultimately shape the nature and character of the structural interventions to be put in place. Many participants agreed with Michael Shaw of the Alameda County Public Health Department when he stated the importance of focusing on testing and early intervention because we have the ability to treat HIV as a chronic disease when intervention occurs at an early stage. They also agreed with him that emphasis should be placed on changing community norms to eliminate the stigma associated with HIV as an important step in preventing new infections. Early education, through the public school system, is one way to effect behavioral change among the members of society most impacted by HIV. He closed his remarks by asking us all to answer the following question. “For HIV prevention we know what to do. The question is: Can we find the political will and capital in the 21<sup>st</sup> Century to prevent a very preventable communicable disease for disenfranchised communities of color?”

In response, Think Tank participants repeatedly emphasized that the domestic epidemic is an aggregation of thousands of local epidemics. Those local epidemics reflect

numerous and often quite different local factors ranging from the availability of HIV prevention education services, HIV care and treatment services, ongoing community support and protection, the availability of drug treatment programs, rates of arrest and incarceration to the degree of racial and economic segregation in housing and the rates of poverty in affected neighborhoods. This reality requires a serious and ongoing commitment to HIV prevention education services and early intervention similar to those operated by municipal public health departments such as the model in San Francisco, shared Israel Nieves-Rivera of the San Francisco Public Health Department.

The contrast between the national discourse on HIV/AIDS and the realities that local public health officials, workers, service providers, and clinicians confront was at the core of the discussions and the recommendations that emerged from the Think Tank. Those key themes are:

***Allocate dollars based on epidemiological data.***

Participants noted that one of the most visible consequences of the current funding structures in HIV/AIDS is that resources don't always go to the groups, the communities or the organizations that are shouldering the burden of the epidemic. Many Think Tank participants cited the gap between rates of infection in one group, *e.g.*, men who have sex with men, and the actual dollars that are available to fund programs to reach this group, especially when it comes to African American and Latino men who have sex with men. Dr. Steve Tierney cited an example of how a local prevention planning group, working with local epidemiological data demonstrated that more funds were needed to address the needs of men who have sex with men in San Francisco. The group prioritized funding for that group according to the percentage of the local epidemic and "defunded" other groups/populations that were not on the priority list. Making the tough decisions and then following through with "defunding" some of the weak agencies was discussed and described as one of the toughest tasks in local HIV/AIDS programming. Representatives from local health departments all agreed that local politics plays a large role in who gets funded rather than where the epidemic is and how effectively it is being addressed, monitored and/or controlled.

Indeed, if the CDC has compelling data about rates of infection in this group, the most cost-effective strategy for preventing new infections would be to fund groups working with the largest levels of infection. Such data would also highlight unmet needs that require immediate attention.

Such surveillance data also could assist in evaluating the effectiveness of prevention and treatment interventions by demonstrating whether or not decreases in new infections and reductions in patterns of HIV-related morbidity and mortality are being observed. While such data are increasingly being collected on the national level for planning and funding

efforts, the availability of accurate data on the local level is lagging, and local program planning that makes use of such data is hampered as a result.

However, even if it were possible with such data to do a better job of targeting resources to “hot spots” and affected groups locally, obtaining funding to support such interventions is complicated by a draconian system for administering the distribution of HIV/AIDS dollars at both the federal and the local levels. With dollars distributed by multiple agencies, often focusing on different issues, different populations, and different priorities, providers and organizations must often create a patchwork of funding in order to meet all the needs with which they are confronted.

Think Tank participants suggested therefore that we:

***Eliminate categorical funding and integrate all Health and Human Service agency funds into one funding entity.***

Think Tank participants called for the integration of all federal AIDS dollars into one funding entity with local communities working with state and local health jurisdictions to develop the framework. All participants agreed that persons living with HIV/AIDS be a larger part of the community developing this framework.

Think Tank members also noted that a change at the source of program funding also would entail changes in other key areas. They suggested that the federal government consolidate planning and solicitation processes to facilitate the quest for funding for local prevention and service programs. They further recommended that in order to reduce the fragmentation of services and to more efficiently deal with such co-morbid conditions as HIV infection and hepatitis C, or mental health conditions and HIV infection, all services be provided together under one funding package and, where possible, within one service-providing agency. Such a consolidation would improve efficiency and eliminate waste. Were the funding for such consolidation to come from one federal source – with similar consolidation being implemented at the state level – much of the inefficiency, duplication, and waste that is present in current federal and state funding might be eliminated.

***Expand partnership with private, corporate, and foundation sectors***

An important component of US response, Think Tank participants all shared their past and current private sector collaborations experiences.

Stuart Burden, speaking from experience in the private and corporate foundation community, reminded Think Tank participants of the role, contributions (and responsibilities) of non-governmental supporters and allies in fighting the continued spread of HIV in the US.

Private foundations and the private (corporate) sector have been crucial partners in testing and developing new ideas and approaches -- both in the US and internationally -- that have contributed to our understanding of what works and what doesn't regarding HIV education, treatment and services. The private sector has played a critical role in slowing the pandemic. Indeed, it was the Levi Strauss Foundation and Gilead Sciences that funded the creation of the City of Oakland and Mayor Dellums' initiative, Get Screened Oakland program and many such programs throughout the United States and across the globe.

Identifying a few of the major private foundations by name, The Ford Foundation and Kaiser Family Foundation, among many others, Mr. Burden described their past and on-going invaluable contributions, adding his observation--it is important to recognize that the Gates Foundation is poised to be a major global force in slowing the pandemic in the coming years. To reiterate, over the past twenty- five years, private foundations have been instrumental in experimenting with approaches that -- when proven successful -- have been brought to scale with governmental funding. Again, this has been true in the US and abroad.

The role the Flowers Heritage Foundation is playing -- bringing representatives of various communities and sectors together to strategize about the future -- is just the kind of support that will be needed in the future to refine our strategies and approaches. This critical work should not be ignored. Private funders and the private sector should continue to seek innovative solutions and serve as critical thought partners in the years ahead.

***Develop national awareness campaigns for HIV/AIDS and for promoting healthy sexual behaviors for adults.***

Think Tank members frequently cited the indifference of the general public to HIV/AIDS and called for a campaign to create a heightened consciousness about HIV. They noted as well that past efforts to create such awareness failed in large measure because Americans typically have deep inhibitions related to discussing sex and sexual behavior openly. A national heightened consciousness about HIV/AIDS is only possible, many participants noted, if there is heightened national capacity to have open, frank discussions about sex. Centering such a national campaign on healthy sex would take an old subject and frame it in ways that have not been used heretofore. Given the continued high rates of sexually transmitted infections that have persisted in the US for generations, having “a difficult conversation” may just be an idea whose time has come.

***Develop centralized, integrated, data information systems to integrate the data for those in treatment to encompass clinical, social and other services.***

A number of Think Tank participants had been and continue to be involved in programs to support victims of Katrina in both New Orleans and in the Gulf Coast region. The problems of providing services for victims of that hurricane provided an important object lesson for many.

Shelley Hayes, for example, was eloquent in describing the difficulty of responding to men and women living with HIV and seeking re-establish themselves in the treatment system in New Orleans “ but who could not tell us the names of their providers, the names of the medications that they were taking, or very much at all of their clinical history. What was worse is that we had no ability to go to a database and provide that information. Who knows how much worse their conditions became because we lacked the means to re-connect them to the services they needed?” Marlene McNeese-Ward, City of Houston HIV Prevention Manager shared Ms. Hayes' sentiments - having been in one of the receiving cities - with no information about level of care, treatment regimens, health care provider, etc.

Participants observed that consumers of AIDS services often have data records distributed and duplicated in a variety of different databases that do not communicate with each other or with the providers who create programs and services for this population. This situation generates waste, the duplication of services, huge inefficiencies in connecting consumers to needed resources, and an inability to follow consumers whose lives are in chaos – the quintessential example would be a man who circulates in and out of the correctional system – in order to provide some continuity in the services that they need.

The irony, of course, is that this country has the potential to create a national database with the capacity to follow patients no matter where they are in the local and/or national system of care. These records would provide all of the data about the clinical history of each consumer, would track disease progression, would permit the assessment and evaluation of the effectiveness of treatment regimens, and would make it possible to preserve key records in the event of a disaster of Katrina-like proportions. One participant noted that in 2005 Hurricane Katrina brought to light importance of a national system when ADAP records in New Orleans were under several feet of water. Displaced citizens sought services in surrounding states, particularly Texas; however these states had little or no way to verify eligibility for these applicants.

The economic crisis that is gripping the nation at the time of this writing means that many Americans will be moving. They will be seeking housing [perhaps because they lost their homes], they will be seeking jobs [perhaps because they were laid off], and they may be seeking access to services elsewhere that are not available to them locally. A database

also would provide states with a way to monitor the mobility of their population so that funding can be adjusted accordingly.

Think Tank participants were largely of the belief that the use of information management technology to improve the efficiency of service provision and to eliminate waste and duplication of effort would be a driving consideration in the future, when resources will become increasingly scarce, and when the need to do more with less will become the rule rather than the exception. Such systems exist, and participants urged that in the future, the creation of a national database with appropriate security features become a part of tool boxes of AIDS programs.

### *CLOSING THOUGHTS*

As the facilitator for this two-day conversation, I came away from it with a realization that HIV/AIDS in this nation is not one epidemic, it is many. All of the many, varied factors that fuel the spread of HIV/AIDS have created a system of responses that has become unwieldy. While local public health and clinical personnel struggle with HIV infected consumers and/or with those who are at risk of exposure to HIV, they have had to deal with a variety of community issues. Each of these issues, depending on how they manifest themselves in a given locale, require the creation of a multitude of programs and services which, in turn, require resources from a bewildering array of bureaucracies at the municipal, state, and federal level. What emerged with great impact from the conversation was the difficulty of working a system that for many Think Tank participants had become incapable of mounting an efficient, focused response to their problems and those of the consumers they serve.

Think tanks such as the one held by the Flowers Heritage Foundation can help to foster meaningful conversations which can contribute critically important content and experience.

A national AIDS strategy seems to be the logical response to an epidemic that is national in scope, but upon close examination, it can only succeed if it is adapted to the needs of hundreds if not thousands of local neighborhoods where the conditions that spawn the epidemic vary significantly from one place to another. Thus, despite their ostensible proximity, Oakland and San Francisco have two very different epidemics requiring very different packages of resources if those conditions, and the disease, are to be successfully eliminated.

Almost all of the recent reports calling for some version of a re-thinking and a reformulation of our approach towards HIV/AIDS have recognized that a national AIDS policy must be multifaceted and would have to contend with a host of complex factors.

But the need to have such approaches grounded in each of the locations where resources would be deployed and implemented has not always come through.

Thus, for example, a structural approach to HIV/AIDS and the prisons must be undertaken nationally and locally, as reminded by Ron Kabir Hypolite, Alameda County Department of AIDS, but as any expert on federal, state, and local department of corrections will point out, we don't have one system of prisons, we have hundreds. Adapting a structural approach will take on a different form and a different meaning in every locale where it is implemented. And the problem continues to be a federally controlled national AIDS strategy, with overlapping agency efforts and many different professional cultures, that is responding to this national health epidemic. Think Tank participants were clear that getting drug treatment services from one agency, HIV medications from another, and resources for HIV testing from yet a recipe for continued failure.

In contrast, PEPFAR funding often is contingent on the recipient nation coordinating and centralizing its efforts. That condition precedent is an implicit recognition that a diffuse, uncoordinated response is essentially no response at all.

But, as Think Tank participants observed, that is precisely what we have here at home. A municipal HIV/AIDS director at a local department of health is often coordinating dozens of funding and resource streams at once. That local responses are often fragmented, ineffective, and unable to respond to changing needs – the quintessential example being a sudden outbreak of syphilis among men having sex with men as a result of a sudden increase in crystal meth use – is our national legacy in an epidemic that is entering its third decade.

If there is one overarching impression that I drew from my two days of listening and facilitating this conversation, it is that we are caught, nationally, in a massive Catch 22: too much attention to the local manifestations of HIV make it difficult to mount a consistent federal response, but the current federal response is insufficient for meeting the complex needs of each local community that is struggling to mount an effective campaign to deal with its epidemic.

It seems clear to me that we must do for ourselves what we have demanded nations engaged in PEPFAR-funded campaigns do: Centralize our epidemic response. Creating such a centralized approach must be driven as much as possible by the AIDS community, *e.g.*, those local agencies and organizations that have been struggling to mount a consistent, coordinated response to their local epidemics by struggling to obtain sufficient funding from all the disparate funding streams that provide prevention and treatment dollars.

It is time to revisit history. Mayor Dellums, while serving in the US House of Representatives called for a Marshall Plan for AIDS in Africa. That call became PEPFAR. The United States needs its own Marshall Plan. That is, a massive effort to build an effective response to the US HIV/AIDS epidemic. In retrospect, the Marshall plan was a marvel of planning, coordination and of cooperation among many different actors in government, the private sector, and within the affected nations themselves.

It deserves mention here because that plan supplies the evidence that the coordination of seemingly impossibly complex tasks can be achieved. At the beginning of the two-day conversation, I asked Think Tank participants to reflect on and react to the following statement: “Crazy is doing the same thing over and over again and expecting different results.”

With a growing epidemic, it seems fair to say that we have not only been the same thing over and over again, we just have been doing more of it each year. With a host of reports calling for better-coordinated national/federal, state, regional and local efforts against HIV/AIDS, this conversation adds an additional voice of what we all hope was a dose of sanity and a vision toward thoughtful change.

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Cover design: “AIDS does not discriminate” photograph by Mitchell Doyle of Campolindo School, Moraga, CA. 2006 ”Don’t Turn Your Back on AIDS” Founder’s Choice winner, Flowers Heritage Foundation-All rights reserved.

**ADDENDUM**  
**Think Tank Work Group Draft Recommendations**

## DRAFT RECOMMENDATIONS

1. Eliminate categorical funding and integrate HIV-related and substance-abuse funding streams to provide treatment services (co-morbidity)
  - a. Treatment services are provided together from one fund (reduces fragmentation of services and improve financial efficiency)
  - b. Consolidate planning and solicitation of those services
2. Eliminate categorical funding and integrate all HHS agency funds (HERSA, SAMSA, CDC, Office of Women's Health, Office of Minority Health, Indian Health Services)
  - a. Treatment services tackle a broader range of co-morbidity issues
3. Consolidate Planning and Solicitation Process which includes one application process
  - a. Improves efficiency, streamlines and establishes one process
4. Establish Fair Funding Formulas and develop formularies that takes into account geographical distances
  - a. Systematic realities and access to care and related costs must be considered and taken into account for populations in rural communities and large geographic areas (specifically for Native peoples in frontier states such as Alaska, North Dakota, Idaho, Iowa, Montana, etc.)
  - b. With adequate founding formulas, increases in service quality, continuity, productivity, and adherence will be possible
5. Require comprehensive age-appropriate sex education for grades K-12 in the mainstream education system in order to achieve
  - a. Reduction in transmission among new population, lower STD transmission rates, and lower teenage pregnancy
  - b. Elimination of the burden on HIV organizations to educate the general public because HIV prevention education will already be a part of a sound public education policy
  - c. Shift in education policy in America to reflect today's realities
6. Centralize regional service(s) navigation system, incorporating information technology
  - a. Addresses multi-prognosis clients in a timely, efficient manner with multiple service providers
  - b. *Regional* defined as a reasonable geographical area that includes the cluster of client-registration services that they need to access

7. Champion the US Department of Health and Human Services to develop a *national* partnership with Microsoft to develop the technology to support the transfer medical records between and among community-based organizations
  - a. Public service systems could transfer health records between health departments and correctional institutions, service providers and community health centers, etc.
8. National training program and use of technology for current HIV prevention staff dealing with acute HIV infection
  - a. Reduces spread of infection
9. Fund complementary therapies (including traditional medicine) in order to
  - a. Decrease lost of care, improves quality of life, reduced hospitalization, and increased adherence to care
10. DOLLARS SHOULD FOLLOW THE EPIDEMIC, this will require fine-tuning and maturing the surveillance technology so that resources can follow the epidemic
  - a. What does that mean, "*following the epidemic?*" Whose epidemic, which one(s)?
  - b. The data follows the epidemic all over the place, but it is not about the surveillance data: **it's about the funding.** If we have a national strategy to our surveillance system and the funding is actually following, then we have to account with cost-effectiveness. **The community has to own this process and decide upon a model for allocation decisions.** If not, then it has to be okay that San Franciscans get \$4,000 per capita and Los Angeles residents get \$2,000 and the concerns, arguments and hostilities must end
11. The US Department of Health and Human Services should use its leverage to address at the policy level, the health disparities in the national prison system – and develop a sound HIV prevention intervention program, including condoms in prisons, HIV testing in prisons, etc. They should have the ability to politicize and speak to the issue. The Department of Justice can request congressional power to do what they want nationally. Most State prisons will support this as long as their culpability and vulnerability in the courts is taken on by the Feds, given that its federal dollars they are spending. Is State surveillance data (including data from the corrections) shared with our Federal partners?
12. Develop an AIDS National Coordinating Council response for developing best practice models that supports AIDS research being converted into practice
13. Community Health Center and Public and Community Housing Development co-location

- a. Through the provision of HIV education screening and treatment on-site, HIV incidence will decrease
  - b. This also has the potential to increase health care access and outcomes
- 14. *The Time is overdue for a national and mature conversation on Sexuality and Sexual Behavior:*  
A national health message through diverse media outlets targeted toward sexually active adults about the risks associated with barrier-free sex
  - a. Even if there is a Cure for HIV, the Cure will not and does not equal solution to today's realities in HIV
- 15. Assess and clarify the expectations and percentage of expenditures around who will address what portion of the epidemic. Can we figure out where the public, private, insurance finance and federal dollars are going so that we're caring for everyone who is touched or will be touched by this epidemic? How do you balance financial eligibility with public health responsibility?
  - a. Clarity and identification about the gaps, as well as the parameters for intervention successes. So we can calibrate our interventions.
  - b. Addresses issues of lack of trust and "permission" to tackle specific issues
  - c. It helps us chart a course, develop a roadmap for what populations need what services
- 16. Include advocacy and prevention efforts for youth in the foster care system
  - a. Sexual health needs are being discussed and addressed outside of health promoting venues targeting youth.
- 17. Institute mandatory HIV testing for marriage licenses
  - a. Knowing HIV status reduces HIV incidence
- 18. Expand the use of community pharmacies to support treatment guidelines. Community pharmacists need to be reimbursed for the services they are providing.
  - a. Improve psycho-social morbidity
  - b. Greater integrate pharmacies with public health care
- 19. Establish a comprehensive national plan to have Persons Living With HIV/AIDS (PLWHA) participate in AIDS planning, policy, and advocacy
- 20. Make non-profit management training mandatory
- 21. Develop national standards for Latino Men who have Sex with Men (MSM) HIV Prevention Work with sanctions for non-compliance
  - a. Improves quality of services for Latino MSM community, and a model for African MSM communities

22. Executive order to identify AIDS as a National Health Crisis
  - a. Public health issues are local issues, so as long as it's defined as a public health issue, it's going to be viewed by lawmakers as a localized problem; Change the language
23. Support an integrated service model for Care, Treatment and Prevention
24. Combine the American with Disabilities Act funding streams into one process, revolving around the housing crisis issue
25. Federally fund needle exchange, drug treatment for persons living with HIV and expand harm reduction program funding
26. Incorporate indigenous healing practices into treatment services
27. Compare and Consolidate National HIV Awareness Campaigns
  - a. Awareness of risks for at-risk groups (i.e. 55+)
  - b. Awareness campaign directed toward underscoring the urgency of the epidemic to the general public
  - c. Awareness to the need to be tested
  - d. Awareness of risks targeted at various ethnic and racial groups
28. Stop making a distinction between HIV and AIDS, HIV is the virus.
29. Address structural issues in the "AIDS Industry" on the ground: there is not enough existing or emerging capacity to respond to today's HIV epidemic
30. Increase the availability of substance-abuse treatment including treatment for alcoholism and related addictive disorders
31. Prioritize the importance of educating faith-based organizations, churches, and community organizations about HIV
32. Make universal comprehensive health care a priority of the national government
33. Make universal health care for people living with HIV
34. Offer routine HIV testing in the doctor's offices in support of making HIV testing a component of regular medical services

35. Develop more non-traditional partnerships or a larger circle of partners, i.e. Tattoo Parlors, Starbucks, neighborhood markets, barber shops, beauty parlors, day spas, hair solons, health clubs and gyms, etc.
36. Re-engineer public health and HIV community advisory councils to include a larger scope of those affected by HIV in communities today. HIV has shifted within communities to affect many of those thought before to be at low-risk. Risk is risk.
37. Expand volunteer programs, establish a HIV Americorp-style volunteer program
38. Mandate a Health/Science curriculum in all schools and include the teaching of HIV and a related sexuality health curriculum
39. Create safer injection facilities a la the Vancouver, Canada model
40. Create a Federal task-force to coordinate programs across government agencies and provide the task force with an appropriate budget
41. Establish a Manhattan-type project for an HIV vaccine (mobilize the industry in search for a cure, specifically bio-tech and pharmaceutical companies)
42. Create a system for HIV care and treatment in planning for a disaster using electronic medical records and medication distribution and monitoring system
43. Utilize socio-economic indicators as a means for distributing health coverage (i.e. severity of need)
44. Re-think the community planning process and its relationship to today's HIV service, care and prevention needs
45. Offer non-heterosexuality-biased sexuality education and training in all public and private school systems
46. Re-examine the correctional health system in order to prioritize rehabilitation and health, along side the application of penalties.

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