

# *Designing Primary Prevention for People Living with HIV*

Chris Collins  
Stephen F. Morin, Ph.D.  
Michael D. Shriver  
Thomas J. Coates, Ph.D.

In collaboration with participants at the policy forum  
*Primary HIV Prevention: Designing Effective Programs  
for People Living with HIV*

**AIDS Policy Research Center &  
Center for AIDS Prevention Studies**

***AIDS Research Institute  
University of California, San Francisco***

**Policy Monograph Series – March, 2000**

## Acknowledgements

This monograph is based largely on presentations and discussion at the June, 1999 policy forum *Primary HIV Prevention: Designing Effective Programs for People Living with HIV*. The Forum was hosted by the AIDS Research Institute at UCSF and the National Association of People with AIDS. The Forum was sponsored by the National Institute of Mental Health (NIMH), the NIH Office of AIDS Research (OAR), and the Centers for Disease Control and Prevention (CDC). We wish to thank the panelists and participants in the Forum for taking the time to present their views. (See Appendix for list of Forum participants.)

*“Risky behavior by positive people is not the norm. Most of us take extraordinary steps to make sure that we are not infecting our partners, and we’re doing so without a whole lot of support. There aren’t massive public health interventions out there. There aren’t big campaigns supporting us staying safe in our relationships. We’re doing it of our own accord.”*

Terje Anderson, Deputy Executive Director, National Association of People with AIDS

# Table of Contents

<b>Executive Summary .....</b>	<b>v</b>
<b>1. The growing need for prevention for positives .....</b>	<b>1</b>
<b>2. Crafting the prevention message .....</b>	<b>5</b>
Seeking Intimacy (and More) Through Sex .....	5
People Living with HIV Must Lead .....	6
Altruism and Responsibility Without Shame .....	7
Is Disclosure the Answer? .....	7
Communication.....	8
Substance Use and Lack of Control .....	8
Context is key.....	9
Diversity must be a guiding principle .....	10
Personal Protection and biomedical questions .....	11
Policy is a tool and an impediment .....	12
<b>3. We know enough to act (examples of intervention).....</b>	<b>14</b>
AIDS Action Committee, Boston.....	14
Los Angeles Consortium.....	15
AIDAtlanta .....	16
Asian & Pacific Islander Wellness Center, San Francisco.....	17
Prevention Case Management .....	17
<b>4. We need to learn more (examples of research in progress) ...</b>	<b>19</b>
TLC (Teens Linked to Care) .....	19
MSMs and IDUs in Urban Settings .....	20
Sero Discordant Couples.....	22
Women in Non-urban Communities.....	23
Clinicians as Prevention Providers .....	24
Reaching People in Prison Facilities.....	24
<b>5. A proposed research agenda.....</b>	<b>25</b>
Understanding the context.....	25
Developing and testing behavioral interventions .....	26
Structural issues.....	26
Rapidly transferring knowledge .....	27
<b>Appendix: List of forum participants .....</b>	<b>28</b>

# Executive Summary

HIV prevention is not reaching one of its most important audiences. People living with HIV have always had an essential role to play in preventing new infections, but prevention campaigns have too often failed to address the unique prevention needs of HIV-positive individuals or acknowledge their significant efforts to avoid infecting others.

Primary prevention for people living with HIV must become a priority on the prevention agenda. One positive person is involved in each case of HIV transmission, yet for far too long prevention providers and researchers have shied away from a focus on “prevention for positives.”

This avoidance can be attributed to justifiable concern about stigmatizing people living with HIV or splitting communities between positive and negative individuals. In the first 18 years of the epidemic, HIV prevention interventions have been designed in an environment where people with the disease are at grave risk for discrimination and stigma, in addition to a deadly virus. In the AIDS service community, diverging care systems grew up seeking to provide prevention interventions for those who were negative, and health care and support services to those with HIV disease — with little interconnection between them.

Today, there are new reasons for a sharper focus on prevention for people living with HIV. Growing numbers of people with the disease are living more healthy, sexual lives. Recent evidence suggests that risk taking among both HIV-positive and negative people is increasing. After nearly two decades of life in the shadow of AIDS, communities are growing weary of traditional prevention messages and many people are openly grappling with difficult questions of intimacy and sex. Increasingly, people living with HIV also face multiple complex economic and substance abuse challenges that complicate prevention efforts.

## **Successful interventions must be replicated**

There is an urgent need – and sufficient expertise – to move forward with prevention campaigns focused on helping people living with HIV and AIDS avoid passing their infection along to others. Numerous innovative interventions for people with HIV show promise, including:

- a social marketing campaign for gay men and a five-session group intervention for women living with HIV in Massachusetts,
- a chat line for positives and a group session program for Latinas/Latinos in Los Angeles,
- Internet chat room interventions in Atlanta,
- a group session for gay Asian American-Pacific Islander Americans living with HIV in San Francisco, and
- Prevention Case Management programs newly funded by the Centers for Disease Control.

### **New and expanded research is needed**

To be most effective, current prevention intervention models must be tested and the unique prevention needs of people living with HIV better understood.

Behavioral researchers should continue to expand research on prevention for positives. Examples of research already underway include:

- In-depth studies of HIV-positive gay men and injection drug users in urban settings,
- a multi-part intervention for positive teens,
- an intervention for sero-discordant gay male couples,
- a group intervention for women in rural communities,
- a program designed to help clinicians be more effective prevention providers, and
- a multi-session pre-release program for HIV-positive inmates in prison.

Further research on the context of risk, the meaning of sexual experiences and the effectiveness of particular interventions, as well as the rapid transfer of this knowledge, must be pursued.

### **Unique issues must be addressed**

There are many ways in which lessons learned from earlier prevention work can inform design of prevention interventions for people living with HIV. But a number of issues are particularly important for this population and they must be considered in the design of interventions. The challenges include:

- communicating responsibility to not infect others without promoting shame or stigma,
- acknowledging the need for intimacy through sex,
- improving communication between partners,
- considering diverse opinions on disclosure as a prevention approach,
- understanding the diversity of the epidemic and the need for multiple interventions,
- addressing the multiple contextual factors that contribute to risk (including substance abuse), and
- communicating clear messages in the absence of absolute answers to important biomedical questions.

Policy issues, including the ability to use federal funds for prevention to people living with HIV, need to be more closely examined.

Stigma and discrimination against people with HIV remains a reality in America and prevention providers must work within this social framework. But the time is long past for greater acknowledgement and support of the valiant efforts of people living with HIV to avoid infecting others, and an increased focus on primary HIV prevention for people living with the disease.

# 1 The Growing Need for Prevention for Positives

In October, 1997, a chilling story out of Chautauqua County, New York, manifested the fears of AIDS advocates and the general public alike. A man named Nushawn Williams, in jail for the sale of crack, admitted to public health authorities that he had had unprotected sex with 50 to 75 young women, most of them teenagers.

The story was exceptional, since only isolated incidents of willful exposure to HIV had ever been reported in the press. But the political reaction was swift, with a state Assemblywoman calling for mandatory names reporting of HIV infection and proposing a new category of crime from knowingly exposing someone to HIV. AIDS advocates and people with HIV worried that the unusual story would lead to increased stigma against those battling the disease.

It is an obvious statement that one person with HIV is involved in every new infection. People with HIV disease have always had an extremely important role to play in controlling the epidemic. Yet the Chautauqua County story points out that in America, public discussion about the role and responsibilities of HIV-positive people is fraught with potential social and political repercussions.

That some Americans, including political leaders, still view people with HIV primarily as threats to the public health was brought home in a February 2000 statement by H. Morgan Griffith, the House Majority Leader of the Virginia House of Delegates. Speaking in favor of legislation that would criminalize the intentional spread of HIV, Griffith said, "There are individuals who use this as a weapon. They say, 'If I'm going out, I'm taking a bunch of people with me.'"

HIV prevention interventions have always been designed in an atmosphere where people with the disease were at risk of suffering discrimination and stigma. At least partly in response, diverging care systems grew up in the AIDS service community that sought to provide prevention interventions for those who were negative and health care and support services to those with HIV disease. There was little overlap.

The result was that for too long HIV prevention efforts missed an important audience – people with HIV. The "condom code" urged everyone to act as if all their partners were HIV-positive. The message was that everyone should protect himself or herself and few messages were tailored to the particular situations of people living with HIV. HIV testing was encouraged, but was rarely followed up with support and prevention campaigns to help those who had tested positive to consistently maintain safe behavior.

Any tendency to deliver a message about the responsibility not to infect others was held back by fears that it would be perceived as “blaming” or stigmatizing people already facing discrimination and a life threatening disease. During all this time, the diligent efforts of tens of thousands of people with HIV not to infect others went largely unacknowledged.

*“The people who are contracting [HIV] now are much more in need of services, much more likely to have drug use problems, and be homeless, and come from family problems..they need not just prevention messages, but they need services..”*

Jeff Kelly, Director, Center for AIDS Intervention Research, Medical College of Wisconsin

In recent years, the landscape of prevention has changed. HIV prevention providers have developed creative responses to the delicate task of delivering prevention for positives. There are several new reasons why these interventions should play an increasing role in HIV prevention.

The success of new treatments for HIV infection mean that there are now more people living with HIV disease than ever before, and many of these individuals are feeling healthier and better able to participate in the normal activities of life, including sex. HIV negative people are affected by these treatments as well. Several recent studies suggest that awareness of the success of combination therapies has lead to increased risky behavior among both HIV-positives and negatives.

In early 2000, Stan Lehman from the Centers for Disease Control (CDC) reported research findings that, of a sample of gay men, intravenous drug users (IDU), and heterosexuals visiting Sexually Transmitted Disease (STD) clinics, 31% were “less concerned” about contracting HIV because of what they had heard about new treatments for HIV.<sup>1</sup> One quarter (25%) of gays and bisexuals and 30% of heterosexuals reported being less concerned about AIDS.

Lehman’ s findings are consistent with earlier research, including work by James Dilley and colleagues finding that 26% of men who have sex with men enrolled in a study said they were “ ‘less concerned about becoming HIV-positive’ because of the new treatments.” Thirteen percent said they “somewhat” or “strongly” agreed with the statement, “I am more willing to take a chance of getting infected when having sex.”<sup>2</sup>

---

<sup>1</sup> 7th Conference on Retroviruses and Opportunistic Infections, January/February 2000, cited in *Kaiser Daily Summary*, February 1, 2000

<sup>2</sup> Dilley, James, Woods, William, McFarland, William, “Are Advances in Treatment Changing Views about High-Risk Sex?,” letter in *The New England Journal of Medicine*, August 14, 1997, vol. 337, no. 7, pgs. 501-502

Other recent research has confirmed increased rates of sexual risk taking. In January, 2000 Paul Denning of the CDC reported on a dramatic rise in STDs among gay men. Gonorrhea in gay men nearly tripled between 1992 and 1998. Among HIV-positive gay men, the increase has been even more substantial – a 250% increase in cases between 1994 and 1998.<sup>3</sup>

*“I’ve felt very much as if our prevention programs have remained pre-protease, while the discussion among folks, both positive and negative, about their sexual relationships and their risk taking is very much post-protease.”*

Don Howard, Act-Up Golden Gate

Another study released the same month found that significant numbers of both young people and adults continued to practice risky sexual behaviors after HIV diagnosis. Young people (defined as diagnosed with HIV before age 22) were more than twice as likely to engage in risky sex than adults. (It is important to note that a large percentage of people in this study had been diagnosed with a psychiatric disorder.)<sup>4</sup>

The emerging evidence of increased risk taking among HIV-positive and negative individuals speaks to the need for new and expanded prevention efforts that reach both groups. But prevention providers confront numerous challenges in crafting messages that have legitimacy to people with HIV. First, several unanswered biomedical questions complicate the prevention message. Are people with HIV at significant risk of re-infection with HIV or super-infection with a more virulent or drug resistant virus? Is low or undetectable viral load an indication of reduced infectivity? What are the real risks of oral sex? How safe is pregnancy? These and other questions are on people’s minds as they think about sexual behavior and the potential risks for partners and their own health. The lack of solid answers makes unequivocal prevention messages difficult.

Second, an increasing number of people with HIV disease face multiple challenges in their lives -- beyond securing health care and dealing with a life threatening disease. Many are also confronted with economic emergencies, experience racism, homophobia or both, have concerns about caring for their children, face threats of violence and abuse drugs and/or alcohol. On top of such complicating factors, positive people live in a society that has labeled them as potential risks. All states have adopted provisions making willful transmission of HIV a felony. News stories, like that from Chautauqua County, exacerbate the

---

<sup>3</sup> 7th Conference on Retroviruses and Opportunistic Infections, January/February 2000, cited in *CDC Daily Summary*, February 10, 2000

<sup>4</sup> Diamond, Catherine, Buskin, Susan, “Continued Risky Behavior in HIV-Infected Youth,” *American Journal of Public Health*, January, 2000, vol. 90, no. 1, pgs. 115-118

barely concealed fear that HIV-positives have little care about spreading the disease.

None of these challenges will be easily solved. Prevention providers in community based organizations, public health departments and federal agencies must grapple with these complexities as they respond to the need for expanded prevention for positives. Yet there are already examples of successful programs and the wealth of lessons learned from prevention interventions focusing on HIV negative individuals can help guide development of new programs.

## 2 Crafting the prevention message: factors to consider

Sexuality is part of a normal, healthy life – for positives and negatives. HIV-positive individuals wrestle with competing emotions, including altruistic concern for their communities, burnout from years of thinking about their infection, uncertainty about the expectations of partners and loss of control in sexual situations due to coercion, economics, power imbalances or drug and alcohol use.

There are many ways in which lessons learned from earlier prevention work can inform design of prevention interventions for people living with HIV. But there are a number of issues that are unique or particularly important to the challenge of developing primary prevention for positives. Several of these themes are summarized below.

### Seeking Intimacy (and More) Through Sex

The oft-heard prevention message from years ago that “safer sex is hotter sex” has fallen on deaf ears. People engage in sex to satisfy many complex needs, including intimacy, excitement, self-esteem, pleasing of their partner and escape. As noted above, both Robert Remien and Cynthia Gomez have identified the desire for intimacy and closeness in sex as an important dynamic. When couples don't want to “bring HIV into the bedroom,” simplistic messages marketing the ease and satisfaction of condom use and other safer sex rules have little meaning.

Sexual intimacy is a hot topic of discussion in the gay community. Tony Valenzuela became “the poster boy of unsafe sex” when he was the subject of a *POZ* cover story on “barebacking.” “There's no space or safety to explore desire,” Valenzuela is quoted as saying, “like talking about semen exchange and how in moments of lust, moments of intimacy, a different set of priorities rushes through your body.”<sup>5</sup>

In an article in *POZ*, Stephen Gendin, an HIV-positive writer, chronicled the difficulties he faced with his boyfriend who was HIV-negative when they met. Gendin described a complex set of feelings that were involved with the couple's eventual practice of unsafe sex, that included guilt and shame, but also the acknowledgement that “there was – and is – something very fulfilling about having sex without a piece of latex separating me and my partner.” Gendin felt unable to discuss the unsafe sex outside the relationship: “I was so ashamed of

---

<sup>5</sup> Gendin, Stephen, “They Shoot Bare Backers, Don't They?,” *POZ*, February, 1999, p. 51

my behavior that I couldn' t seek help from my friends. It seemed too awful to admit to anyone.”<sup>6</sup>

In a study of HIV-positive MSMs, Colleen Hoff and colleagues found that positive men in discordant relationships were more likely to have unprotected anal intercourse with a non-primary partner than positive men in concordant relationships. The researchers noted that the desire for “guilt free sexual gratification” was a theme among men who had unsafe sex outside their primary relationships.<sup>7</sup>

*“At the couple level, the most significant thing that we hear about is the desire for intimacy, desire to be close..the desire to be ‘as close as I can with my partner’ ”*

Robert Remien, Researcher, New York State Psychiatric Institute, Columbia University

## People Living with HIV Must Lead

People living with HIV have often been the leaders in HIV prevention advocacy. Uninfected people have rarely organized to demand HIV prevention services. People living with the disease have recognized the importance of others avoiding the challenges posed by becoming infected and many are willing to take the lead on primary HIV prevention. They are in a strategic position to reinforce the community norm -- that every effort should be taken to avoid transmitting HIV to another person. It is only with this leadership from the community of infected people and the groups that represent their interests that primary HIV prevention designed for people living with HIV will be successful.

*“From the beginning of the epidemic, one of the problems has been that we define prevention as something that' s done for and with sero negative people, and care and services were something that were done for and with sero-positive people, and never the twain shall meet.”*

Terje Anderson, Deputy Executive Director, National Association of People with AIDS

---

<sup>6</sup> Gendin, Stephen, “Protect Me from What I Want,”*POZ*, November, 1999, p. 82

<sup>7</sup> Hoff, Colleen, “HIV-positive MSM in Discordant Relationships Report Sexual Risk Taking with Primary and Non-Primary Partners,” presented at 12<sup>th</sup> World AIDS Conference, Geneva, June/July, 1998

## Altruism and Responsibility Without Shame

One of the major underreported stories of the AIDS epidemic is the valiant efforts of people with HIV to change their behavior and avoid infecting others. Though many people may accept it as obvious that a person infected with HIV has a responsibility not to pass that infection on, the psychological challenges that positive people encounter as they try to consistently maintain safer sex behavior over many years is rarely supported or acknowledged. The challenge is to deliver a message about accountability and responsibility without promoting feelings of shame or encouraging social stigma.

In a study of HIV-positive men, Richard Wolitski and colleagues found that “participants typically agreed that HIV sero-positive individuals have a special responsibility to protect others from HIV infection,” and the perception of responsibility was associated with being less risky over the last year.<sup>8</sup> The authors conclude that self-perceived responsibility should be addressed in counseling and intervention programs for HIV-positive individuals.

### Is Disclosure the Answer?

Disclosure of HIV status has been held up as a key to reducing new infections. Mark King of AIDAtlanta has argued that partners should disclose their status to each other. “The ‘everyone is positive’ concept is based on distrust – why bother asking when they’ll probably lie to you? . . . Whether you are positive or negative, say it. Whatever the status combo, behavior will probably change for the better when partners know HIV status.”<sup>9</sup>

Others are not so sure disclosure is the answer. Tim Vollmer, a medical anthropologist based in the Bay Area, has written that disclosure should not become “an official prevention policy.” He points out that many people simply do not know their HIV status, making a reliance on disclosure problematic. “A disclosure-based prevention policy would encourage gay men to self-sort by HIV status, which could lead to a de facto form of viral apartheid.”<sup>10</sup>

Disclosure of HIV status is particularly difficult given the legal and social context many people face. Advice that positives should readily disclose their status becomes extremely complex if states have criminalized HIV transmission, or if states have instituted HIV name reporting and/or mandatory partner notification laws -- particularly if individuals have potentially violent current or past partners.

---

<sup>8</sup> Wolitski, Richard, Gomez, Cynthia, Parsons, Jeffrey, Ambrose, Timothy, “HIV Seropositive Men’s Perceived Responsibility for Preventing the Transmission of HIV to Others,” presented at 12<sup>th</sup> World AIDS Conference, Geneva, June/July, 1998

<sup>9</sup> King, Mark, “First Person: Changing the Rules,” *New York Blade News*, July 10, 1998

<sup>10</sup> Vollmer, Tim, “Disclosure Isn’t the Answer,” *San Francisco Examiner*, 1998

Disclosure is also highly problematic for mothers concerned about custody of their children.

*“ We need safety. We need freedom from discrimination..discrimination has fallen off the national HIV agenda in the last several years, because people think ADA [the Americans with Disabilities Act] took care of it. People think we’ ve made such progress. It ain’ t the case. People still get fired from their jobs. People still get kicked out of their houses. And the fear is there, and present.”*

Terje Anderson, Deputy Executive Director, National Association of People with AIDS

## Communication

Whether or not partners disclose their status, many fail to communicate about how and whether to protect each other in sexual situations. Interviews with positive and negative gay and bisexual men in San Francisco found that many men were making assumptions about the sero-status of their partners – and acting on those assumptions – based on non-verbal clues. “ In many instances,” the researchers found, “ study participants deferred the responsibility for choosing condom use or discussing HIV serostatus to their sexual partner based on how the partner behaved and what he said or did not say within the context of the sexual episode.”<sup>11</sup>

As noted earlier, Robert Remien identified lack of communication between sexual partners as an important theme in his research. Cynthia Gomez found study participants making assumptions about the sero-status of their partners without direct communication.

## Substance Use and Lack of Control

Substance abuse plays an increasingly important role in the domestic HIV/AIDS epidemic. In a study of HIV-positive MSMs, David Purcell and Jeffrey Parsons found that substance use before or during sex was common. They also reported a relationship between drinking alcohol before or during sex and the likelihood to

---

<sup>11</sup> San Francisco AIDS Foundation, “Executive Summary. A Qualitative Interview Study of 92 Gay and Bisexual Males Regarding HIV Risk and Sexual Behavior.” Research sponsored by the San Francisco AIDS Foundation in partnership with the Center for AIDS Prevention Studies, University of California, San Francisco, December, 1997

engage in insertive anal intercourse without a condom with HIV negative or status-unknown partners.<sup>12</sup>

As noted above, Cynthia Gomez found that a sense of lack of control in sexual situations was an important factor for many people. Substance abuse, dynamics with partners and threats of violence were among the influences diminishing a sense of control in the situation.

## Context is key

Sex and injection drug use, and hence decision making around safer sex and needle use, take place within a myriad of contexts. The better these are understood, the better we can design prevention programming, conduct meaningful research and enact rational policy.

A partial list of the multiple contexts that can affect risk behavior includes:

- **Personal** (e.g. current health status, time since HIV infection, success of HIV treatments)
- **Partner** (e.g. attractiveness, power dynamics within the couple, desire to please)
- **Race** (e.g. power dynamics, assumptions about roles and HIV status)
- **Community** (e.g. an urban setting or a rural setting with less chance for anonymity, presence or absence of HIV-positive peers, communal myths about the origins of HIV including the perception that HIV was created to eliminate certain groups, the degree to which HIV infection stigmatizes or “lionizes” an individual, ability to feel accepted in the community and discuss challenges with practicing safer sex)
- **Substances** (e.g. physical or emotional dependence on drugs and alcohol)
- **Economic situations** (e.g. homelessness, economic crisis, dependence on sex for money exchanges)
- **History** (e.g. memory of the Tuskegee syphilis study in which treatment for syphilis was denied African American men)
- **Availability of health care and prevention** (e.g. supportive education campaigns, condoms).

---

<sup>12</sup> Purcell, David, Parsons, Jeffrey, “Substance Use and Sexual Behavior Among HIV-Seropositive Gay Men” presented at 12<sup>th</sup> World AIDS Conference, Geneva, June/July, 1998

*“I’ m HIV-positive, but I just started triple combination therapy a couple nights ago, so I’ m actually waiting for the behavioral disinhibition to hit..the context is completely being lost in all this...STDs, poverty, power dynamics, age, and ability to negotiate. I’ m very clear that we’ re at a point now where we’ ve got a chance to actually make a change, in the five [CDC] demo sites, and some of the community planning groups..it’ s an opportunity that can’ t be lost.”*

Mike Shriver, AIDS Research Institute, UCSF

## Diversity must be a guiding principle

HIV-positive individuals come from diverse backgrounds, racial/ethnic groups, have different and multiple risk factors and live in both cities and rural areas. They may face multiple challenges, including drug and alcohol abuse, poverty and caretaking responsibility for children. Different kinds of interventions are needed to reach these diverse populations. Social marketing, one-on-one and group interventions should all play a role in prevention. Health care workers, community based providers, schools and health departments must all be engaged.

*“ Minority women, black women, usually..we come to the table with an attitude. That’ s just the bottom line. ..We’ ve got a lot of baggage that we’ re bringing. Our man did us wrong and yada yada yada. ..So I think that, when we’ re talking about what we can do...we need to understand that there is an attitude to begin with, and [we need to think about] addressing that attitude and dealing with that attitude, and meeting that female wherever she is in life, whether we like where she is in life or not..”*

Catherine Morley, Women on Maintaining Education and Nutrition

## Personal Protection and biomedical questions

Prevention for people living with HIV can emphasize the personal benefits of safer sex and needle use in addition to altruistic motivators. The difficulty is that many issues around self-protection – including re-infection and super-infection, pregnancy and anti-retroviral therapy – are based on inconclusive science. Other areas are clearer: co-infection with Hepatitis C is clearly extremely dangerous for people living with HIV disease.

Other scientific unknowns complicate the ability to send decisive messages about risk behavior, including infectiousness with low viral load, the relative infectiousness of women vs. men, the significance of specific STDs for transmissibility and the potential for infection through oral sex.

Recent research offers hints on biomedical realities of HIV infection and transmission, but many more answers are needed. A study released in late January, 2000 suggests that HIV-infected individuals with low viral loads are likely less infectious than those with higher viral loads. The study involved 415 heterosexual, sero-discordant couples in Uganda. Researchers found that the higher the HIV viral load in the infected partner, the higher the risk of HIV transmission.<sup>13</sup>

In a study on the perceptions, attitudes and sexual risk among men living with HIV, Robert Remien and colleagues found that 17% of men in the sample reported engaging in unprotected insertive anal sex with an HIV negative partner, or a partner of unknown status. Researchers found that, “seropositive men who are on HAART (highly active antiretroviral therapy), who have undetectable viral loads and are also engaging in high risk sex with HIV negative men tend to believe that their acts carry minimal risk for HIV transmission.”<sup>14</sup>

In February, 2000 research was presented at the Retrovirus Conference that its authors said suggested “super-infection” with a more virulent strain of HIV had accelerated AIDS-related symptoms in an HIV-infected individual who had been positive for eight years but had experienced few, if any, symptoms of HIV disease. After having sex with a man with advanced stage HIV disease, the non-progressor’s physical condition deteriorated. The study revitalized concerns about the potential of super-infection, though some advocates pointed out that the research did not firmly establish super-infection had occurred, or that it was associated with the rapid physical decline of the long-term non-progressor.<sup>15</sup>

Another study released at the Retrovirus Conference found that the risk of contracting HIV through oral sex is far greater than had been previously assumed. A study involving 102 newly infected gay and bisexual men found that 8% of those infections resulted from unprotected oral sex.<sup>16</sup> UC San Francisco research Dr. Frederick Hecht was quoted as saying that the risk involved in oral sex “was higher than we expected. This may be a significant way that men who

---

<sup>13</sup> New York Times, “Study Finds Low HIV Levels May Lessen Spread of Virus,” *New York Times*, January 31, 2000

<sup>14</sup> Remien, Robert, Halkits, Perry, O’ Leary, Ann, Hays, Robert, “Perceptions, Attitudes, and Sexual Risk Among HIV-positive Men with Undetectable Plasma Viral Loads,” presented at 12<sup>th</sup> World AIDS Conference, Geneva, June/July, 1998

<sup>15</sup> Angel, J.B., et al, “Documentation of HIV-1 Superinfection and Acceleration of Disease Progression,” 7th Conference on Retroviruses and Opportunistic Infections, January/February 2000

<sup>16</sup> 7th Conference on Retroviruses and Opportunistic Infections, January/February 2000, cited in “Oral Sex: Study Reveals Risks for HIV Transmission,” *Kaiser Daily HIV/AIDS Report*, February 2, 2000

have sex with men get infected. [while] there' s a lot less unprotected anal sex .there hasn' t been the same reduction in unprotected oral sex..”<sup>17</sup>

With these questions in mind, many have raised the concern that prevention will become overly “medicalized,” emphasizing HAART and STD treatment, for example, over targeted behavioral interventions.

## Policy is a tool and an impediment

Public policy set by federal, state and local governments has a direct effect on the lives of people with HIV and on the ability to deliver meaningful prevention to them. Concerns about disclosure noted earlier are just one example. The challenge is to reach more people living with HIV in the presence of criminalization laws, name-reporting for HIV infection in a majority of states and threats in Congress to mandate one-size-fits-all partner notification and forced testing of accused assailants.

*“ We haven’ t yet looked at a lot of the policy structures that are actually encouraging risk for sero-positives, instead of discouraging the risk factors. And you know, this run for name reporting at CDC at the same time that they’ re promoting demo sites seems really, really counter intuitive – that you want to do demonstration sites to encourage positive prevention programs, and at the same time go against good data and go for name reporting.”*

Mike Shriver, AIDS Research Institute, UCSF

On a structural level, policymakers need to examine the ability to use federal funding and programs to deliver HIV prevention. The Ryan White CARE Act funds numerous kinds of programming that provide excellent opportunities to reach positive people with a prevention message, yet CARE dollars generally cannot be used for prevention. CDC encourages use of PCM funding for interventions with positives, but it is unclear whether community planning bodies are receiving sufficient guidance to consider prevention for positives, or whether they are choosing to implement such programs.

One speaker at the June, 1999 conference described the several levels of resistance he and others have encountered in promoting HIV prevention for positives. He has heard the message that positives already have Ryan White CARE funding and should not try to take scarce prevention dollars.

---

<sup>17</sup> 7th Conference on Retroviruses and Opportunistic Infections, January/February 2000 “Oral Sex: Study Reveals Risks for HIV Transmission,” *Kaiser Daily HIV/AIDS Report*, February 2, 2000

Federal and state funding for prevention and care remains a key policy issue. Leaders at AIDS service organizations have noted that without additional funding, their organizations cannot hope to mount substantial prevention programs and pursue related objectives, such as treatment of STDs.

## 3 We know enough to act

Community based agencies and the CDC have launched numerous prevention interventions designed to help people living with HIV avoid infecting others. The National Institute of Mental Health has also funded several research studies on prevention programs targeting positive individuals. At this writing, little conclusive research has been published on the effectiveness of existing interventions.

Lack of published research findings is no reason to delay the implementation of prevention programs for people living with HIV. Programs already in the field can help providers design their own interventions and forthcoming research can assist in improving interventions. Many of the lessons learned from more traditional HIV prevention can also be applied to prevention for positives.

Following is a summary of selected interventions that have been, or are now being, delivered around the country. The list of interventions is based largely on presentations made at a June, 1999 conference hosted by the AIDS Research Institute (ARI) at the University of California, San Francisco and the National Association of People with AIDS.

*“Healthy people have healthy sex lives..it is a measure of well being to have a healthy sex life..sexual satisfaction, and the integration of sexuality into living with HIV has emerged as a much more central issue for consideration with the advent and the success of antiretroviral therapies.”*

Steve Morin, AIDS Research Institute, UCSF

### AIDS Action Committee, Boston

AIDS Action Committee (AAC) has created a social marketing campaign targeting both HIV-positives and negatives. A major goal of the intervention is to “normalize the discussion” around avoiding transmission of HIV. Five years ago the agency launched a statewide campaign using posters over urinals in gay bars and sex clubs, and the campaign has been ongoing since then. One survey of gay men leaving these bathrooms found that 70% of them had unprompted recall of two or more of the messages.

Several of these prevention posters have been targeted to positives. During the “Don’ t ask, don’ t tell,” controversy, one poster read, “Ask. Tell.” Two others read, “Let’ s stop new infections now. Don’ t let yourself get infected. Don’ t infect anyone else. You know what you do,” and, “No excuses, accidents, or

rationalizations.” One poster includes the tag line, “ It's not cool to fuck without a condom if there is any chance you are HIV-positive.” A forthcoming poster campaign will address the assumptions gay men make about the sero status of their partners and the regret a positive man feels for having infected his lover.

AAC has a Prevention Case Management program for HIV-positive clients of the agency. The agency offers intensive prevention counseling within the context of social services case management and HIV health promotion services to individuals who have been assessed to be at very high risk for engaging in high risk behaviors. In addition, 50 to 60 AAC volunteers call about 250 clients once or twice a week to check in and do case management. Volunteers are trained to do prevention counseling and prevention-related issues come up frequently in these calls. Two thousand other clients of AAC get a call every three to five months. When a specific need is identified, the agency tries to offer more intensive prevention services.

*Encounters* is a monthly meeting sponsored by AAC. One hundred and fifty to 200 HIV-positive gay men typically show up at a local gay bar. People come to socialize, but the gatherings are also an opportunity to talk about treatment and adherence issues. Many of those who come have “ dealt with a lot of rejection from negative men,” according to Brian Byrnes of AIDS Action Committee.

*Women Initiating New Directions* (WIND) is a five-session curriculum for women clients of AAC, and prevention is frequently raised as an issue by clients.

*“ Before the stigma of AIDS, there was a stigma of race. And so, in this country, the interaction of race and AIDS takes on a unique set of factors. .such that communities of race have very difficult times dealing with issues of sexuality, because historically, sexuality issues have been perverted for them.”*

Ella Kelly, Research Psychologist, Center for Community Health, UCLA

## Los Angeles Consortium

The *Positive Images* program was set up by a six-agency multicultural consortium of AIDS community organizations. The goals of the intervention include raising awareness about the role of HIV-positive men and women in HIV prevention, providing social networks that promote self-esteem and self efficacy to practice safer sex, encouraging clients to reduce their risk for co-infection with other STDs, and, promoting HIV testing.

The program has several components. A telephone chat line gives people living with HIV the opportunity to talk anonymously about their feelings concerning sex

and safe drug use. Each chat lasts two and a half hours and is facilitated by one of the participating agency's peer staff members. Several different chat groups have been set up, including calls for women, gay Asian men and Latinos. Facilitators can have private conversations with individual callers if there is a need to have confidential conversation. The *Positive Images* program also offers a drop in support group.

The Los Angeles County Health Department provides *Vidas Positivas* for Latinas and Latinos, which offers Prevention Case Management (PCM), peer support, social occasions and other opportunities for HIV-positive people to interact. The County also uses case finding, based on targeted outreach in clinics and providers in Latino and African American communities. At-risk people identified are offered movie tickets for getting tested and having a risk assessment. Where appropriate they are "invited into care or continued prevention care, depending on their needs."

*"Right at this point in time, there is a big push for prevention with men of color..what they seem to forget..that men of color have sex with men, and they also have sex with women! ..I' m speaking from the world that Marva lives in. I don' t see how you can have prevention programs that' s geared towards men, if you don' t also align it with women."*

Marva Miller, Women on a Mission

## AIDAtlanta

AIDAtlanta has several prevention programs reaching people living with HIV, including social marketing campaigns and a behavior modification program designed specifically for African American women. One innovative program places trained volunteer educators in Internet chat rooms. The volunteers include hot button words (such as barebacking, drugs, etc.) in their online "profiles" to encourage other people online to contact them about prevention issues. Agency staff believe they have been able to reach many people who would not necessarily show up for an extended group session or other intensive prevention interventions. AIDAtlanta also previously ran a program called *HIV Stops with Me*, a six-week group for positive clients that emphasized the personal responsibility not to transmit HIV.

*"There' s a large population like me that are disconnected..from any of the conversations that we' ve had today..they' re off doing drug combination cocktails, living life, being perfectly happy."*

Mark King, AIDAtlanta

## Asian & Pacific Islander Wellness Center, San Francisco

The Asian & Pacific Islander Wellness Center is currently designing an eight-session group intervention specifically for the MSM Asian American and Pacific Islander American (API) community. The program addresses multiple issues, tailored to a Gay API clientele. Because disclosure of status to family members is particularly challenging for many API MSMs, the issue of disclosure is dealt with in two segments: talking to your family and talking to a date. Another component of the intervention deals with safer sex, addressing assumptions about status, implications of new treatments and other issues. The group also talks about the meaning of being gay, API and HIV-positive. The intervention will be pilot tested, both as an eight-session program over eight weeks and as a weekend retreat. Funding to pilot the intervention as a research project was granted in July, 1999 and is currently in the process of being implemented.

*“ Our agency tried to integrate our prevention and our client services departments, and it was very difficult..Prevention was telling people ‘ this is horrible, you don’ t want to get it’ and the Client Services was going, ‘ Oh, it’ s OK. It’ s all right. You know, it’ s not so bad.’ ”*

Vince Crisostomos, Asian and Pacific Islander Wellness Center

## Prevention Case Management

The CDC guidance for Prevention Case Management (PCM) suggests that priority for these services should be given to HIV-positive persons. CDC guidance defines PCM as “ client-centered HIV prevention activities with the goal of promoting the adoption or maintenance of reduced HIV [transmission] behaviors.” Goals of PCM include providing specialized assistance to people with multiple and complex needs, offering individuals multiple session HIV risk reduction counseling, assessing the presence of STDs and ensuring appropriate treatment. CDC has identified seven essential components of PCM: client recruitment, screening, risk reduction counseling, development of a client plan, coordination of services, follow-up monitoring and discharge.

CDC has researched implementation of PCM at several agencies and has found a wide variance in the types of programs going on around the country. Almost all programs serve both positive and negative clients. Assessment of client needs and case management are components of most of the programs. Several barriers to a successful PCM program have been identified, including lack of

interest by clients, lack of clear definition of PCM, lack of referral resources in the community and difficulty with evaluating the outcome of case management.

# 4

## We need to learn more

The National Institute of Mental Health has funded a variety of research projects on prevention interventions for positives, though only preliminary results are available for most of these studies. The CDC has also funded five demonstration projects to “develop comprehensive continuums of primary HIV prevention for HIV-positive individuals,” though results will not be available for some time.

Below is a summary of ongoing research, most of which was presented at the June, 1999 ARI-NAPWA conference. This is not meant to be comprehensive lists of interventions and research projects, but to give readers some reference points to use in planning prevention campaigns.

### TLC (Teens Linked to Care)

Marguerita Lightfoot – University of California, Los Angeles

Marguerita Lightfoot is working with colleagues at UCLA to evaluate the *TLC* program, an NIMH-funded study of an intervention designed to change the risk behavior of youth living with HIV. In developing the intervention, the UCLA group did an ethnographic study of youth in San Francisco, Los Angeles and New York. Based on approximately 40 interviews of young people in these cities, the investigators designed a three-module intervention, with each module consisting of several group sessions.

The project recruited HIV infected youth between the ages of 14 and 23. Participants were randomized into two groups with one “lagged control” group receiving the intervention approximately one year later than the other group.

**Module 1** was twelve sessions focused on “staying healthy.” Issues addressed included adherence to medical treatment, disclosure of status and stigma experienced by HIV-positive youth.

**Module 2** sought to help participants “act safe” and targeted risky sexual and substance abuse behavior. Topics included proper condom use and safer sex, and dealt with questions such as having children, disclosure and responsibilities to partners. Participants were encouraged to think about the emotional correlates to their substance abuse.

**Module 3** focused on quality of life issues and was designed to help participants feel good about and get pleasure out of their lives.

The “staying healthy” module made a greater impact on females than males. Many of the youth took a number of steps to improve their health, such as exercising or taking vitamins. Results for the “act safe” module showed a more than 40% reduction in the number of sexual partners and fewer HIV-negative partners. There was a 78% reduction in the number of unprotected sexual acts. Researchers also recorded a 30% reduction in the use of substances. After the “quality of life” module, youth who attended the intervention appeared to have significantly lower levels of emotional distress than those who did not participate in the intervention.

Researchers pointed out that many of the participants reduced risky behavior spontaneously before the intervention began. Researchers noted the need to assess the appropriateness of the group intervention format, given that it may be difficult for some young people to be open and forthcoming in a group. Recruitment to the program was a challenge and took researchers longer than they had anticipated.

## MSMs and IDUs in Urban Settings

Cynthia Gomez -- University of California, San Francisco

Cynthia Gomez is involved in several research studies relevant to prevention for positives. The Seropositive Urban Men’ s Study (SUMS) and the Seropositive Urban Drug Injectors Study (SUDIS) are designed to:

- Describe the sexual behavior, disclosure and drug use patterns of sample of HIV-positive men who have sex with men (MSM) and of a sample of HIV-positive heterosexual male and female IDUs.
- Identify demographic, psychosocial and contextual factors that help or hinder HIV sero-status disclosure and risk reduction practices among HIV-positive MSMs and IDUs with HIV-negative partners or partners of unknown status.
- Identify feasible intervention strategies to promote the prevention of HIV transmission among HIV+ MSMs and HIV-positive IDUs.

Researchers have already learned several things about the participants in the study, including:

- MSMs and IDUs living with HIV continue to be sexually active after diagnosis of infection and have distinct prevention intervention needs.
- HIV-positive IDUs are engaging in similar sexual behaviors with HIV-positive and HIV-negative partners.

- HIV-positive IDUs are reporting riskier sexual behaviors with their main partners as compared to secondary partners.
- HIV-positive MSMs are reporting rates of unprotected sex similar to those reported by HIV-negative MSMs.
- HIV-positives MSMs are using some harm-reduction strategies to prevent transmission of HIV.

Gomez and her colleagues have identified several themes in their SUMS and SUDIS studies. Many MSMs reported lack of control over their own behavior, often linked to use of substances and occasionally, threats of violence. Characteristics of partners were another important factor in risk taking, including the attractiveness of the partner and his role in the sexual encounter. Assumptions about status – without verbal confirmation – were frequently observed.

Researchers learned that many of the IDUs in their study are in relationships with people they have known much of their lives, and who are knowingly engaging in risky behavior. Economics plays a critical role and many HIV-positive women reported frequent exchange of sex for drugs. Many of these women have little or no control over the kind of sex they have in these situations.

Gomez was also involved in studying an intervention for sero-discordant heterosexual couples (the California Partners Study). The intervention was four sessions, followed by two “booster” sessions. It was focused on couples, but each member of the couple came in for his or her own separate sessions. The intervention was developed with the input of HIV-infected individuals and their negative partners. Researchers found that many of the couples in the intervention were consistently engaging in unprotected vaginal intercourse.

The expressed need for “love and intimacy” plays an important role in sexual decision-making. According to Gomez, some “couples simply feel that they do not want to carry HIV into the bedroom.” For other couples, economics was a key issue. These couples had the perception that HIV infection actually connects people with important resources and they therefore did not see HIV infection as a completely negative consequence.

Gomez is currently also working on *SUMIT* (Seropositive Urban Men’s Intervention Trial), a new intervention for HIV-positive MSMs about to be launched. This will be a six-session intervention that will bring together 50 HIV-positive men. The goal is to create a social environment that does not feel like a traditional support group.

In addition, Gomez recently received a grant to do a study on HIV-positive IDUs. The study, called *INSPIRE* (Intervention for Seropositive Injectors – Research

and Evaluation), will develop an intervention to reduce sexual risk and increase utilization of HIV care and treatment and adherence.

*“ There is also a strong economic piece among the injectors, in terms of their survival, and whether it be through trying to maintain their habit and their addiction, or whether it be for women, HIV-positive women, a lot of exchange for drugs. And in that context, most of the time, these women have no control over the type of sex that is being had.”*

Cynthia Gomez, Researcher, AIDS Research Institute, UCSF

## Sero Discordant Couples Robert Remien – Columbia University

Robert Remien is working on an NIMH-funded study of a group intervention for gay male sero-discordant couples. Couples came together in groups for eight sessions. The design was based on earlier interviews researchers had done that identified high levels of distress and hopelessness as well as feelings of isolation among these couples.

Remien has identified several themes in his research relative to sexual risk. The “ most significant” finding was the expressed “ desire for intimacy, desire to be close..the desire to be ‘ as close as I can with my partner.’ ” Remien has found the same concern when working with heterosexual partners. Researchers also have observed that when partners in the study practiced risky behavior, it was often at the request of the HIV-negative partner. Many of the men in the study reported being surprised by some of the comments made by their partners during the group sessions. Remien reported “ When it comes to issues around risk behavior, they’ re often experiencing the same fears and concerns but they’ re not expressing them to each other because they feel a need to ‘ protect’ each other emotionally. This avoidance of communication can contribute to taking behavioral risks.”

Retention of participants has been a major challenge in the intervention and several of the couples initially enrolled in the study have broken up. Remien believes this is because couples who are having relationship difficulties are drawn to the intervention. However, Remien has noted the important potential of working with couples and the ability to engage in difficult issues around prevention, risk and taking care of each other by working with both members of the couple. Many of the HIV-positive individuals in the study were concerned about several issues in addition to preventing transmission of the virus, including self-protection, acquisition of sexually transmitted diseases (STD) and re-

infection, as well as medical treatment issues, dealing with uncertainty and making future plans.

*[Sero discordant couples felt that] “ ‘ No one’ s paying attention to us, we don’ t get a lot of support, we don’ t feel validated. We feel closeted’ ..Friends and family are not supporting them being in the sero discordant relationship, whether they were positive or they were negative. So they felt isolated.”*

Robert Remien, Researcher, New York State Psychiatric Institute, Columbia University

## Women in Non-urban Communities Gina Wingood – Emory University

Gina Wingood is studying an intervention called “ Willow,” (Women Involved in Life, Learning from Other Women), a group intervention designed for HIV-positive women primarily in non-urban communities. The program focuses on two issues: enhancing quality of life and reducing unsafe sex among participants. One goal of the intervention was to build the social networks of the women participants, because these networks do not exist for many women in rural communities.

The intervention was divided into four sessions:

**The first session** focused on gender pride. This session was designed to enhance women’ s self-worth, self-esteem and sense of pride. Session activities included examining important women in the participants’ lives and discussions about things in the participants’ lives of which they are proud.

**The second session** concentrated on emotion-focused coping skills. Women in the group noted that they have much stress in their lives and face great challenges in coping with stress. Relaxation techniques, exercise, journal writing and assertiveness were all discussed during this session.

**The third session** focused on risk reduction, including condom use, sexual negotiation skills and potential risks of super-infection.

**The fourth session** dealt with healthy relationships and addressed fear of abandonment, fear of status disclosure to partners and emotional and physical abuse. No data is available yet on the effectiveness of this

intervention, but retention in the program has been impressive: the six-month follow up rate was 100%.

*“ Often, women who are living with HIV have a lot of abuse in their relationship. It's not just sexual abuse or it's physical abuse – it's fear of abandonment. It's emotional control. It's fear of disclosure by partners.”*

Gina Wingood, Rollins School of Public Health, Emory University

## Clinicians as Prevention Providers

William Fisher – University of Western Ontario and

Jeffrey Fisher – University of Connecticut

William Fisher and Jeffrey Fisher are working on formative research on an intervention targeted to clinicians and the HIV-positive clients they serve. The program is based on the assumption that many HIV care clinicians are not sufficiently skilled to provide HIV prevention services to their clients. The goal is to develop a physician-directed HIV prevention intervention for people with HIV that can be delivered over time and that is easy to integrate into the context of continuing primary medical care.

Fisher and Fisher intend to integrate laptop computers into the intervention. These laptops would be used to collect individualized information from patients and generate a patient profile. A prescription pad will be used for physicians to “prescribe” prevention. Clinicians will be trained to be empathetic and non-judgmental, as well as to conduct motivational dialogue with patients on HIV prevention issues.

## Reaching People in Prison Facilities

Olga Grinstead – University of California, San Francisco

Olga Grinstead and her colleagues at the Center for AIDS Prevention Studies (University of California, San Francisco), worked in collaboration with Centerforce, Health Programs Division to develop and test an 8-session pre-release intervention for HIV-positive inmates at a state prison. They found that men who attended the intervention session reported more use of community resources and less sexual and drug-related risk behavior in the months following their release compared to men who signed up for the program but were not able to attend.

# 5

## A Proposed Research Agenda

There are numerous areas where additional behavioral research would aid in the development of effective prevention interventions. It is essential that people living with HIV be involved in the development of these research projects. In addition, it is important that data gathering be done in a way that captures the often subtle choices that sexual partners make. For example, when measuring risk behavior and anal intercourse, it is important to ask whether an individual is insertive, receptive, or both, and in which situations he or she uses condoms.

*Key research questions include:*

### Understanding the context

**The Context of risk taking** -- What are the relational, environmental, and legal elements of society that shape people's lives and influence their behavior? Includes: community norms, race, socioeconomic status, drug use, community myths, power in relationships, and public policies. More personal issues such as differential state of disease progression must also be considered.

**Understanding the meaning of sexuality** -- What is the meaning of sexuality for different groups of HIV-infected individuals? How do people perceive their responsibilities as HIV positive sexual partners? What constitutes a healthy sexuality for HIV infected individuals? How does a researcher or public health worker promote healthy sexuality for HIV infected individuals? How does the public discourse about healthy sexuality among HIV infected persons encourage healthy behaviors without creating stigma or a backlash?

**The biological – behavioral intersection** -- What do we know about biomedical questions that can be included in prevention for people living with HIV? How can this information best be delivered? In the absence of answers to biomedical questions, how can prevention programs most effectively convey the current understanding of these issues? Biomedical questions include: infectiousness at different time-points, “re-infection”, “super-infection”, the role of STDs in infectiousness and transmissibility, riskiness of oral sex, the meaning of Hepatitis C co-infection, and the relative infectiousness of semen with low or non-detectable viral load in blood.

## Developing and testing behavioral interventions

### **Adaptability of existing prevention technology**

What are the lessons from HIV prevention research today that can be transferred to prevention for positives? How should practitioners approach translation of more traditional prevention curricula to prevention for positive individuals? How can we build upon existing interventions to reach HIV-positive persons? How is it possible to target an intervention at people living with HIV without engendering a sense of shame or encouraging stigma? How can HIV-positive individuals be acknowledged and supported for the altruistic act of protecting others? Considering the central role of drug abuse in the epidemic, how can standard interventions for drug users be adapted for HIV-positive drug users?

### **Interventions for injection drug users**

What interventions can successfully help HIV-positive IDUs reduce their risk behavior? It will be important to do IDU research in several types of communities, including rural and urban.

### **Community level interventions**

How can social marketing and other community level interventions be used to most effectively? How can these interventions be used in tandem with other programming to maximize the prevention message? How can these interventions be used to reach those who are thriving and currently “disconnected” from prevention messages? Social marketing may include: marketing of practices and behaviors, knowledge, ideas, marketing as an agent of social and political change, Internet chat rooms, free forums for safe sex education and discussion.

### **Multi-component interventions**

What combination of interventions, including social marketing, one-on-one counseling, group interventions, and school-based interventions can have the greatest prevention impact? What have we learned from traditional HIV prevention that can inform multi-component prevention for positives?

## Structural issues

### **Laws, policies and prevention**

How do federal, state, and local laws and policies affect personal decision-making concerning risk, disclosure, participation in prevention programming, and access to care? Examples include: criminalization of transmission, HIV name reporting, partner notification, child custody, controls on confidentiality of medical records, Americans with Disabilities Act protections.

### **Opportunities in health programming**

Which federally funded programs provide opportunities to offer prevention for positives? Are there limits on the use of funds in these programs that preclude

delivery of positive prevention interventions? Examples include: Ryan White CARE Act, Medicare/Medicaid, Substance Abuse and Mental Health Services, and Veterans Administration programs. What private sector health care and other programs provide opportunities to deliver prevention for positives? How can the federal government assist these private entities in improving their work in this area? Examples include: health maintenance organizations.

## Rapidly transferring knowledge

### **Technology Transfer**

How can we speed the process of dissemination of research findings, and make that process more effective? The goal is to move beyond the established pathway of researcher to journal to public. Instead, research findings should move outward from the researcher in many directions at once, not to scientific journals alone. Technology influences awareness, it shapes science, guides interventions, and often times profoundly influences behavior.

# Appendix: List of Forum Participants

Primary HIV Prevention: Designing Effective Programs for People Living with HIV

June 17, 1999

San Francisco, California

## **Panelists:**

Abu Abdul-Quader, Centers for Disease Control and Prevention  
Terje Anderson, National Association of People with AIDS  
Bill Barnes, Office of Mayor Willie L. Brown, Jr.  
Brian Byrnes, AIDS Action Committee, Boston  
Reggie Caldwell, Office of AIDS, State of California  
Thomas Coates, AIDS Research Institute, UCSF  
Vince Crisostomos, API Wellness Project/Living Well Project, San Francisco  
Rene Durazzo, San Francisco AIDS Foundation  
William A. Fisher, University of Western Ontario, Canada  
Gunther Freehill, Los Angeles County Department of Health Services  
Paul Gaist, Office of AIDS Research, National Institutes of Health  
Steve Gibson, STOP AIDS, San Francisco  
Cynthia Gomez, AIDS Research Institute, UCSF  
Martin Gonzalez-Rojas, CALOR, Chicago  
Heather Hauck, Washington Hospital Center, DC  
Don Howard, ACT UP Golden Gate  
Ella Kelly, Center for Community Health, UCLA  
Mark King, AID Atlanta  
Steve Lew, Support Center for Non-Profit Management, San Francisco  
Marguerita Lightfoot, Center for Community Health, UCLA  
Marva Miller, Women on A Mission, Kansas City, Missouri  
Douglas Morgan, HIV/AIDS Bureau,  
Health Resources and Services Administration  
Catherine Morley, Women on Maintaining Education and Nutrition, Nashville  
Jeffrey T. Parsons, Center for HIV/AIDS Education Studies and Training,  
New Jersey City University, Newark  
David Purcell, Centers for Disease Control and Prevention  
Robert H. Remien, New York State Psychiatric Institute, Columbia University  
Walt Senterfitt, Los Angeles County HIV Epidemiology Program  
Mike Shriver, AIDS Policy Research Center, UCSF  
Troy Suarez, Center for AIDS Research, Medical College of Wisconsin  
Steve Wakefield, The Night Ministry, Chicago  
Phill Wilson, AIDS Social Policy Archive, University of Southern California  
Gina Wingood, Rollins School of Public Health, Emory University

**Participants:**

Carol Crump, Office of AIDS, State of California  
Randy Cupp, STOP AIDS, San Francisco  
Pamela DeCarlo, Center for AIDS Prevention Studies, UCSF  
Beth Dillon, Centers for Disease Control and Prevention  
Dogan Eroglu, Centers for Disease Control and Prevention  
Karena Franses, AIDS Research Institute, UCSF  
Cheryl Gore-Felton, Center for AIDS Intervention Research,  
Medical College of Wisconsin  
Kristin Hackl, Center for AIDS Intervention Research,  
Medical College of Wisconsin  
Elizabeth Hirky, New York State Psychiatric Institute, Columbia University  
Mallory Johnson, AIDS Research Institute, UCSF  
Robert Klitzman, New York State Psychiatric Institute, Columbia University  
Tracey Packer, San Francisco Department of Public Health  
Tomas Rodriguez, Centers for Disease Control and Prevention  
Nicolas Sheon, AIDS Research Institute, UCSF  
Raymond Smith, New York State Psychiatric Institute, Columbia University  
Dale Stratford, Centers for Disease Control and Prevention  
Craig Waldo, AIDS Research Institute, UCSF  
Richard Wight, Center for Community Health, UCLA

**Rapporteurs:**

Ellen Goldstein, Center for AIDS Prevention Studies, UCSF  
Steve Morin, AIDS Policy Research Center, UCSF  
Willo Pequegnat, National Institute of Mental Health, National Institutes of Health  
Susan Tross, New York State Psychiatric Institute, Columbia University