

Best Practices

in Prevention Services for Persons Living with HIV



BEST AVAILABLE RESEARCH

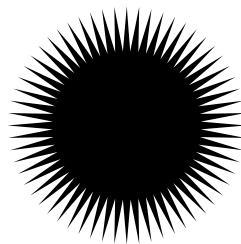
PROGRAMMATIC EXPERIENCE

EXPERT SOURCES



Best Practices

in Prevention Services for Persons Living with HIV



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Acronyms

AED	Academy for Educational Development
AIDS	Acquired Immunodeficiency Syndrome
APLA	AIDS Project Los Angeles
CAPTC	California STD/HIV Prevention Training Center
CBO	Community-Based Organization
CDC	Centers for Disease Control and Prevention
CHBT	Center for Health and Behavior Training
CLI	Community-Level Intervention
CTR	Counseling, Testing, and Referral Services
FDA	Food and Drug Administration
GLI	Group-Level Intervention
HAART	Highly Active Antiretroviral Therapy
HE/RR	Health Education and Risk Reduction Intervention
HIV	Human Immunodeficiency Virus
HRSA	Health Resources and Services Administration
IDU	Injection Drug User
ILI	Individual-Level Intervention
MMWR	Morbidity and Mortality Weekly Report
MSM	Men Who Have Sex with Men
NIH	National Institutes of Health
PCM	Prevention Case Management
PCRS	Partner Counseling and Referral Services
PLWHA	People Living with HIV/AIDS
PTC	Prevention Training Center
STD	Sexually Transmitted Disease
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on AIDS

Preface

The third decade of the HIV/AIDS epidemic has presented dynamic and complex challenges in the United States. Although HIV/AIDS prevention and treatment science has improved significantly since the beginning of the epidemic, the incidence of annual HIV infections in the United States has remained constant at approximately 40,000 cases over the last decade. The Centers for Disease Control and Prevention (CDC) is extending efforts to address the current challenges of HIV transmission and devise new strategies to meet prevention needs. The two priority strategies that are being employed are: 1) assisting and supporting HIV-positive individuals in reducing high-risk sexual and drug injecting behaviors; and 2) locating, engaging, and recruiting individuals who are unaware of their serostatus for testing and prevention and care services.

Over the course of the epidemic in the United States for the past quarter century, prevention programs have traditionally focused on helping uninfected individuals avoid infection. While it will continue to be critical to target HIV negatives with prevention services, it is also necessary to focus prevention efforts on HIV-positive individuals in order to achieve a reduction in HIV transmission to their sexual and injecting drug partners. Research indicates that HIV-positive persons who are aware of their serostatus reduce their sexual and drug use risk behaviors, potentially resulting in reduced HIV transmission to their partners. Unfortunately though, recent studies have reported that these behavioral changes are not generally sustained and many HIV-positive individuals continue to practice high-risk behaviors (Kalichman, 1999).

This new emphasis on prevention with HIV positives in the battle against HIV/AIDS is critical to the future course of the epidemic. Prevention with positives has potential to reduce the transmission of HIV significantly.

This document is designed to provide staff and decision makers in health departments and community-based organizations (CBOs) with general guidance on developing and implementing prevention programs with positives. The document is a compilation of information from the best available research, programmatic experience, and expert sources. The strategies and approaches described here are based on best practices recommended by consumers, stakeholders, researchers, and experts who have extensive experience in working with individuals living with HIV and a comprehensive understanding of their prevention needs.

Introduction and Purpose

Between 850,000 and 950,000 individuals in the United States are living with HIV/AIDS today and new infections are continuing to occur (Fleming et al., 2002). According to the Centers for Disease Control and Prevention, there are approximately 40,000 new infections with HIV each year (CDC, 2001b). Rates of new HIV infection in the mid-1980s were more than 150,000 annually; today, they are about a quarter of that number. Preventing new infections continues to be a clear priority.

Traditionally, prevention programs have focused on helping uninfected individuals avoid infection. However, there is a growing recognition of the need to also focus prevention efforts on HIV-positive individuals because every new infection involves an HIV-positive person who has unknowingly, or knowingly, infected another person. People living with HIV/AIDS (PLWHA) have a range of options they can use to reduce their risk of transmitting HIV to others, including being tested for infection, receiving counseling and services, and engaging in safer sex and drug injecting practices. Communicating prevention messages and effectively engaging people in interventions is crucial, particularly because half of all infected individuals are unaware of their serostatus or remain outside of care and prevention networks (Fleming et al., 2002).

Prevention efforts with HIV-positive individuals have not received much attention in the past, in part because of concerns about stigmatizing PLWHA and in part out of fear of splitting communities between positive and negative individuals (Collins et al., 2000). Moreover, those campaigns that do focus on prevention with

positives have generally failed to address the unique needs of HIV-infected individuals and thus have failed to reduce the further transmission of HIV from infected to uninfected populations. In addition to barriers that both HIV-positive and HIV-negative individuals face in engaging in safe behaviors, PLWHA are also burdened with additional barriers, including social stigma and myriad difficulties associated with living with a life-threatening illness.

A. The Purpose of this Best Practices Document

Although many organizations, agencies, and stakeholders have discussed the need to develop and expand interventions that focus on individuals who are HIV positive, scientifically and programmatically sound data and guidance on effective interventions are limited. Several publications provide useful guidance for implementing prevention with positives interventions, including the CDC's *Prevention Case Management Guidance* (1997) and the CDC's *Procedural Guidance For Selected Strategies And*

Interventions For Community Based Organizations Funded Under Program Announcement 04064 (2004). Additional research, however, is needed on the development of prevention with positives programs, and access to this information is essential to reducing HIV-associated morbidity and mortality.

Best Practices in Prevention Services for Persons Living with HIV fills some of these information gaps. It is designed to provide staff and decision makers in health departments and community-based organizations with general guidance on developing and implementing prevention programs with positives. The intention is not to present new findings from basic research, but rather to compile information from the best available research, programmatic experience, and expert sources and to present it in an easily understood format. The strategies and approaches described here are based on best practices recommended by consumers, stakeholders, researchers, and experts who have extensive experience in working with individuals living with HIV and a comprehensive understanding of their prevention needs. The document places particular emphasis on ethical and legal issues, including discrimination and stigmatization, privacy, and access to care. These factors must be considered in developing prevention programs for HIV-positive persons to ensure that all efforts are made to reduce or eliminate the possibility that participation will place an individual at undue risk of harm.

This document addresses two methods to identify HIV-positive clients and engage them in effective prevention activities. In addition to increasing HIV testing rates among persons at high risk for HIV infection, these two strategies focus on improving outreach and recruitment specifically to address the prevention needs of those living with HIV. This document also examines the key areas

involved in implementing programs for HIV-positive clients once they are located. The two methods in this document are:

- Locating, engaging, and recruiting clients for services; and
- Designing and implementing services and prevention programs for HIV-infected individuals.

B. The Organization of this Best Practices Document

The seven chapters in this document provide readers with key information covering client recruitment and outreach strategies, the scientific basis to support prevention with positives information, intervention information, and legal and ethical issues. Chapter highlights include:

- Chapter 2 describes the rationale behind prevention programs for those with HIV, including persistent rates of infection and sources of these high rates. The chapter also provides an overview of current CDC initiatives and activities in this area, including, the *HIV Prevention Strategic Plan Through 2005* and the *Advancing HIV Prevention Initiative*.
- Chapter 3 describes strategies to effectively locate, engage, and recruit clients to services, and considers issues that influence test seeking and avoidance behaviors. The chapter outlines approaches that CBOs can use to enhance their outreach to high risk groups and improve linkages among the key types of prevention, care, and treatment services needed by PLWHA.
- Chapter 4 describes the scientific underpinnings of strategies to promote prevention among positives, and provides

information on risk behaviors and risk reduction.

- Chapter 5 provides background on prevention with positives interventions and provides greater detail on individual-, group-, and community-level interventions.
- Chapter 6 offers guidance on the legal and ethical issues involved with providing prevention services to individuals living with HIV.
- Chapter 7 highlights conclusions and key points from preceding chapters.

C. Methodology

To develop this document, a variety of experts were involved from community-based HIV prevention agencies and state and local health departments. HIV-infected and affected groups were included. Three major sources of information were used to develop *Best Practices*:

1. EXPERT CONSULTATIONS

In May 2001, more than 30 representatives from CBOs, health departments, and the prevention community attended “Case Finding and Linkage to Services,” the first of three expert consultations held by CDC and convened by AED to gather information about the best available research and programmatic experience related to prevention with HIV-positive individuals. This consultation was followed by a second meeting, “Prevention Interventions,” in June 2001, which was attended by more than 30 different members of CBOs, health departments, and the prevention community. Finally, an additional 25 participants from CBOs, health departments, and the prevention

community attended the third consultation on “Ethical and Legal Issues” in July 2001.

Before each consultation, CDC provided participants with an annotated bibliography on the consultation topic, as well as a brief Issues Paper. Each consultation followed a similar format consisting of brief presentations to the entire group on the specific issues to be addressed, followed by small, facilitated discussion groups. After each of the meetings, participants received consultation summaries.

2. LITERATURE SEARCHES

Preliminary literature searches were conducted in Spring/Summer 2001, and were updated again several times in 2003 and 2004. Materials were organized into categories matching the expert consultation topics. Additional studies were identified through the bibliographies of articles identified in the literature searches. Consultation participants received these annotated bibliographies, which were also used to outline this document. Other resources, including additional articles, names of individuals and programs, and program materials were obtained from consultation meeting participants. Ongoing literature searches were conducted throughout the development of *Best Practices* to ensure that information about the science behind and current approaches to prevention with positives was up-to-date.

3. KEY INFORMANT INTERVIEWS

Finally, key informant interviews with organizations and research institutions across the country were conducted between October and December 2002 to gain insight into prevention with positives activities and research and to obtain in-depth information on existing

programs and resources. To prepare for these interviews, AED and CDC developed a list of CBOs, STD/HIV Prevention Training Centers (PTCs), and clinics nationwide that carry out prevention programs with positives. The list of agencies selected for interviews included many groups that participated at the expert consultations. These agencies also identified other programs for AED to interview. CDC Project Officers and other staff identified additional programs which were added to the list. The convenience sample included organizations and individuals involved in prevention with positives work. Of the 55 organizations and institutions identified, 26 researchers, program managers, clinic directors, and directors of CBOs and PTCs consented to participate in the interview process.

Appointments were set up with all of the participants and a letter that described the purpose of the interview was sent before the scheduled call that typically lasted 45 to 60 minutes. The interviews emphasized the challenges faced and lessons learned by these individuals and their organizations in implementing, developing, and evaluating prevention with positives programs. Notes were taken during each call and content was analyzed and grouped by question. The analysis revealed a diverse variety in the types of programs, interventions used, and populations served.

Prevention with Positives Interventions: CDC Initiatives and Activities

A. Background on the Problem

Approximately 850,000 to 950,000 individuals in the United States are living with HIV/AIDS today. However, an estimated 25% of them are unaware of their infection (Fleming et al., 2002). Effective treatments have allowed more HIV-infected persons to live longer, healthier, and more active lives. Despite these advances in treatment, however, HIV remains an infectious, life-threatening disease that requires complex and costly treatment regimens that may not work for everyone. According to CDC, there are an estimated 40,000 new HIV infections each year — a rate that has not changed since 1992 (CDC, 2003b). In addition to new HIV infections every year, primary and secondary syphilis rates are increasing among men who have sex with men (MSM) in urban areas, many of whom are HIV-positive (CDC, 2001d; CDC, 1999).

There are many reasons for this persistent rate of HIV infection. Some of these reasons include:

- Overly optimistic beliefs about new drug therapies, which can create the false perception that HIV is no longer a major health threat (Dilley et al., 1997; Kravcik et al., 1998; Stall et al., 2000);

- Prevention burnout, resulting in the difficulty to sustain behavior change (among both HIV-negative and HIV-positive individuals) on a daily basis (CDC, 2001d);
- Changing social norms and practices around risk behaviors (e.g., “barebacking” and use of the Internet to locate sex partners) and specific psychosocial factors within some communities (e.g., substance abuse and the “down low” phenomenon) (Mansergh et al., 2002; Elford et al., 2002); and
- Changing demographics of those infected and affected by the epidemic. New social, economic, and racial/ethnic groups—particularly racial and ethnic minorities—are increasingly becoming infected, while other populations are experiencing stabilized or reduced rates of infection.

New HIV infections are primarily occurring in diverse, young, and vulnerable populations. Current data reflect that people of color are disproportionately at risk for HIV infection. Nearly 70% of those currently becoming infected are men. Of the men becoming infected, 60% are MSM, of whom 50% are African American, 30% are White, and 20% are Hispanic (CDC, 2001b).

One study found the rate of new HIV infections for MSM to be nine times higher than for women or heterosexual men (Linley et al., 2003). Research has shown that a “second wave” of the epidemic may be occurring in the gay community (Valleroy et al., 2000). A large majority of young gay men with HIV are unaware of their HIV infection, especially young African American men (MacKeller et al., 2003). Hispanic youth are also disproportionately affected. According to the Henry J. Kaiser Family Foundation, Hispanic youth represent approximately 14% of United States teenagers, but accounted for 20% of new AIDS cases reported among teenagers in 2000 (Swartz, 2002).

Because more new infections occur in these diverse populations, interventions must be designed with attention to the unique cultural, generational, ethical, and legal dimensions of HIV infection in specific populations. Current at-risk populations increasingly are people of color, who already face a history of discrimination and are often marginalized in their communities or in society at large. Tailored interventions are needed to identify people at risk for HIV, encourage them to be tested, and provide them with access to care and prevention programs if they are diagnosed HIV-positive.

B. Rationale for Focusing on Prevention with Positives

In addition to the need for continuous prevention strategies aimed at uninfected individuals, there is a growing need to focus prevention efforts on HIV-positive populations—every new HIV infection involves an HIV-infected individual who has infected another person. As people are living longer, an increasing number of transmissions may stem from people who know they are positive and still engage in unprotected sex (Marks et al., 1999).

There are additional reasons for intensifying efforts to reach infected individuals.

1. People benefit from treatment. People who know they are infected can benefit from prophylaxis for opportunistic infections, monitoring of their immune status, antiretroviral therapy (when recommended), and if needed, substance abuse and/or mental health treatment.

Targeting those who are unaware they are infected, or who are aware but are not receiving care, is a key challenge for prevention and care service providers. There are approximately 180,000 to 280,000 people in the United States who are unaware they are infected (CDC, 2003b). There are also many people who are aware of their positive serostatus but are not receiving care—these individuals are not easily accessible to health care and counseling professionals. Moreover, disenfranchised populations are less likely to pursue care. Researchers at the University of California, San Francisco report that race/ethnicity is a predictor of antiretroviral or HIV-related medication use (AIDS Policy & Law, 2002). Pervasive racial disparities in the use of these drugs results in greater mortality rates among particular racial/ethnic groups (Russell, 2002). Individuals that are not receiving treatment for HIV are more likely to be women, minorities, depressed individuals, substance abusers, and the uninsured (Kalichman et al., 2002)—many who were initially at greater risk for HIV infection.

2. Drug resistant viruses can be transmitted. In one study of newly diagnosed HIV-positive people, 26% had reduced susceptibility to one class of drugs, and 2% showed multiple drug resistance (Little et al., 1999). Re-infection with HIV is also possible (Ramos et al., 2002).

3. Most infected individuals take steps to protect their partners when they learn their status.

The vast majority of HIV-infected persons do not want to infect other people (Wenger et al., 1994). In a study of 250 HIV-positive men, most men in the study felt that HIV-positive people have a special responsibility to protect others from infection (Wolitski et al., 1998).

4. People living with HIV continue to have sexual relations. Data show that 70% of PLWHA continue to have sex after being diagnosed as HIV-positive, and the probability of sexual activity increases with the length of time since diagnosis (Wenger et al., 1994). While research suggests that many, if not most, HIV-positives do not want to infect others, Marks and colleagues (1999) and Kalichman (2000) reviewed more than 15 studies conducted from 1988-1999 to seek information about sexual risk-taking behavior. The articles summarized results from these studies, documenting a range of 6% to 61% of the studies' samples of PLWHA continued to engage in unprotected sexual behavior that puts others at risk for HIV and themselves at risk for secondary infections. The studies investigated various sexual risk behaviors—unprotected insertive anal intercourse, unprotected receptive anal intercourse, unprotected vaginal intercourse, and/or unprotected oral sex (Marks et al., 1999; Kalichman, 2000). Depending on the study, from 30%-52% of sexually active HIV-positive men had not disclosed their status to one or more sex partners; disclosure is associated with increased likelihood of having protected sex with uninfected partners (Marks et al., 1999; Wenger et al., 1994; Marks et al., 1991).

Since knowledge of one's serostatus alone does not always result in protective behavior change, HIV-infected populations need support and

prevention skills to establish and maintain healthy and satisfying lifestyles that are safe for them and their partners. A relatively small proportion of HIV-positive individuals engage in persistently unsafe sex or needle sharing without disclosure of status (e.g., "barebacking," in which men intentionally engage in unprotected anal sex [Mansergh et al., 2002]).

5. Specialized prevention programs are needed to address the immediate and ongoing needs of those living with HIV. Although HIV-positive individuals face the same barriers as those who are not positive with regard to consistently engaging in safe sexual or needle sharing risk behaviors, they are also burdened with additional barriers, including social and medical challenges associated with living with a life-threatening illness.

Focusing efforts on HIV-positive individuals does not necessarily represent an "either/or situation" between those who are HIV-positive and those who are HIV-negative receiving prevention services. Prevention with positives is appropriate, as long as prevention programs continue to focus simultaneously on uninfected populations. The ethical issues, however, are different for prevention with HIV-infected populations, because of concerns about stigma, discrimination, confidentiality, and duty to provide access to care and follow-up counseling. In addition, prevention with positives interventions add a complex dimension to implementation of programs because they must be supportive, and avoid blame (Collins et al., 2000) and issues related to notification of partners or legal reporting requirements.

Conducting prevention with positives programs provides both individual and public health benefits. Individual benefits relate to accessing care and

treatment for HIV, and also to preventing opportunistic infections—allowing an individual to take power over his or her illness (Senterfitt, 2001). The related public health benefits include the decrease in the rate of new HIV infections, and the potential for HIV treatment to reduce infectiousness (Janssen et al., 2001). For the reasons described, prevention with positives is becoming an increasingly important strategy for preventing new HIV transmissions and caring for people already infected.

C. The Advancing HIV Prevention Initiative

Recognizing the increasingly urgent need to expand efforts to implement prevention with positives, CDC recently announced a new initiative to reach out to infected individuals so that they can learn their HIV status and obtain appropriate care and prevention services.

In the April 18, 2003 issue of *Morbidity and Mortality Weekly Report (MMWR)*, CDC published *Advancing HIV Prevention: New Strategies for a Changing Epidemic — United States, 2003* (CDC, 2003b). According to the *MMWR*, steady morbidity and mortality resulting from HIV/AIDS, along with concerns about possible increases in HIV incidence among specific populations, availability of a rapid HIV test, and strong partnerships among communities impacted by HIV, call attention to the need to reconsider and modify some of CDC's HIV-prevention activities (CDC, 2003b).

There are several catalysts for this new initiative. Data indicate that HIV incidence may be increasing. Several United States cities have recently experienced primary and secondary syphilis outbreaks among MSM, and there have been increases in newly diagnosed HIV infection among MSM and heterosexuals. These trends suggest that HIV incidence might be on the rise (CDC, 2003b).

Also, AIDS cases and AIDS deaths have leveled since 1998, indicating that contributions from antiretroviral therapy to decreasing HIV morbidity and mortality seem to have ended. Finally, the Food and Drug Administration (FDA) recently approved a new rapid HIV test in the United States, which has created opportunities to overcome some obstacles to early diagnosis and treatment of HIV-positive individuals. This simple test, approved in November 2002, provides HIV results in 20 minutes, can be stored at room temperature, requires no special equipment, and can be performed outside traditional clinical and laboratory settings (CDC, 2003b).

The *Advancing HIV Prevention Initiative* is intended to lessen obstacles to early diagnosis of HIV infection and increase access to care, treatment, and prevention services. The new initiative highlights the use of established public health strategies to reducing HIV incidence and controlling its spread. Similar to action taken to prevent other sexually transmitted diseases (STDs) or any other public health problem, CDC will use these principles to prevent disease and its spread, including: routine screening as indicated; identification of new cases; partner notification; and an increase in the availability of continuous treatment and prevention services for HIV-positive individuals (CDC, 2003b).

The *Advancing HIV Prevention Initiative* consists of four key strategies (CDC, 2003b):

1. Include HIV testing in routine medical care;
2. Develop and employ new models for diagnosing HIV infections outside medical settings;
3. Prevent new infections by working with HIV-positive individuals and their partners; and
4. Achieve additional declines in perinatal HIV transmission.

D. A Training Focus: STD/ HIV Prevention Training Centers

Four regional STD/HIV Prevention Training Centers (PTCs) are receiving supplemental CDC funding to work on activities related to prevention with individuals living with HIV. One example of a training-focused activity is the New York STD/HIV Prevention Training Center for Health and Behavior Training (CHBT) which provides a multitude of training programs that focus on preventing and managing STDs, tuberculosis, and HIV/AIDS. CHBT focuses on enhancing the skills and knowledge of clinical and medical providers who care for PLWHA. Training is provided in the areas of HIV pathogenesis, viral load testing, risk reduction counseling, HIV testing, current medical regimens, medication adherence, and other HIV prevention strategies and interventions. Many of CHBT's curricula are based on stage-based behavioral counseling, such as the Social Cognitive Theory and the Transtheoretical Model of Behavior Change/Stages of Change.

The California STD/HIV Prevention Training Center (CAPTC) is a joint project of the California Department of Health Services, STD Control Branch; the University of California, Berkeley, School of Public Health; and the University of California, San Francisco School of Medicine. CAPTC has developed a provider education curriculum that supports infected persons in maintaining healthy behaviors and in reducing the risk of transmitting HIV. The curriculum "Supporting Client Disclosure of HIV Status: A Skills-Based Training for Providers," primarily assists clinicians with the skills needed to facilitate and foster communication with HIV-positive clients about disclosure issues. The goal of the training is to sensitize providers to the issues of disclosing HIV status and to introduce a four-step model for assisting clients who are prepared to disclose their

status. CAPTC identified a gap in the research and public health messages with regard to the risks associated with HIV-positive persons disclosing their status. CAPTC found that providers were struggling with effective strategies to discuss these issues with their clients. As a result of this information, the center responded by developing the curriculum.

The Dallas STD/HIV Behavioral Intervention Training Center is developing a replication package for the Healthy Relationships (Kalichman et al., 2001) intervention. This intervention assists HIV-positive individuals to develop coping responses for stress when disclosing their HIV status and negotiating, initiating, and maintaining safer sex practices with sexual partners. The intervention was developed for, and has been tested with, sexually active HIV-positive adults. (See Chapter 5 for a more detailed description of the Healthy Relationships intervention.)

Denver STD/HIV Prevention Training Center provides training in preventing and managing STDs and HIV/AIDS through the use of behavioral and social science methodologies. Training programs focus on subject matter that include: risk reduction education programs for homosexual and bisexual men, IDUs, youth and women of childbearing age; training courses for health care providers; maintenance of an HIV resource directory for care providers; provision of no-cost educational materials; training in risk reduction case management of HIV-infected individuals who persist in practicing high-risk behaviors; and evaluation of educational and program interventions. The Denver STD/HIV Prevention Training Center works in collaboration with the Denver Health Department and the University of Colorado.

E. Summary

Prevention efforts to date have focused primarily on uninfected persons at high risk for acquiring HIV infection. However, because every new HIV infection involves an HIV-infected individual, CDC is supporting prevention programs that address the needs of those who are living with HIV. Those needs may include, in addition to the typical barriers to risk reduction, challenges such as coping with HIV-associated stigma, living with a life-threatening illness, dealing with the symptoms of the disease, and managing therapies and side effects.

Locating, Engaging, and Recruiting Clients for Testing and Other Services

A. Introduction

Addressing the prevention needs of individuals living with HIV necessitates a comprehensive approach to identifying and locating seropositive individuals at risk and ensuring that they are engaged in appropriate services. The CDC's *Advancing HIV Prevention Initiative* is focused on reducing the barriers to early diagnosis of HIV infection and providing increased access to quality medical care, treatment, and ongoing prevention services (CDC, 2003b).

Addressing needs of HIV-positive individuals requires greater attention to improving links among HIV prevention, care, and treatment services and enhancing recruitment and retention strategies. One element of the *Advancing HIV Prevention Initiative* is the recommendations for *Incorporating HIV Prevention into Medical Care of Persons with HIV Infection* document (CDC, 2003e). This document outlines strategies that health care providers can use to provide risk screening, implement and link HIV-positive clients to behavioral interventions, and provide partner counseling and referral services.

This chapter describes approaches that CBOs can use to enhance their outreach to high-risk groups and improve linkages among the key types of prevention, care, and treatment services needed by

PLWHA. These approaches focus on:

- Describing high-risk PLWHA;
- Locating members of the target population;
- Identifying barriers to testing; and
- Engaging clients in testing and other linked services.

B. Locating, Engaging, and Recruiting Clients

Because many high-risk individuals have not yet been identified, improved client recruitment requires an assessment of who is being missed and informed speculation about why they have not been identified or are not seeking HIV testing. These analyses require outreach to the community.

1. DESCRIBING HIGH-RISK PLWHA

To improve the success of client outreach and recruitment, HIV counseling and testing interventions and other prevention efforts need to be targeted and tailored to specific risk populations. To understand which HIV-positive clients are missing from existing prevention interventions and how they can be reached, program planners should follow these steps:

“There is a need for enormous amounts of outreach to break down the ‘us and them’ attitudes. It is important to use the pronoun ‘we’.”

–Pandora Singleton,
Project Azuka, Georgia

- Determine who is currently being reached and how. This essential first step in designing an intervention can lead to information about which individuals or groups are not being reached and why. Prevention and care programs at the state level (and in some localities) are required to develop special tools to determine which populations to target for services.

For example, every state, the six cities with CDC cooperative agreements (Chicago, Houston, Los Angeles, New York, Philadelphia, and San Francisco), the District of Columbia, and eight United States Territories are required to develop comprehensive HIV prevention plans that include descriptions of priority target populations and interventions to reach the priority populations.

- Develop a plan to conduct process evaluation of programs to ensure that they are implemented with fidelity, identify and address implementation problems, and identify key program components and activities that may need to be adjusted to enhance program impacts. The process evaluation plan should be grounded in the overarching prevention program objectives, and key process measures should be identified which reflect salient, meaningful program elements.

Within a community, there is usually a network of prevention providers which need to work together to make judgments about access (by the target population) to prevention programs, as well as program coverage or reach. In terms of access, process measures can be used to monitor and track the extent to which various prevention programs have engaged in efforts to market or publicize services to populations of different neighborhoods, race/ethnicities, age ranges, sexual orientations, and risk behaviors. Counts of flyers distributed to different populations, estimated attendance of population members at prevention program events intended to increase access, and estimated counts of population members exposed to public service announcements are examples of such process measures. Various prevention programs within a community can work together to document, using process measures, the extent that efforts to increase access have adequately reached the target populations.

Process measures related to program coverage are concerned with measuring the extent that prevention program activities, materials, and messages are reaching target populations. Prevention programs can track and monitor the extent that prevention activities (e.g., outreach to IDUs in specific neighborhoods) are meeting target objectives (e.g., number and estimated percentage of IDUs within these neighborhoods); materials are disseminated (e.g., number of prevention pamphlets distributed at an STD clinic) and/or read (e.g., number of STD clinic clients that self-report reading and using information provided on the pamphlet); and messages are delivered to high-risk populations (e.g., number of risk reduction conversations conducted by trained prevention advocates to their friends). The prevention programs within a community can use process

measures concerned with coverage of unique programs to estimate overall coverage within the community, identify gaps or duplications, and make adjustments to future programs.

- Examine the valuable information that exists in the community. Under the HRSA Ryan White CARE program, Councils/Consortia are required to develop needs assessments and allocate resources to priority populations. The needs assessments, program process data, epidemiologic profiles, and list of prioritized services should be helpful in determining who is currently being reached. This information also will help in determining whether specialized programs exist—or are being designed—for HIV-positive individuals.
- Define what makes each target population unique. Go beyond generic social labels, which are not appropriate when developing a strategy for locating, engaging, and recruiting clients for services. For example, Hispanic communities within the United States can be differentiated based on country of origin, language usage, geographic location, and religious identification. It is important to determine what population and cultural characteristics are relevant to improving HIV prevention, testing, and care interventions within specific groups because culture, language, lack of resources, and time can play varying roles in a population's willingness or unwillingness to participate in interventions. Lastly, HIV prevention community planning groups identify target populations by behaviors because the risk of acquiring HIV depends not on who someone is but on how that person behaves (AED, 2000).
- Spend time in the community to better understand risk behaviors and the factors and people that influence decision making in that

community. This effort allows for the identification, observation, and description of social networks. Collaboration with community partners to build community support and trust helps in identifying populations to recruit for testing and in laying the groundwork for effective programs (Blumenthal et al., 1999). Community gatekeepers and key informants not only confirm the existence and description of social networks, but also guide the entry strategy into the risk community (Higgins et al., 1997).

- Incorporate community organizations and affected populations in program planning and evaluation efforts directed at client recruitment for testing, outreach, and media campaigns. Recruit local “gatekeepers” or community leaders to help identify high-risk groups and describe cultural norms, as well as HIV-positive individuals who are likely to have important knowledge about the community (Ross & Kelly, 2000). Work with HIV-positive individuals to put their experiences and knowledge to work to reach others. Outreach strategies also may include partnering with religious or faith-based organizations and community groups that have established local networks and infrastructure.

2. LOCATING MEMBERS OF THE TARGET POPULATION

Once community-based prevention programs have identified high-risk groups who have not yet been reached and have developed a good understanding of their risk behaviors and social environments, they can take the next step. This step involves locating members of these groups so as to begin the process of recruiting them into prevention, care, and treatment services.

Reaching out to existing health services and systems is the first place to start when seeking to identify and gain access to at-risk populations. For example,

HIV testing sites and walk-in clinics are a traditional means of reaching certain populations, such as heterosexuals, healthcare workers, and victims of sexual assault who worry about their risk but may not perceive themselves at any behavioral risk. Some public health clinics offer services for IDUs or populations with STDs. These populations are high-risk candidates for HIV infection (Weinstock et al., 2002). Populations seeking treatment through these facilities are prime candidates to engage and recruit for services. Innovative prevention programs can be developed that respect the confidentiality and concerns of clinic patients while encouraging them to be tested and counseled.

However, when conducting outreach to locate and recruit groups, CBOs need to look beyond these traditional venues because they reach only a portion of the at-risk population. For example, some individuals with the greatest risk for HIV are likely to avoid walk-in clinics (Hong & Berger, 1994). CBOs have several other potential options for successfully locating high-risk groups.

- Go to the locations where the high-risk populations are likely to be found (e.g., sex parties, Internet chat rooms, bath houses, sites where networks congregate). Bring HIV risk assessment, education, and testing to social venues and events, or create relevant social venues and events in which to provide these services.
- Employ outreach workers who reflect the community of interest. Peer outreach has been found to be one of the most efficient ways to reach some communities, such as IDUs—especially those who are not in treatment to educate them about HIV, encourage them to get tested, and facilitate risk reduction activities. For example, studies have shown that peer- and

street-based outreach is a successful method of increasing HIV testing and combating the spread of HIV among high-risk youth (Johnson et al., 2001).

Similar cautions exist for involving youth living with HIV as peer leaders. A study of community-based service providers that hired youth living with HIV as peer leaders for delivering HIV education to uninfected adolescents found that 23% of the youth peer leaders engaged in substance abuse and sexual behaviors that placed themselves and uninfected youth in their peer educator programs at risk. The study also showed that 8% of the youth reported relapse while they were peer leaders (Luna & Rotheram-Borus, 1999).

Lastly, a number of researchers have investigated the multiple contexts that affect risk behavior, and their results can inform the design of outreach programs. For example, some researchers have described the concept of “sociometric risk networks,” which deals with the study of interpersonal relationships in populations and the associations among their behavioral risk factors. In studying the spread of HIV-infection, the networks often include people characterized by sexual and drug injecting relationships, and the likelihood of HIV infection. Their findings have helped to describe and reveal the pathways along which HIV travels, for example, in drug injecting peer groups or sexual networks of MSM. Locating and identifying the core individuals in these “networks” who encourage high-risk behaviors can help uncover potential pockets of HIV infection (Wood, 2001). Preventing widespread HIV epidemics depends in large measure on preventing HIV from reaching the cores of these networks (Friedman et al., 1997).

3. IDENTIFYING BARRIERS TO TESTING

As described in the previous chapter, HIV testing is a central component of CDC's ongoing efforts to develop and expand prevention efforts among individuals who are living with HIV and their partners. The availability of the FDA-approved OraQuick® Rapid HIV-1/2 Antibody Test provides an opportunity to provide a preliminary positive result in approximately 20 minutes and can be conducted in non-clinical settings. Having access to this simple, rapid HIV test should increase the proportion of those who receive their test results.

Testing is important for a number of reasons, not the least of which is that it can serve as a gateway to other critical prevention services as well as care and treatment services. It is becoming increasingly clear that knowing one's HIV status early and getting into treatment soon after infection can positively influence the course of the disease (Brown, 2002). However, a CDC study conducted at 16 testing sites found that 43% of infected individuals were tested late in the infection (i.e., were diagnosed with AIDS within one year of HIV diagnosis). The majority of late testers (65%) did not get tested until they were symptomatic (CDC, 2003f). Why don't these and other at-risk individuals get tested? A number of factors that provide insight into the problem can help CBOs develop more focused and successful interventions to increase testing and link clients to related services.

- In the early stages of the HIV epidemic, before the availability of current therapies, many people felt that taking the test was more dangerous than the disease itself because of the social stigma or discrimination that might occur should they be seen taking the test or by testing positive. One study found that among high-risk individuals, 70% reported that they would only get tested if “no one could find out” (Phillips et al., 1997).

The tension between those who wanted to use traditional public health measures of case identification for testing and AIDS activists who actively resisted these methods led to a series of guidelines that recognized the ethical dimensions and political realities of HIV testing and stressed the importance of pre-test counseling, confidentiality, and the voluntary nature of testing.

- For other people, the reasons to avoid HIV testing are highly personal and based in denial, diminished self-image, fear of disease, damage to personal social networks, and alienation from friends and family (Siegel et al., 1998; Phillips & Coates, 1995). For example, a study of gay men found that 83% of seronegative respondents and 74% of untested respondents preferred seronegative partners for romance (Hoff et al., 1992). In addition, 15% of seronegative respondents and 12% of untested respondents preferred seronegative individuals for friendship. Therefore, the need to belong to a group and not be spurned because of HIV status may be a strong disincentive to HIV testing.
- Some individuals are afraid that a positive test result might signal to a sex partner that they have been unfaithful. This may result in problems for a relationship, including violence and abuse, making it all the more important to combine testing with counseling that assists individuals with partner notification or disclosure strategies (Maher et al., 2000; Rothenberg & Paskey, 1995).
- Lack of understanding about risk behaviors, ignorance of partner risk practices, lack of information about HIV-related symptoms, and perceived invulnerability to infection are also reasons why individuals do not recognize their risk status or choose not to get tested.

- Independent of sociodemographic characteristics, risk perception, and risk behaviors, persons covered by Medicaid had a higher level of voluntary HIV testing, suggesting that the type of health insurance may affect a person's access to HIV counseling and testing services (Tao et al., 1998).
- Many settings offering HIV counseling, testing, and referral services are challenged by low rates of return for test results (CDC, 2001c). New testing technologies, in particular the FDA-approved rapid tests, can greatly reduce turnaround time for obtaining test results (CDC, 2001c). Other technologies, such as oral fluid tests, may increase a person's willingness to be tested and learn his or her HIV status (Branson, 1998).
- Finally, for some members of a community, HIV infection is not the most serious or immediate concern. Finding food and shelter may be more pressing survival priorities. For IDUs, meeting the demands of their addiction is often more important in their daily lives than HIV testing and dealing with potential positive results. For many low-income women, childcare, nutrition, and safety are more important than HIV testing.

These factors clearly point to the need for vigorous, targeted, and creative outreach efforts to bring the highest risk groups into counseling and testing and then into other prevention, care, and treatment services.

4. ENGAGING CLIENTS IN TESTING AND OTHER LINKED SERVICES

Many factors on the individual, structural, and societal levels influence whether individuals at risk for HIV seek testing, whether they return for their results, and whether they get appropriate care if

they are found to be HIV positive. The following overarching principles can help program planners develop and implement a successful outreach and testing program. These principles were developed based on feedback obtained from the CBO staff, health department staff, and representatives from the prevention community that attended the three consultations CDC held to gather information about the best available research and programmatic experience related to prevention with HIV-positive individuals.

Principle #1: Offer voluntary testing as a component of comprehensive diagnostic services and integrate HIV testing into other public health programs (e.g., STD prevention, substance abuse, mental health).

Prevention interventions with positives emphasize that the primary goal is not only to identify individuals who could benefit from testing, but also to provide links to care and prevention services.

- Set priorities among the health concerns of HIV-positive clients. People infected with HIV have a variety of health, emotional, and social concerns that must be considered when planning services. Prevention should be integrated with coordinated care that begins at the moment of HIV testing. This requires that testing organizations be knowledgeable about care options and services in their area, and be ready to help individuals find out where to go for services. HIV testing staff must know how to bring positive individuals into the care setting and help clients identify support systems for their ongoing care. Prevention must be integrated into the total health care message.
- Ensure that HIV testing is part of a continuum of care. Testing and subsequent health care should be integrated with services that meet

other needs, such as food, jobs, housing, and substance abuse treatment. This requires that outreach and other workers be equipped and trained to provide these linkages so that existing needs can be met. It also requires coordination among the spectrum of services offered in that particular community.

- When test results are positive, it is important that service providers take a more active role in ensuring that HIV-positive individuals reach referral agencies. It is critical that clients are linked to additional services after they receive their test results. Providers must be extremely knowledgeable about community resources, and be able to network and develop relationships with other service providers (e.g., STD clinics, substance abuse treatment centers, support groups). These networks can work to ensure that everyone is knowledgeable about and effectively uses referrals to medical and social services. It is essential to create environments that are safe and connected with integrated health services. For this reason, some have questioned the value of stand-alone test facilities, which can carry stigma because of their obvious mission.
- Suitable referral plans should be developed that are flexible and take into account the client's needs. Peer or "buddy" programs are essential for support, even if the individual already has an established relationship within the care system. The knowledge that one is positive can disrupt familiar relationships and shatter support systems. Counselors should help identify support systems before the test is conducted so they can be tapped into when the results come back.

Principle #2: Build strong relationships with health providers.

A crucial element of success is strong relationships among providers. CBOs should incorporate HIV services into broader health care programs in the community, and not just HIV/AIDS-related services. Under its new *Advancing HIV Prevention Initiative*, CDC is encouraging that HIV testing be a routine part of medical care. Health care providers need to be involved in client recruitment, testing, and referral. Both CBOs and health departments must maintain good working relationships with other community health providers.

Physicians can play an influential role in promoting HIV testing by discussing HIV risk behaviors with patients and offering voluntary HIV counseling and testing to those at risk (Samet et al., 1997). Physicians can be especially effective with youth, who are more likely to have access to some type of health care. One study found that patients were more than twice as likely to get tested for HIV when their doctors advised it (CDC, 2001a). In addition, nurses have been found to play a critical role in reaching hard-to-serve women who have a history of substance abuse and mental illness and who test positive for HIV (Anderson et al., 1999). Clearly, an opportunity is lost if a patient already in a health care setting is not provided information and support that could lead to testing and regular care and treatment. Capitalizing on this opportunity, however, will require an increased level of training and sensitivity among health care professionals.

EXPERIENCE FROM THE FIELD:

How Do Programs Link HIV-Positive Persons to Needed Services?

All of the agencies interviewed for this document reported that they refer or link clients to services that they do not provide. While many of the agencies reported serving clients with multiple service needs, they often did not offer the particular services needed to address the clients' immediate needs. As a result, the vast majority of agencies interviewed had formal or informal relationships with other human service organizations that were able to assist their clients with their presenting needs or crises.

Many of the agencies provide active referrals for clients—i.e., take clients to services needed—because the populations they serve may find it difficult to follow-up and seek services on their own due to mental illness, active drug or alcohol addiction, or lack of transportation. The type of services typically sought by clients indicates the level of personal, social, and emotional needs that many PLWHA have to contend with along with managing their disease. Data on uptake of these services is generally unavailable. Agencies typically link clients to a variety of services including:

- Medical care
- Drug and alcohol treatment
- Housing and shelters
- Emergency food programs
- Medical insurance and disability programs
- Mental health services
- Support groups

Source: AED, 2003a.

Principle #3: Provide incentives for HIV testing.

Incentives can be used to encourage testing and follow-up for results. They can aim to meet basic needs and simple pleasures. For example, some programs have used phone cards, gas cards, movie tickets, food, transit tokens, and cash incentives to generate new client referrals from other clients and encourage return visits for receiving test results.

Case managers at AIDS Project Los Angeles (APLA) work with clients to find out what type of incentives might be most appropriate (AED, 2003a). The Oasis Project in Los Angeles has had success with this tactic in combination with relying on social networks of clients (AED, 2003a). One study found

that small monetary incentives enhanced enrollment and participation compared with other incentives of similar value. Thus, money may be useful in encouraging high-risk individuals to participate in and complete counseling or other public health interventions (Kamb et al., 1998).

Some incentives can be related to problems of access. Many populations cannot afford fees for counseling and testing, and some people have no means of transportation to access services that are being provided. Mobile units can be taken to communities where access would otherwise be difficult. However, in order to increase use, these vehicles should be discrete—they should not advertise as an HIV testing site.

EXPERIENCE FROM THE FIELD:

How Do Agencies Use Incentives?

“Our organization uses various incentives to sustain clients in program or encourage individuals to get tested. The incentives differ based on the population. For example, we provide gloves, socks, caps, or blankets to IDUs because this population is often homeless and living in the street. We give away makeup kits and scarves to the transgendered community, and we give movie passes and phone cards to youth.”

–Victor Martinez
Bienestar Human Services

“We offer incentives such as telephone cards, food vouchers, and concert tickets to see local artists or national rappers. We not only try to get people at risk to get tested but we also try to get their friends and social contacts to come in and get tested. Our philosophy is that if they are engaging in risky behaviors, their friends probably are too.”

–Greg Miller
Bay Area Consortium Quality Health Care

Source: AED, 2003a.

Principle #4: Train staff and outreach workers to be sure their skills are at the highest level possible. Conduct program monitoring and quality assurance activities to ensure high-quality counseling, testing, and referral services.

With the many recent improvements in the medical management of HIV, the benefits of early detection of the virus have increased significantly. Staff members need training and education on how to provide counseling, testing, and referrals. They also need feedback on their work and support from supervisors. Ensuring high-quality HIV prevention counseling, testing, and referral (CTR) services requires that providers conduct routine assessments to ensure that the following elements are appropriately addressed in their setting (CDC, 2001c):

- **Staff training and education.** Counselors should complete training in the use of at least one HIV prevention counseling model targeting personal risk reduction. Formal training on HIV/AIDS (e.g., its natural history, opportunistic infections, treatment, prevention case management) is also recommended. Staff members providing referral services should receive adequate training and education to make and manage referrals. They should be familiar with the communities they serve and the available referral opportunities for HIV prevention and support services. Staff members providing referral services must understand client needs, have skills and resources to address these needs, have authority to help the client procure services, and be able to advocate for clients.

- **Direct observation and feedback.** Periodic supervision of counselors during counseling sessions is an effective strategy to ensure that objectives are met. Provision of feedback to the counseling staff is recommended soon after observation in order to address areas for improvement.
- **Case conferences.** Meetings among counselors and supervisors can identify areas of needed improvement and provide the opportunity for information sharing. Counselors can use these meetings to discuss specific or problematic questions asked by clients.
- **Staff incentives and rewards.** To help programs and agencies retain staff, incentives and rewards should be given to staff members who achieve a high rate of referral and a successful response rate. In addition, individual staff members can be provided with incentives (e.g., money or time off) to achieve the best return rates, or incentives can also be provided to staffing units (e.g., parties, retreats).
- **Evaluation of physical space and waiting time.** Periodic time-flow analyses or client surveys can be helpful in evaluating the adequacy of private counseling and testing space and length of waiting periods for appointments.
- **Counselor or client satisfaction evaluations.** CTR services should be continually evaluated to ensure that services meet client needs and to provide accountability to stakeholders. Information obtained from the evaluation can be helpful in adjusting and/or improving CTR services. The information assembled during the evaluation process should be analyzed and reported to individual persons affected by the service. Information and feedback gained during the evaluation process should be used to plan and prioritize CTR services.
- **Program monitoring and quality assurance.** Written protocols should be developed, made available to all staff members providing CTR services, and routinely implemented. All staff members should receive training and orientation regarding quality assurance. Quality assurance activities should address the following:
 - 1) accessibility of services; 2) compliance with written protocols for provision of service to clients; 3) services and materials that are culturally and linguistically competent; 4) staff performance; 5) supervision of staff members, including routine feedback; 6) compliance with program guidelines and performance standards; 7) appropriateness of services to client needs, measured with client satisfaction tools; 8) record-keeping procedures, including confidentiality and security; 9) availability of community resources; 10) collection, handling, and storage of specimens; and 11) assurance of adequate funding and support for CTR services.

Key Issues for Counselors and Clients in Increasing Effectiveness of HIV Testing and Client Follow-Up

COUNSELORS:

- Must be able to identify different stages of readiness for testing and respond appropriately.
- Must be able to identify an individual's strengths for coping with a positive HIV test. Programs should ensure that providers and all other staff (from the front desk to the physician) are properly trained to handle the psychosocial issues likely to arise in a testing and care venue.
- Need to identify and address other life challenges facing the client.
- Must make it clear that the need for testing may also signal the need for behavior change.
- Should ascertain an individual's motivation for testing.
- Should be aware that their own biases and beliefs (leading to homophobia, racism, elitism) may communicate to a client, who may as a result not share important information regarding risk behavior.
- Should know that some populations, especially minority, often mistrust health care agencies or representatives. Making sure that a provider relationship with the client does not end with testing is an important means of building trust. The responsibility for building trust is shared among health departments, AIDS service organizations, and other service organizations.

CLIENTS:

- Must be educated about the benefits of knowing their serostatus; this can sometimes be best achieved in small groups.
- Must understand the timeline regarding returns for test results and the limits of privacy and confidentiality regarding test results.

Source: AED, 2001.

C. Summary

Addressing the needs of HIV-positive individuals requires CBOs to use approaches to enhance their outreach to high-risk groups and improve linkages among the key types of prevention, care, and treatment services needed by these individuals. As outlined and described in this chapter, effective approaches include: describing high-risk PLWHA; locating members of the target populations; identifying barriers to testing; and engaging clients in testing and other linked services. Each of these approaches involves multiple steps.

Accurately describing high-risk PLWHA allows CBOs to target specific populations and to tailor interventions to specific risk populations. Developing a comprehensive and accurate description necessitates determining who is being reached and how, developing a plan to conduct process evaluation, effectively measuring the extent to which prevention activities have met target objectives, and examining the target community and incorporating community members and affected individuals into various planning and implementation efforts.

Once high-risk PLWHA have been identified and described, these individuals must be located and recruited into prevention, care, and treatment services. While some members of these populations may be accessed in traditional venues like walk-in clinics, many others must be searched out in less public sites where high risk networks congregate. In many cases, training members of target communities to conduct outreach work with high-risk members has also been an effective tool in reaching PLWHA. As individuals and groups are located, they can be recruited for participation in testing, care, and prevention activities.

As described in this chapter, recruiting and retaining PLWHA into interventions and other programs can be very difficult. Factors deterring HIV positives from participating in interventions include fear of discrimination, stigma, and social isolation;

psychological and emotional factors such as denial; and limited access to health services. To effectively address some of the factors that deter individuals from seeking care and to better address the needs of high-risk populations, four overarching principles to help program planners develop and implement successful outreach and testing programs were defined. To effectively address the needs of PLWHA, programs should offer voluntary testing as a component of comprehensive services and integrate HIV testing into other public health programs so as to provide health workers greater access to high-risk populations. Building strong relationships between HIV testing and care sites, providing incentives for HIV testing, and training staff and outreach workers to ensure that their skills are at the highest possible level are also important program components.

The Scientific Basis for HIV Prevention with Positives Interventions

A. Introduction

The growing numbers of people with HIV in the United States who are living healthy and sexually active lives necessitates the implementation of prevention with positives interventions. Prevention programs must assist PLWHA to maintain safer sex and injection practices and must be delivered in a way that is culturally relevant to specific infected populations. Historically, prevention activities were only directed at HIV-negative individuals and persons of unknown status. They have not addressed the unique needs of HIV-positives. This must now be a priority in the evolving prevention battle against HIV/AIDS.

Persons living with HIV/AIDS who do not consistently develop or maintain safer behavior put themselves and their sex/injection partners at considerable risk for HIV and other STDs (when not practicing safer sex). Increased understanding and identification of the psychological correlates of continued sexual and injection risk behaviors could provide critically needed information for the development and implementation of effective interventions. This chapter reviews what is known about HIV risk behaviors. This information is essential to create a foundation for program planners as they develop prevention with positives interventions.

B. Understanding Risk Behaviors

Research on the factors affecting risk behaviors of PLWHA provides important information to inform intervention development. However, published research findings on effective prevention interventions with HIV-infected persons are limited. Recently, some interventions have been designed specifically for PLWHA, however, the need for additional models to meet their prevention needs in the field is substantial (Kalichman et al., 2001; Rotheram-Borus et al., 2001). Although there is a dearth of comprehensive and effective interventions targeting PLWHA, some data are available that shed light on behaviors associated with risk taking among HIV-positive individuals.

1. FACTORS AND LIFE EVENTS THAT AFFECT RISK BEHAVIOR OF HIV-POSITIVE INDIVIDUALS

A variety of psychological, interpersonal, and social factors affect risk behavior among PLWHA. As a result of these factors, HIV-positive individuals may have difficulty in maintaining safer sex and drug injection practices over an entire lifetime. The motivation of PLWHA to protect, or not protect, themselves and their partners is impacted and influenced by a variety of factors, including (Kalichman, 2000; Schlitz & Sandfort, 2000):

- Personal and sexual relationships – HIV status of partners;
- Economic conditions – linkage between HIV/AIDS and poverty (i.e., HIV/AIDS is driven by use of injection drugs with limited access to syringe resources, closed sexual and social networks, and trading sex for money or drugs);
- Emotional conditions – effects of positive moods, depression, and anxiety on risk practices;
- Substance abuse – effects of substance abuse on risk behaviors; and
- Personality dispositions – severe mental health problems (e.g., manic episodes, hypersexuality, and serious personality disorders).

The difficulty of developing and maintaining safer sex behaviors was illustrated by a study that examined psychological and social factors associated with continued high-risk practices among HIV-positive men and women. In this study, 203 HIV-positive men and 129 HIV-positive women were recruited from infectious disease clinics and AIDS service agencies in Atlanta, GA. The findings demonstrated that 42% of both men and women reported at least one occasion of unprotected anal or vaginal intercourse in the preceding six months, thereby defining them at high risk for HIV transmission. Unprotected intercourse frequently occurred outside long-term relationships and with partners whose HIV serostatus was unknown. The HIV-infected men and women reported alcohol and drug abuse, including use before sexual episodes. However, in this particular study, an association between substance use and unprotected sex was modest for men and was not present for women (Kalichman, 1999).

2. DISCLOSURE SKILLS AND PERCEPTIONS ABOUT TREATMENT IMPACT RISK BEHAVIOR

The skill sets around the disclosure of one's HIV status and one's perceptions of HIV/AIDS treatment effects also affect risk behavior (Kalichman, 2000). The perceptions around HIV/AIDS treatment effects revolve around both the perception that a low viral load will reduce infectivity and that HIV can be managed as a chronic disease (Kalichman, 2000). Support services are needed to help with communication skills about HIV serostatus, so that individuals have a repertoire of skills for managing disclosure situations. Research has shown that a variety of factors (e.g., cultural values and social pressures) can affect HIV-positive individuals' abilities to disclose their HIV status (CDC, 2003d). Many such forces impact the fact that not everyone who knows their status is consistently disclosing it (Kalichman, 2000).

Another complication results from the misperception that combination therapies reduce viral load. This has created some confusion that HIV-positive individuals can be in a non-infectious state (Kalichman et al., 1998) and that there is no risk of transmitting the virus to sexual partners. Similarly, viral load affects risk behavior among MSM, because it has been shown that people believe it is more difficult for an HIV-infected partner to transmit HIV infection when they have an undetectable viral load (Venable et al., 2003). There is a growing body of literature examining how attitudes toward new treatments affect the behavior of HIV-positive persons. For example, in one study of 54 gay and bisexual men, 26% were less concerned about becoming HIV infected because of new treatments, and 15% indicated they were more willing to take sexual risks because of new therapies (Kalichman, 2000). Consistent messages to HIV positives about viral load and the continued need for HIV prevention are needed.

C. Risk Behaviors and Population Groups

The literature shows that individual factors affecting behavior vary according to the risk population and risk activity (Crepaz & Marks, 2002; Dilley et al., 1997; Vanable et al., 2003; O’Leary et al., 2003; Marks et al., 1998; Carmona et al., 1999). Among MSM, for example, the following factors affect risk behavior: having an attractive partner; having a partner who is willing to engage in risky sex; being on HAART; having an undetectable viral load; and having a history of childhood sexual abuse (O’Leary et al., 2003).

HIV-positive IDUs engage in similar patterns of continued risk behaviors as HIV-positive MSM (Kalichman, 2000). Among IDUs, risk behaviors in sexual situations are affected primarily by whether an IDU is having sex with an IDU partner (regardless of whether syringes or equipment were shared) or with a non-IDU partner (Hankins, 1997; Friedman et al., 1994). Drug-use risk behaviors include sharing and reusing syringes, preparation equipment, drug solution, and water (Koester, 1998). Sharing injection equipment may be perpetuated by laws and regulations that either require prescriptions to obtain syringes, limit the sale of syringes, or make syringe possession a criminal act (Gostin et al., 1997). Access to substance abuse treatment also significantly affects risk behavior of IDUs as it allows them a chance to work on reducing risk behaviors (Jones & Vlahov, 1998).

Research indicates that race, ethnicity, and acculturation may also impact risk behaviors. For example, some studies show that among Hispanics, the more acculturation the person has experienced, the more risk behavior is exhibited (Carmona et al., 1999). However, other research on acculturation tempers this finding, with studies showing that the lack of citizenship is associated with more unprotected sex. In addition, some evidence indicates

that the more acculturated Hispanics are, the higher the likelihood that they will disclose their HIV status (Carmona et al., 1999; Poppen et al., 2003).

Research shows that high-risk behavior patterns of HIV-positive women are similar to those of other HIV-positive populations. For example, one study found that half the women in the sample experienced difficulty maintaining safer sex practices and 46% had difficulty disclosing their HIV status to sex partners (Kalichman, 2000). Factors specific to women engaging in risk behavior include: having less perceived control over the male partner’s use of condoms; having less empathy toward partners; being more rebellious; being less assertive; using other forms of contraception; and having a male partner who desires children (Carmona et al., 1999).

D. Summary

Recent research is shedding increasing light on the variety of psychological, interpersonal, and social factors affecting sexual and needle sharing risk behaviors of PLWHA. Interventions must consider these factors carefully and integrate them when they are implemented among target populations. These factors can be identified by conducting formative research and needs assessments with target populations.

The difficulty of maintaining safer sex practices over a lifetime is a powerful factor affecting risk behavior. Disclosure of one’s HIV status is also a formidable issue that affects risk and adherence, and can be addressed in prevention with positives interventions and when offering mental health support services and substance and alcohol abuse treatment services.

The full range of prevention with positives approaches should include interventions that focus

on psychological processes, behavioral skills, and the dynamics of sexual interactions and relationships. Along with individual- and group-level interventions, wider societal-level approaches that focus on changing community attitudes, values, stigma, and practices are also important. These approaches may include addressing attitudes and behaviors that discriminate, stereotype, or reinforce differences related to gender, race/ethnicity or other social status and social power differences. Combining an ecological, societal approach with individual- and group-level interventions for HIV-positive persons will provide opportunities for reducing the incidence of HIV infections (Crepaz & Marks, 2002).

Community providers that participated in the consultations convened for this report requested that additional research issue areas be identified. These include: an examination of the competing demands on HIV-positive individuals that make it more difficult to maintain safer sex practices; better understanding of the influence of substance abuse on prevention and disclosure practices; the extent of perceived responsibility to protect partners from HIV infection; and structural issues such as the effect of federal, state, and local laws and policies on personal decision making concerning risk, disclosure, and access to care and services. These structural issues include laws and regulations on syringes and injection equipment, as well as HIV reporting requirements (AED, 2001).

HIV Prevention with Positives Interventions

A. Introduction

Most persons diagnosed with HIV infection change their risk behavior. Others need a less intensive intervention, such as a group to lead to significant behavior change, and others may need a more intensive mix of services (Purcell, 2003). One intervention does not necessarily fit all high-risk persons living with HIV. The CDC's *Procedural Guidance For Selected Strategies And Interventions For Community Based Organizations Funded Under Program Announcement 04064* (2004) provides an overview of effective prevention with positives interventions in more detail than this document. A continuum of effective and ethically sound prevention interventions for HIV-infected people should be developed in the context of addressing multiple and often competing medical, social, and personal needs of HIV-positive populations. Participants in the consultations that were convened for this report expressed with strong conviction that approaches to prevent the spread of HIV infection must be multi-faceted and customized for each community and setting.

Developing and implementing effective prevention interventions with PLWHA requires innovative solutions at the individual, group, and community levels. *Interventions focusing on individuals* entail changing transmission risk attitudes and behaviors among HIV-positive individuals (Temoshok & Frerichs, 1998). Individual-level interventions generally are one-on-one efforts to achieve change. *Interventions*

focusing on groups focus on the social needs and nature of individuals, and address acquisition of knowledge, intention to change, and behavioral skill development. For example, they are designed to develop coping skills and change group norms, and they can be coordinated with individual-level interventions. *Interventions focusing on the community* aim to remove the stigma of HIV infection, and create an environment that allows PLWHA to function freely in society and to more openly communicate their HIV status to others (Temoshok & Frerichs, 1998). Community-level interventions can also change community norms related to unsafe behaviors or address other social, structural, and community barriers and facilitators.

The right mix of programs and interventions is critical, and the mix varies depending on the community and the needs of the target population. Participants in the consultations convened for this report agreed that a continuum exists between levels of interventions (i.e., individual-, group-, and community-level interventions) and that interventions on each level affect the other levels; effects at each level must be considered before implementing an intervention. It is important that interventions be clearly delineated and do not be blur into the other.

This chapter provides general guidance on issues and approaches to consider when developing and implementing prevention interventions with HIV-positive individuals. It examines issues specific to the implementation of individual- and group-level interventions.

B. Implementation Issues

When addressing prevention with positives implementation issues, the CBO staff that participated in the consultations and key informant interviews varied considerably in their approaches. Some used one full-time staff person and others used up to six part-time staff people to carry out their prevention with positives activities. They received funding from a variety of sources, including federal, State, private funding from foundations and pharmaceutical companies. Despite their different programmatic approaches and funding, they all agreed that careful planning is essential to any successful prevention with positives program. This planning generally covers three major issues—needs assessment, the intervention, and evaluation.

1. CONDUCTING A NEEDS ASSESSMENT

When developing prevention with positives programs, as with all prevention programming, it is critical to conduct a needs assessment. This formative research process consists of obtaining and analyzing information to determine the current status and service needs of a defined population or geographic area and requires conducting research about the current conditions for the population, and the resources, programs, and approaches already available to address those needs (AED, 2000). Once this information is gathered, program planners can analyze the met and unmet needs of specific target populations and their community. From this analysis, planners set priorities and develop strategies to address unmet needs that are identified and prioritized. The results of a needs assessment should be shared with the community so that they can provide feedback, be involved, and understand why selected approaches are adopted. In conducting needs assessments, program planners must recognize that communities might reveal certain information

but withhold other information. Consequently, the person asking the questions and determining needs, and the way in which the assessment is conducted, can affect the outcome of the assessment.

2. DEVELOPING COMMUNITY-SPECIFIC INTERVENTIONS

An intervention that is successful in one community will not necessarily be effective in all other others. Similarly, each component of a program cannot always be exported to another community. Interventions will need to be implemented with fidelity to their basic theoretical core, but may also have to be adapted to a particular community or population.

Consultation participants cited four issues that are important for program planners to consider when developing, or adapting, community-specific interventions. First, prevention interventions need to address locally specific needs at both individual and community levels. The formative research with the target population described above is critical. HIV-positive infected and affected people must be involved with the design and implementation of programs to ensure that they actually meet the needs identified and prioritized and that they are relevant to the intended audience.

Second, it is important for planners to know that the boundaries between interventions directed at individuals, groups, and community are not always clear. Despite the importance of interventions at the individual level, it is equally important to change social norms at the group and community levels so that people and communities become more receptive to and supportive of people who are infected.

Third, organizations need to choose the type of intervention carefully, based on the population's

EXPERIENCE FROM THE FIELD:

What Types of Interventions Are Organizations Using?

COMMUNITY-BASED ORGANIZATIONS COMMONLY USE FIVE TYPES OF INTERVENTIONS:

- **Individual-Level Interventions:** one-on-one sessions carried out one or more times
- **Group-Level Interventions:** sessions designed for multiple individuals, such as meetings, workshops, training, and other types of sessions
- **Community-Level Interventions:** interventions focused on the community as a whole, rather than on intervening with groups or individuals
- **Prevention Case Management (PCM):** intensive, individual client-centered approach to counseling, case management, and referrals to additional services
- **Counseling and Testing:** pre and post HIV-testing counseling and services

ADDITIONAL PREVENTION AND SERVICE RELATED ACTIVITIES INCLUDE:

- **Outreach:** venue-based, street, and general outreach strategies
- **Substance Abuse Counseling and Treatment:** drug abuse and alcoholism counseling, treatment, rehabilitation, and continuing care services
- **On-Site Mental Health Services:** therapeutic mental health services
- **Community Forums:** educational community meetings
- **Online Educational Services:** online downloadable HIV prevention education materials
- **Partner Services:** couples counseling, discordant couples services, and partner support groups

Source: AED, 2001; AED, 2003a.

needs and a sound theoretical model that has been evaluated and proven to be effective. It is important to recognize that individuals are part of communities and groups that can either stigmatize or support them depending on the approach used. As a result, individual-, group-, and community-level interventions must work in tandem.

Finally, to create programs that respond effectively to these multi-faceted needs, it is critically important that HIV-positive infected and affected individuals be involved in all levels of program design and development, from conception through

implementation and evaluation. However, some consultation providers working in the area of prevention felt that peer-based methodology, while useful, may not be broadly applicable. For example, individuals in some ethnic groups may be less open to peer education and outreach efforts than to professional service. The strategy of involving peers needs to be thoroughly considered in each setting, and could even involve the recruitment of individuals who may not be principal members of the target audience. In addition to including HIV-positive people in program design and development, lessons can also be learned from interventions with

HIV-negative populations. Studies suggest that many important factors that influence sexual risk behavior among HIV-infected persons may be similar to those that influence persons who are uninfected (Simon et al., 1999).

C. Individual-Level Interventions: Science and Practice

Changing behavior, and knowing how to facilitate such change, can be a daunting challenge. The HIV-positive individual is often asked to make changes in his or her behavior that he or she may not want to make or that may be inappropriate to make and unsupported in his or her social setting (Marks et al., 1999).

An individual-level intervention, such as one-on-one counseling, is an approach that focuses on promoting, reinforcing, and maintaining behavior changes in HIV-positive persons. These interventions help clients make plans for behavior change and ongoing appraisals of their own behavior and include skills-building activities, and are appropriate for persons who need more intensive services. One-on-one counseling also facilitates linkages to services in clinical and community settings, which support behaviors and practices that prevent HIV transmission and counselors may assist clients in obtaining these services. Services addressed might include substance abuse treatment, domestic violence prevention, or housing.

Individual-level interventions are important modes of prevention because they provide confidentiality and privacy and can be tailored to meet the specific needs of the client (DiScenza et al., 1996). Furthermore, the one-on-one attention provided by individual-level interventions is often critical to provide insight, skills, and support and to guard against isolation for those who, by virtue of being

HIV-positive, may lose their links with family, institutions, or community. In addition, establishing an ongoing one-on-one relationship with clients might be the only way for providers to reach some individuals because some people are unwilling to talk about personal topics, such as sex and bathhouse use, until they have established trust and a rapport with the counselor (AED, 2002).

1. PREVENTION CASE MANAGEMENT

PCM—the most intensive HIV prevention intervention—is designed to accommodate the special needs of HIV-positive individuals with a range of medical, social, and economic challenges. The CDC *Advancing HIV Prevention: Interim Technical Guidance for Selected Interventions* recommends PCM as a prevention intervention for HIV-positive clients who find it challenging to engage in behaviors that reduce or prevent HIV acquisition, transmission, or reinfection (CDC, 2003a).

The CDC *HIV Prevention Case Management: Guidance* defines PCM as a client-centered intervention that supports HIV-positive and HIV-negative individuals through initiating and maintaining risk-reduction behaviors (CDC, 1997). In a study examining 25 PCM programs, many agencies did report that it had been adapted to become or included a group-level intervention (Purcell, 1998). The main principle behind PCM is that some individuals will not place emphasis on HIV prevention when they consider other problems they are confronting to be more important or to require their immediate attention. The PCM intervention combines HIV risk-reduction counseling and standard case management. Through intensive, regular, one-on-one prevention counseling and support, PCM addresses HIV risk as it relates to substance abuse, HIV/STD treatment, mental health, and other sociocultural and economic factors. PCM

also focuses on assisting clients in accessing medical, psychological, and social services.

The goals of a PCM program include:

1. providing assistance to individuals with various HIV risk-reduction needs;
2. providing one-on-one, multiple-session HIV risk-reduction counseling to encourage behavior change;
3. determining risks of acquiring other STDs and effectively diagnosing and treating them;
4. referring clients for medical and psychosocial services; and
5. providing information and referrals for HIV-positive individuals to prevent them from becoming ill or dying from HIV-related illnesses or opportunistic infections (CDC, 1997).

The following seven important elements are included in PCM programs:

1. Client recruitment and engagement;
2. Screening and assessment for HIV and STD risks, in addition to medical and psychosocial needs;
3. Development of a client-centered Prevention Plan with behavioral objectives for HIV risk reduction;
4. Multiple-session HIV risk-reduction counseling;
5. Active coordination of services with follow-up;
6. Monitoring and reassessment of clients' needs, risks, and progress; and
7. Discharge from PCM upon attainment and maintenance of risk-reduction goals (CDC, 1997).

Using published studies to illustrate the issues, the following sections highlight some of the main themes that CBOs and program planners and implementers should consider when designing and carrying out individual-level interventions.

2. FAMILY AND COMMUNITY CONTEXT OF INDIVIDUALS

It is important to recognize that individuals are part of families, groups, and communities, which has a direct bearing on the ability of the infected person to cope with this myriad of issues. *“You could train somebody to feel comfortable disclosing their HIV status, but if they are in a hostile environment, what does it matter?”* asked one consultation participant. Individual-level interventions are important in general, and the reality is that programs will always be needed at the individual level for people who are so marginalized from their own families or communities that they do not feel that they have a safe haven or home. This is often true for IDUs, sex workers, people with mental disorders, and people who feel disenfranchised from their community. *“Working with those folks individually may give them a moment of beginning to feel that they are worth some personal attention and can build a little bit of hope into their lives. Then they begin to care about not infecting others,”* stated another consultation participant.

Studies have shown that individuals with lower levels of perceived social support from family members and higher levels of drug use were associated with greater risk behavior, suggesting that support and help in identifying an adaptive coping mechanism is relevant to risk behavior avoidance (Heckman et al., 1998; Kimberly & Serovich, 1999; Lutgendorf et al., 1998).

3. “KEEP IT REAL, KEEP IT BASIC, AND MEET PEOPLE WHERE THEY ARE”

Efforts at behavior change must address the complexity of the moment in which someone is engaged in a potentially risky behavior and the factors that contribute to that complexity (e.g., substance use, emotional state). Trust is essential in individual-level interventions, and building trust

takes time. Once trust has been established, even short counseling interventions using personalized risk reduction plans have been useful for HIV-negative individuals in increasing condom use and preventing new infections, demonstrating that effective counseling can be conducted even in busy public clinics (Kamb et al., 1998). Additional research must be conducted to determine whether short counseling sessions are also effective in increasing condom use among HIV-positive individuals.

Prevention programs must find the most effective venue of communication for an individual, whether it is face-to-face, online, or by beeper or telephone. Because individualized interventions require that programs go to the clients, or have them come to the programs, transportation and access issues must be addressed. Programs also need to recognize the power of denial, and be prepared to discuss clients' views on sex or drug use and how they affect their risk of transmitting HIV infection.

4. INVOLVING PEER EDUCATORS

Peer counseling is an approach that has been used in many types of programs, from breastfeeding promotion to asthma control to psychological support for family caregivers and students. However, the use of peers for HIV outreach and prevention interventions has demonstrated mixed results. One study found that using peers in education programs as a form of health outreach was an effective intervention tool in terms of the utilization of sexual health services, but was less effective in achieving actual sexual behavior change among homosexual men (Williamson et al., 2001). Another study found that mobilizing young gay men to support each other about safer sex is an effective approach to HIV prevention, but these programs must be sustained to continue to be effective (Kegeles, 1999).

Peer-driven interventions have been used among IDUs, with some success. This model uses existing social networks of HIV-positive people to educate and recruit IDUs as peer outreach participants. The IDUs are given nominal financial rewards for being interviewed, for recruiting IDUs to the program, and for educating their recruits. Peer-driven interventions, such as this, build a discourse of prevention in the community through the daily interactions of peer educators with other IDUs (Hughes, 1999).

Although data suggest that peer-driven interventions can be an effective means to reaching HIV-positive populations, the ability of peers to successfully implement theory-based counseling interventions in health and social service settings has been shown to be effective in only a few locations (Cabral et al., 1996). Effective counseling is a skill that carries emotional risks for the counselor. The use of peers for one-on-one counseling requires supervision by and support from staff to ensure continuity, minimize burn-out, and provide emotional support. When using peers, program planners need to consider setting appropriate boundaries for their involvement, and address issues such as confidentiality of the information exchanged with clients, strategies to undertake if a peer relapses into unsafe behavior, and concerns that clients may have about the peer being part of their same social network. These are all critical issues that have surfaced in peer-driven or peer-implemented interventions in the past and must be considered in future planning.

5. BUILDING PARTNERSHIPS IS CRITICAL TO SUCCESSFUL INTERVENTIONS

Because individual-level interventions require a substantial investment of resources, those who develop this type of program need to be mindful

that the integration of multiple interventions is essential to a more efficient use of scarce resources. Individualized interventions are more effective when programs build a variety of relationships among providers and clients. Studies have found a relationship between individuals' access to medical, mental health, and social support services and their successful avoidance of transmission risk behavior (Kelly et al., 1993).

Funders and service providers at all levels need to support changes in health care communications, services, and research to ensure that integration occurs. Prevention with positives should be conceived as a part of the overall continuum of wellness services.

D. Group-Level Interventions: Science and Practice

Group-level interventions are useful for addressing the variety of needs that an HIV-positive person has (e.g., developing coping skills and recognizing group norms) and can often be synchronized with individual-level interventions. Group-level interventions entail health education and risk-reduction counseling that shift the delivery of service from the individual to groups of varying sizes. Group-level interventions use peer and non-peer models involving a range of skills, information, education, and support. Group-level interventions also have a skills-building component.

To reach many risk-taking individuals, HIV prevention activities must be embedded in social activities and community life (Kegeles et al., 1996). However, confidentiality is a concern when trying to develop group-based intervention programs. Participants have to be comfortable with being openly HIV-positive.

Participants in the consultations convened for this report identified elements that are conducive and obstructive in group-setting interventions. It is important to have strong facilitation, set ground rules, be aware of other relevant groups for referrals, be tolerant of differences among members, and make clear rules about the level of disclosure in the groups. Dynamics that are not helpful to the group include presence of cliques; domination of politics or personal opinions of group members; and the existence of a “free-for-all” atmosphere that lacks discipline, structure, or respect.

1. GROUP-LEVEL INTERVENTIONS FOR HIV-POSITIVE PERSONS

Three studies have evaluated group-level interventions for HIV-positive persons, and each has shown a reduction in at least one measure of risk behavior.

Healthy Relationships

In a study by Kalichman and colleagues (2001), men and women living with HIV were randomly assigned to either a five-session, behavioral risk-reduction group intervention or a comparative five-session, health-maintenance support group. This skills-based, behavior-change intervention model was grounded in the Social Cognitive Theory, and was tailored for HIV-positive people within the context of managing stress related to disclosure of HIV status and practicing safer sexual behavior. The intervention focused on developing skills and building self-efficacy and positive expectations about new behaviors through modeling behaviors and practicing new skills.

The behavioral risk-reduction cohort—the Healthy Relationships intervention—focuses on developing decision-making and problem-solving skills to enable participants to make informed and safe decisions about disclosure and behavior. The

sessions create a context where people can interact, examine their risks, develop skills to reduce their risks, and receive feedback from others. The core elements of Healthy Relationships are:

- Defining stress and reinforcing coping skills across three life areas: 1) disclosing to family and friends, 2) disclosing to sexual partners, and 3) building healthier and safer relationships;
- Using modeling, role-play, and feedback to teach and practice skills related to coping with stress;
- Teaching decision-making skills about disclosure of HIV status;
- Providing personal feedback reports to motivate change of risky behaviors and continuance of protective behaviors; and
- Using movie clips to set up scenarios about disclosure and risk reduction to stimulate discussions and role-plays.

In the study, both the behavioral risk-reduction intervention cohort and the comparative cohort met for five 120-minute sessions with two sessions held per week over 2.5 weeks. Participants completed questionnaires at the beginning to establish baseline understanding. Immediately after, at three months after, and at six months after the intervention, questionnaires were completed again to track the impact of the intervention. Results showed that those in the behavioral risk-reduction cohort had significantly less unprotected intercourse and increased condom use at follow-up than those in the comparative cohort. Transmission risk behaviors with non HIV-positive sexual partners and estimated HIV transmission rates over a one-year horizon also were significantly lower for the behavioral risk-reduction intervention cohort.

Holistic Harm Reduction Program (HHRP)

In a study by Margolin and colleagues (2003), HIV-positive IDUs entering a methadone maintenance program received one of two interventions over the

course of six months. The treatment intervention—HHRP—included daily methadone doses, weekly individual substance abuse counseling, case management, a six-session HIV risk-reduction intervention, and also manual-guided group psychotherapy sessions two times a week. The primary goal of HHRP is to provide group members with resources (i.e., knowledge, motivation, and skills) they need to make choices that reduce harm to themselves and others. The control intervention included the same components as the treatment intervention, except there was no manual-guided group psychotherapy sessions provided. The program is based on the Information, Motivation, Behavior (IMB) model of behavior change that aims to reduce harm, promote health, and improve the quality of life of HIV-positive IDUs. In addition to providing substance abuse treatment, HHRP addresses medical, emotional, and social problems that may impede harm reduction behaviors.

Treatment goals are not simply abstinence from recreational drugs or sexual risk behaviors, but also reduced drug use, reduced risk of HIV transmission, and improved medical, psychological, and social functioning. HHRP activities, such as the harm reduction approaches listed above, are designed to address clients as the complex human beings that they are; the programs offered must realistically assist clients in attaining physical, emotional, social, and spiritual well-being. The study found that participants in the treatment intervention reported lower addiction severity scores, and were less likely to engage in high-risk sex and drug-related behaviors than were those in the control intervention. Specifically, participants of HHRP had decreased their addiction severity after three months, decreased their risk behavior after three months, and had significant improvement in behavioral skills, harm reduction knowledge and behaviors, motivation, and quality of life.

Teens Linked to Care (TLC)

The third study that evaluated a group-level intervention for HIV-positive persons assigned HIV-infected youths aged 13 to 24 years to small group cohorts that received either a two-module intervention totaling 23 sessions of two hours each (the intervention condition) or no intervention (the control condition) (Rotheram-Borus et al., 2001). An incentive was paid for two baseline assessments conducted at a three-month interval. Intervention Module 1 (“Staying Healthy”) focused on coping with learning one’s serostatus, carrying out new daily routines to stay healthy, dealing with issues of disclosure, and participating in health care decisions. Intervention Module 2 (“Acting Safe”) aimed to reduce substance abuse and unprotected sexual acts by having youths identify their risk behavior triggers, modify their patterns of substance use and increase their self-efficacy of condom use and negotiation skills. HIV transmission behaviors and health practices were examined over a period of 15 months after the intervention.

Of those in the intervention condition, 73% attended at least one session. After Module 1 (“Staying Healthy”), the number of positive lifestyle changes and active coping styles increased more often among females who attended the sessions than among those in the control condition. Social support coping also increased significantly among males and females attending the intervention condition compared with those attending the control condition. Following Module 2 (“Acting Safe”), youths who attended the intervention condition reported 82% fewer unprotected sexual acts, 45% fewer sexual partners, 50% fewer HIV-negative sexual partners, and 31% less substance use, on a weighted index, than those in the control condition.

The intervention was further developed into TLC—an effective intervention targeting youth between

the ages of 13 and 29 who are living with HIV. TLC is delivered in small groups using cognitive-behavioral strategies to change behavior. Young people meet regularly to provide social support, learn and practice new skills, and socialize. This program helps young people identify ways to improve the quality of their lives by setting new habits and daily social routines. They set goals regarding their health, sexual relationships, drug use, and daily peace.

The intervention is based on Social Action Theory and consists of three modules, each of which focuses on different outcomes.

- **Module I:** *Staying Healthy* targets health care and health behaviors.
- **Module II:** *Acting Safe* addresses sexual and drug use-related transmission acts.
- **Module III:** *Being Together* focuses on improving quality of life.

The following sections describe several key themes that CBOs and program planners and implementers should consider when designing and carrying out group-level interventions.

2. INTEGRATE SOCIAL FUNCTIONS INTO GROUP-LEVEL INTERVENTIONS

Group-level interventions can alleviate isolation and normalize interactions among individuals. For this reason, pre-existing social and community events are often effective settings for conducting group-level interventions. Such venues and activities must be safe, comfortable, interesting, and relaxed. Group-level interventions provide a unique opportunity for socialization, allowing participants to talk about their experiences. For example, social functions integrated into group-level interventions may encourage MSM, IDUs, and sex workers to discuss their relationships and what motivates them

to behave the way they do. Programs that use group-level approaches report that this method promotes goal setting and provides a forum for participants to discuss successes and failures in their behavior change efforts (AIDS Action, 2001). Participants in the consultations convened for this report felt that funding socialization activities for HIV-positive individuals was important—providing powerful opportunities for prevention discourse and building a peer network to support positive behavior change in the future.

3. INVOLVING HIV-POSITIVE PEERS

Peer-driven group interventions can meet several needs of effective prevention activities. They have been found to help individuals protect their confidentiality, fuel the empowerment of newly diagnosed individuals, and help people cope with disclosure issues. In some contexts, group-level interventions that are peer-driven may be more effective. Some peer-driven group interventions focus on developing strategies for individuals within the group, while others focus on altering the behavioral norms and attitudes of entire social networks through peer leadership and modeling.

The peer leadership and modeling approach is effective in reaching particular segments of a target population because it relies on individuals with whom community members directly interact. These peer leaders can correct misconceptions about HIV/AIDS, recommend relevant and proven strategies to help individuals carry out risk reduction, and sanction social acceptability of making behavioral changes (Kelly et al., 1991). As with all effective community interventions, the peer approach needs to be tailored to its target audience and demonstrate sensitivity to ethnic and cultural nuances. For example, one consultation participant pointed out that in his experience, Hispanic women do not often respond well to the peer approach

because they demonstrate a preference to have someone in authority, rather than a peer, provide the intervention (AED, 2002).

4. PAYING ATTENTION TO GROUP COMPOSITION AND CHARACTERISTICS IS CRITICAL

It is important for programs to recognize the diversity of possibilities and composition of the group in this type of intervention. Formative research can help guide the choice and composition of group-level interventions. Sometimes it is best if all members of the group share common social and/or demographic characteristics (e.g., teens, MSM, IDUs in urban or rural settings, serodiscordant couples, heterosexual women, or incarcerated populations). In other circumstances, it is more effective to include both HIV-negative and positive individuals or other combinations of people in a group. In planning group-level activities, organizations must recognize that regional variations may exist within a given local area, impacting potential success if not addressed. Moreover, in some parts of the country stigma associated with HIV-positive status is more pervasive than in others. In cases such as these, group settings might be more difficult to initiate and sustain effective and sustainable prevention programming.

5. LINKAGES AND NETWORKS CAN PROMOTE THE SPREAD OF EFFECTIVE MODELS

Effective models for group interventions can be shared, adapted, and utilized in many communities throughout the country. In addition, for groups with a strictly defined identity (e.g., the transgender community, or migrant farm workers) it is useful to create a network of similar groups to maintain for transient populations. This way, referrals can be made from one city to another (AED, 2002) and ongoing prevention and healthcare services can be sustained. Consultation participants recommended

the use of peer-to-peer training for program providers to make contacts and to visit successful group-based programs in other locales to learn from their experiences.

6. TRAINING AND TECHNICAL ASSISTANCE IS A CRITICAL REQUIREMENT FOR EFFECTIVE GROUP-LEVEL INTERVENTIONS

Training for providers and peers that lead group-level interventions is important and should be supplemented with preparation in self-advocacy, education, safer sex counseling, and adherence counseling. Program providers should look at clinical care settings as a potential setting for group-level interventions and also should take clinicians out of the clinical care setting to expand their potential reach to the target audience. Funders should not merely provide funds to an organization and hope for the best; they must also provide technical assistance or funds for technical training on how to run groups or organizations. Conversely, programs should not expect that a prevention service provider is going to be able to come into any setting and have the cultural competency or the ability to work with the group.

E. After the Intervention: Maintaining Safe Behaviors

In an article on methodological issues in HIV prevention interventions, Ostrow and Kalichman (2000) report that maintaining safe behaviors is likely to be a general problem in HIV prevention interventions. A better understanding of this issue is complicated by the fact that most studies do not report assessments that are extended over enough time to evaluate behavioral maintenance. Long-term follow-up is further challenged because of the high probability of relapse when individuals are engaged in changing high-risk sexual and drug use behaviors.

There are several ways that prevention with positives programs help their clients maintain their newly acquired safer behaviors. Consultation participants and key informant interviewees reported that the techniques used by agencies to maintain risk reduction behaviors among their HIV-positive clients were similar to the interventions each agency uses to change behaviors among HIV negatives. The primary maintenance strategies used by agencies include social support, ongoing counseling, social interaction, and using HIV-positive program staff. Participants particularly emphasized the need for agencies to have staff or volunteers who are HIV positive, and to develop sustainable, ongoing relationships with clients. Many of the agencies felt that having a PLWHA on staff or working as a volunteer in a prevention with positives program, legitimized and helped to strengthen the relationship and trust clients have with staff and the agency. Participants felt that this led clients to be more inclined to maintain safe behaviors.

F. Summary

Currently, a limited number of science-based interventions exist for PLWHA. Although research on actual interventions remains understudied, research on the factors affecting risk behaviors of PLWHA provides important information that can lay a foundation for development of prevention with positives interventions.

This chapter has provided background on individual- and group-level interventions and the issues that need to be considered in planning and implementing them. A successful prevention strategy within a community balances individual-, group-, and community-level interventions so that multiple needs are met. Most organizations cannot implement all three levels of interventions on their

own, thus requiring that partnerships be encouraged and funded.

Consultation participants felt strongly that the lines between interventions directed at individuals, groups, and community are not always clear. It is important to recognize that individuals are part of the group and community, and it is equally important to change individual behaviors and social norms at these levels. As a result, individual-, group-, and community-level interventions must work in tandem to ensure that people and communities are receptive to and supportive of individuals who are infected.

Evaluating the effectiveness of prevention with positives interventions is of paramount importance.

Little information exists to guide evaluation efforts in this intervention area. Consultation participants shared information about their evaluation activities, and all are doing some evaluation ranging from simple to complex designs. They also emphasized that reduction in new infections is one goal, but that other endpoints need to be examined as well.

Interventions are urgently needed to support PLWHA in maintaining long-term safer drug injection and sex practices, especially as new treatments allow them to live longer and healthier lives. Mental health services and substance abuse treatment settings are among the important venues for HIV risk reduction and disclosure skills enhancement interventions (Kalichman, 1999).

Legal and Ethical Issues Associated with Prevention with HIV-Positive Individuals

A. Introduction

The challenges in developing prevention interventions that meet the needs of HIV-positive individuals encompass assuring access to high quality care and treatment as well as changing risk-related behavior. Prevention with positives is both a health care and a public health issue. Public health seeks to ensure “societal conditions under which people can lead healthier lives, minimizing threats to our health that can be averted or lessened only through collective actions aimed at the community” (Kass, 2001). Current public health strategies to control the spread of HIV infection can be broadly defined as activities that stress mass education, counseling, voluntary testing, interventions, and protecting those who are vulnerable from discrimination and invasion of privacy. The goals of these strategies include delivery of effective individual-, group-, and community-level interventions; provision of prevention, care, and treatment services for persons infected with HIV or at high risk for infection; and maintenance of strong links between prevention and primary care.

Disease reporting is a public health function that is “distributionally unfair,” that is, the burdens of

the program are borne by those with the disease, generally for the benefit of those who do not have the disease (Kass, 2001). Some of these issues have been previously debated in the context of STD prevention, and parallels have been drawn between, for example, gonorrhea and HIV. However, until HIV/AIDS can be cured in the same way as some other infectious diseases, it retains a unique position in the ethical and legal landscape. It is incumbent on those collecting data to ensure that these uneven burdens are balanced by benefits.

Even with the advent of effective therapy, and an evolving sensitivity to the needs of the HIV-positive community, prevention with positives continues to present a struggle between individual rights and the protection and improvement of the public’s health. This tension has existed since the beginning of the HIV epidemic, and as the number of people living with HIV climbs, prevention programs focused on those who are already HIV positive increasingly raises concerns from some in the community that public policy is “blaming the victim.” HIV-positive people are being asked to behave in ways that minimize the likelihood of transmitting the virus and to be accountable for their actions (Marks et al., 1999).

Prevention with positives programs need to be presented in a new light, so that their efforts to minimize transmission are seen to embody protections of privacy, confidentiality, and individual civil liberties as well as to advance public health.

These issues are further complicated by the complex and troubled history of legal precedence in the sexual domain, in which certain acts and activities have been criminalized. Clearly, HIV prevention efforts must include the goal of providing the social conditions that encourage and reinforce safe behavior (Burris, 2002).

Within this broad topic of accommodating the rights of individuals while at the same time protecting the public health, conducting prevention with positives interventions raises a host of specific legal and ethical issues that should be discussed by program planners before programs are carried out. These issues include concerns about privacy and confidentiality, concerns about stigmatization and discrimination, and concepts of responsibility and blame. For example,

- What kinds of information can be shared between prevention and care providers? What kind of information should be available to prevention providers about the local social, political, or healthcare contexts and barriers to effective prevention interventions with HIV-infected persons?
- How can health professionals reconcile their duty to warn if someone with HIV is continuing to expose people to HIV infection without their knowledge?
- How should health professionals manage patients who are non-compliant or unwilling to seek or accept HIV treatment?

Furthermore, these legal and ethical issues involve complex societal realities and they vary or are unique to specific contexts (e.g., care and treatment settings, corrections settings, a monogamous relationship, or an anonymous sex venue) or populations (e.g., undocumented immigrants, youth, prisoners [Cozza, 1998]). It is therefore useful for program providers to consider these contexts and populations, for the ways in which these issues are addressed are not likely to change the need to adhere to the basic principles of fairness and justice, but they can change the manner in which HIV prevention efforts, such as recruitment, testing, counseling, and interventions, are offered.

Programs focusing on HIV-infected persons will be developed in local community contexts. Therefore, planners should ensure that programmatic, agency, and community policies and processes are in place to address legal and ethical issues as they arise. For example, what are the programmatic and staffing implications of issues such as disclosure of HIV status and duty to warn of high-risk behavior by individuals who are known to be HIV-positive? Additionally, how can relationships among community stakeholders be developed so as to avoid activities that infringe on the privacy or rights of HIV-positive individuals?

Program planners should keep in mind two core principles when embarking on prevention with positives interventions. These principles were derived from points raised by participants in the consultation held on ethical and legal issues that was convened for this report.

- ***Core Principle #1: Prevention programs with HIV-positive individuals should be developed in keeping with the principles underlying all effective HIV prevention. Prevention efforts are effective only when privacy is protected.*** Protections for positives

must be in place before programs are implemented. Programs focusing on HIV-infected persons need to be developed with care taken to do no harm to affected populations, given the social and political contexts within specific communities and the stigma that HIV/AIDS and associated risk behaviors and lifestyles carry in some communities.

- **Core Principle #2: Messages within prevention with positives interventions must first be delivered within the context of care and treatment.** Prevention and care should be integrated and coordinated from the moment someone gets an HIV test. Testing staff should be knowledgeable about care and services options in their area, and be ready to help individuals locate and use these services. Testing and counseling cannot be one-time events. Rather, they must be part of a continuum of care.

B. Protecting Privacy and Confidentiality

It is impossible to think about the prevention strategies that evolved in the early days of the HIV epidemic—which focused on voluntary rather than coercive measures and on HIV negatives rather than HIV positives—without understanding the extraordinary role played by AIDS activist organizations led by gay men. For gay men, the protection of privacy and confidentiality was critically important because of the context within which homosexuality existed in the United States. These issues still remain today. Up until a June 2003 Supreme Court ruling, gay men could be prosecuted in some states for having sex. In most states, even now, a person living openly in a gay relationship has no protection from discrimination (Marks et al., 1999). A tension still exists between the commitment to privacy and confidentiality on the one hand and the strategies that are essential

and central to traditional public health practice on the other. It is essential that correct information be provided to individuals. If those requirements are onerous, there must be a collective effort to change them. Careful attention to protecting privacy and confidentiality can actually advance public health. The challenge is how to promote public health without violating individuals' fundamental privacy rights.

A primary consideration in recruitment, referral, and service linkages is protecting the confidentiality of the individual. Because stigma remains a real concern, and due to the presence of other issues related to discrimination or the law (e.g., immigration status, injection drug use), providers must be particularly attentive to protecting confidential information. Many consultation participants perceive that violations of privacy and confidentiality disproportionately occur in disenfranchised populations. Moreover, these populations often have no legal recourse when breaches of confidence occur.

Although concern about confidentiality may not be cited as the most common reason to delay or defer testing, it is an important consideration for a minority of individuals—the very segment that is at highest risk of contracting HIV and is often the most focused target for campaigns to encourage HIV testing. The particular concerns of this critical high-risk population must be directly and carefully addressed and not lost in a general assessment of population-wide attitudes or concerns about HIV testing (Solomon et al., 1999). In addition, cultural differences in views about privacy also must be addressed. For example, some cultures value individual privacy while others consider individual information to belong to the community. These cultural differences must be noted and accounted for in developing privacy protections.

Programmatic activities require that reporting occur in some cases and that databases be maintained. The infrastructure for those databases must be secure and protected, despite the costs associated with such protections. Clients have a legal and moral right to privacy, which includes confidentiality of all information related to the client or gathered by the client's service provider. Even so, the right to privacy is not total. Under certain circumstances, that right must yield to a state's fundamental right to enact laws to promote public health and to ensure public safety and welfare.

To establish the policy and procedures for conducting prevention interventions with positives, it is important for programs to:

- Research their ability to legally protect confidentiality and be knowledgeable about federal, state, and local law in this area.
- Understand the relevant reporting and disclosure requirements for their specific state and jurisdiction.
- Disclose to individuals their duty to report to authorities the results of testing and follow up when relevant, particularly if immigration or legal concerns exist.

Most states are required to conduct partner notification as a condition of their receipt of federal funds for HIV prevention—although the method is not prescribed—and many offer anonymous testing programs. These approaches, when combined with effective counseling and intervention, have been shown to be a cost-effective means to preventing HIV transmission (Jordan et al., 1998; Varghese et al., 1999), and might be more productive when accompanied by anonymous testing (Kassler et al., 1997). However, partner notification programs must be confidential and voluntary.

Partner notification raises significant ethical concerns, especially when the provider feels compelled to warn an individual identified to be at risk for HIV. What responsibilities do outreach workers and communities have when they see HIV-positive individuals engaging in risky behavior? This potential violation of one person's privacy to protect another's welfare can be justified on medical grounds but contested on legal grounds, and some wonder whether it will actually dissuade some individuals from being tested (Bayer & Toomey, 1992). Training is essential, in particular, for the circumstances in which an individual asks a health care provider to disclose their status for them.

Partner notification should be flexible, voluntary, and accountable. Similarly, when the person to be tested is a minor, special concerns arise about the requirement for parental consent or involvement of parents if the test results are positive. Although it is best that parental and family rights issues be evaluated, a majority of states have enacted laws that allow minors to consent on their own to testing and treatment for STDs, including HIV (Boonstra & Nash, 2000). Moreover, these issues should be explored when a minor seeks HIV counseling and testing so the provider can assess whether parental notification or involvement will be a risk or benefit to the child. It is evident that providers need more training in the skills required for dealing with youth and adolescent populations.

When the HIV-positive individual is a pregnant woman, ethical issues arise about the obligations of the provider to disclose to others the serostatus of this individual. Many believe that the rights of the woman are subordinate to the rights of the baby. However, a substantial body of established law protects a woman's right to privacy in medical decision making and interest in refusing unwanted medical treatment (*Cf. Ferguson v. City of Charleston*, 532 U.S. 67(2001)).

Providers should talk to pregnant women about current medical knowledge and the risks and benefits—for mother and child—of HIV testing and treatment during pregnancy, during labor, and after birth. The *2001 Revised Guidelines for HIV Counseling, Testing, and Referral and Revised Recommendations for HIV Screening of Pregnant Women* recommend voluntary HIV testing and support a woman's right to decline testing. They emphasize HIV testing as a routine part of prenatal care and recommending HIV testing for all pregnant women. The guidelines also recommend that pretest counseling not be a barrier to testing for either the provider or patient.

In the November 15, 2002 issue of *Morbidity and Mortality Weekly Report* (MMWR), CDC published data on prenatal HIV testing rates in the United States and Canada. The data indicate that an “opt-out” approach and mandatory newborn screening yield high testing rates. The “opt-out” approach includes notifying pregnant women that an HIV test will be included with the standard prenatal tests, while informing them that they can decline HIV testing. This approach contrasts with the “opt-in” approach, which requires that pregnant women specifically consent to an HIV test, usually in writing. In light of the data, CDC recommends clinicians use an “opt-out” approach when screening women for HIV, perform rapid HIV tests during labor for women whose HIV status is unknown, and test newborns immediately post-partum if the mother's HIV status is unknown (CDC, 2003c).

Also, the CDC's *Advancing HIV Prevention Initiative* places a strong emphasis on achieving further reductions in perinatal HIV transmission by encouraging routine HIV testing of pregnant women, along with routine testing of infants born to mothers who were not tested.

Criminalization is not an acceptable practice in prevention with positives. On the other hand, laws, in most cases, actually protect individuals from breaches of confidentiality; thus, the law should be seen as protecting rather than harming confidentiality. For example, those who violate privacy or breach confidentiality should be punished so as to discourage future occurrences.

C. Reducing Stigma

Despite the fact that stigma has existed since the beginning of the HIV epidemic, it is still poorly understood. It is believed that effectively decreasing HIV/AIDS stigma is critical to stemming the epidemic (Cameron, 2000; UNAIDS, 2000). There are a limited number of programmatic models available to combat HIV-related stigma, and those that have been documented were not always rigorously evaluated (Brown, 2002). The Ford Foundation and AED are implementing a five-site demonstration project to collect data on community-level interventions targeting African Americans, Asian and Pacific Islanders, Latinos, and immigrant communities (AED, 2003b). CDC and HRSA are engaged in a collaborative process to develop an anti-HIV related stigma funding stream, and held a consultation in November 2003 to explore the topic. Additionally, CDC convened a consultation in August 2003 to better understand how best to implement and operationalize the activities of the *Advancing HIV Prevention Initiative* without stigmatizing people living with HIV.

A recent UNAIDS report stated that:

“Stigma emerges from, and reinforces, other stereotypes, prejudices and social inequalities, including those relating to gender, nationality, ethnicity, and sexuality, as well as activities that are criminalized (e.g., sex work, drug use, or male-male sex)” (UNAIDS, 2002).

Interwoven in HIV/AIDS-related stigma are other social prejudices including racism, homophobia, ignorance of drug use and addiction, and fear of contagion. Race and accompanying issues related to stigma cannot and should not be ignored in designing programs.

The long-term approach to overcoming stigma associated with HIV infection is to do the difficult work of changing social norms regarding frank discussion of sexual behaviors and the risks posed by injection drug use. Another strategy is to create programs that provide a mechanism for buffering people against stigma. Establishing support groups for people allows them the opportunity to come together with others who are experiencing what they are, which can help bolster them against stigma and discrimination. Providing individuals with a “safe place” in which to work through thoughts and behavior change also can alleviate the effects of living with stigma.

Prevention approaches need to be crafted carefully so as not to shift blame for the epidemic to those who are infected. One way to alleviate the stigma that might be associated with prevention programs is to make clear that prevention programs are focused on positive and negative serostatus individuals alike, because both groups must work toward stopping the HIV epidemic. Programs need to support the need to unify both groups around a common goal rather than divide them by serostatus. *“We need to avoid language that implies HIV-infected individuals are ‘carriers,’”* said one consultation participant.

As the science, medicine, and technology surrounding HIV testing and treatment continues to evolve, the ethical and legal issues also will evolve and will need continual discussion. In HIV-positive persons, stigma is one area that could be exacerbated if steps are not taken to address it.

D. Exploring Individual Morality and Disclosure of Serostatus

“It is always a challenge to integrate a discussion of morality with public health issues,” said one consultation participant. Discussion centered on whether it is “morally normative” to avoid infecting a partner and how to address what some called “situational morality.” That is, how can counselors address an apparent conflict between “individual morality” and “community morality?” In this country, community morality is often synonymous with laws. Thus, the message can be distorted to read that if one does not adopt community morality one might be prosecuted. Some participants wondered where to draw the line between willful exposure versus accidental exposure, and if the law cannot distinguish the difference, whether it matters to public health.

Virtually all HIV-positive individuals wrestle with issues of self-disclosure, particularly with sexual partners and with family members. It is important that prevention with positives programs provide appropriate counseling for HIV-positive individuals and the opportunity for discussion of disclosure issues.

Recent studies have shown that HIV-positive men tend to weigh the consequences of disclosure before confiding to others about their status, and if such a disclosure is likely to result in fights, blame, or loss of a relationship, disclosure is less likely to occur (Bonn, 2002). A common reason for failing to disclose fully is fear of rejection (Klitzman, 1993). Disclosure to known partners often occurs more frequently than disclosure to anonymous partners (Wolitski et al., 1998; Marks et al., 1999). Clearly, the issues around disclosure are emotionally charged and context specific. More research is needed to examine notification procedures and to better tailor them to specific populations, as well as to assess the effect of new HIV testing technologies on partner

notification, and to understand the consequences of partner notification for HIV-positive persons and their partners.

Many individuals consulted for this report stressed the need to create a norm of disclosure, that is, encouraging individuals to inform sexual partners of their serostatus. Partner notification programs can assist clients who are having difficulty disclosing HIV status to past or current sexual partners. Some studies show that provider referral generally ensures that more partners are notified and medically evaluated than does self-referral (Jordan et al., 1998). However, the traditional argument—that it is in the best interests of public health to disclose serostatus and prevent infection—might not have currency with some populations, such as street youth.

It is apparent that more information should be collected about the “disclosure experience,” such as, what works best and under what circumstances. It cannot be assumed that disclosure is always the most beneficial approach because some individuals could face a violent response from a spouse or partner. Disclosure norms are likely to vary by community and setting (e.g., committed monogamous relationship versus public sex venue)—a topic that deserves further study.

E. Ensuring Access to Care

Prevention with positives messages must first be delivered within the context of care, thereby integrating two essential elements of healthcare. Ethical tenets require that medical/health interventions be undertaken with the best interests of the individual as the primary concern. These tenets become less clear in the context of public health.

Programs need to know the care options and services in their area, and be prepared to help

individuals link to services. However, because people infected with HIV have a variety of health, emotional, and social issues that must be considered when designing an intervention, prevention should be integrated with coordinated care that begins at the moment of testing. HIV counseling and testing cannot be a one-time event; they must be part of a continuum of care. Otherwise, individuals risk being treated as means to an end, rather than as persons.

F. Summary

There is limited information on the actual extent of discrimination in the United States and on other social risks associated with being HIV positive. This dearth in knowledge makes a discussion of ethical and legal issues associated with prevention with positives challenging at best. However, protections for positives must be in place for prevention with positives to occur. Programs focusing on HIV-infected persons need to be developed with care taken to do no harm to affected populations, given the social and political contexts within specific communities and the stigma that HIV/AIDS and associated risk behaviors and lifestyles carry in some communities.

Prevention messages must first be delivered within the context of care. Prevention and care should be integrated and coordinated from the moment a person gets tested. Testing staff should be knowledgeable about area care and services options, and be ready to help individuals locate services. Testing and counseling cannot be one-time events. Rather, they must be part of a continuum of care. Until sufficient services are available for those who are considering HIV testing, some may choose to avoid being tested.

In the HIV testing setting, the consent process must include disclosures about the limits of the test,

information about the length of time the test results might take to obtain, and an overview of the duties and obligations of the provider if results are positive. Consent to testing should not be inferred to include consent to participate in prevention activities.

Program providers should be aware of the types of issues that emerge in HIV prevention with positives, including concerns about privacy and confidentiality associated with recruiting and engaging those who are positive, contact tracing, partner notification, collection of vital statistics, and research; stigmatization and discrimination; and appropriately changing concepts of responsibility and blame.

Program providers must be cognizant of their ability to legally protect confidentiality, and of relevant federal, state, and local laws, regulations, and policies. In addition, providers must be knowledgeable about relevant reporting and disclosure requirements. Providers must disclose to

individuals their duty to report to authorities the results of testing and follow-up, when relevant, particularly if there are immigration or legal concerns. Partner notification programs should be flexible, voluntary, and accountable.

Prevention with positives approaches must be carefully crafted so as not to shift blame for the epidemic to those who are infected. To reduce stigma, professionals as well as the general public must be thoroughly educated regarding modes and likelihood of HIV transmission, comparative risk, and the ethical and legal obligations to protect the rights of HIV-positive individuals and ensure their access to care.

HIV-positive individuals need appropriate counseling and opportunity for discussion of disclosure issues. The recognition that others may not accurately disclose their status can be a powerful motivator of safer sexual practices, and help in formulating appropriate and effective public health and prevention messages.

Conclusions

As we enter the third decade of the HIV epidemic in the United States, new strategies to combat the infection are clearly needed. Rates of new HIV infections have remained stable at an estimated 40,000 new infections per year since the early 1990s.

Prevention providers are operating in an environment where there are optimistic beliefs about drug therapies, which leads some to believe HIV is not the major health threat it once was. Those being targeted for prevention messages often suffer from “prevention burnout” which results in difficulty among both HIV-negative and positive individuals to practice safer behaviors perfectly and consistently. Additionally, there are changing social norms around risk behaviors within some communities, and changing demographics of those infected and affected by the epidemic. Racial and ethnic minorities in the United States are increasingly and disproportionately becoming impacted, and deal with a host of issues including racism, poverty, homophobia, and lack of social support.

Since the beginning of the HIV/AIDS epidemic, prevention programs have focused on working with HIV-negative individuals to avoid future infection. However, the past years of experience and research indicate there is also an urgent need to focus prevention efforts on HIV-positive individuals. The epidemiologic reality is that every new infection involves an HIV-positive person who has unknowingly, or knowingly, infected another person. To date, prevention with positives interventions have received limited attention and resources compared with those

focused on prevention with HIV negatives. Previously, there was great concern about stigmatizing HIV-positive individuals, and it was thought that focusing on them might drive a wedge between those infected with the virus and those who were not.

PLWHA have a range of options they can use to reduce their risk of transmitting HIV to others, including being tested for infection, receiving counseling and services, and engaging in safer sex and drug injecting practices. Getting people engaged in these interventions is crucial to their success.

Getting people tested for HIV, linking them to appropriate services, and providing them prevention with positives services is a key focus of the CDC *Advancing HIV Prevention Initiative* and other related CDC activities. Because of effective therapies to treat HIV infection, people are living longer and healthier lives. Research shows that the majority of infected individuals protect their partners upon learning their HIV status. However, knowledge of one’s serostatus alone does not always result in protective behavior change. In fact, HIV-infected populations need support and prevention skills to establish and maintain healthy and satisfying lifestyles that are safe for them and their partners. These

individuals need specialized programs that take into account their particular life situations and unique needs.

It is critical to highlight that the new approach to conduct prevention with positives activities does not come at the expense of HIV prevention targeted to HIV negatives. Prevention providers must maintain focus on uninfected populations at risk while adding interventions with HIV-positive individuals at the same time. For both approaches to HIV prevention, there are difference and similar ethical issues that must be considered and addressed regarding stigma, discrimination, and confidentiality.

There are both individual and broader public health benefits of conducting prevention with positives programs. Individuals participating in these interventions benefit by getting linked into HIV care and treatment, and the public benefits because of the potential to decrease HIV transmission. Prevention with positive programs must build upon the foundation of lessons learned and what we already know about conducting effective HIV prevention interventions from the past decades. Providers must employ proven approaches to effectively engage, recruit, and retain clients for HIV testing and care provision. These programs

must develop a sound understanding of the theories and science of risks and risk behavior reduction, while involving the target population in the planning process. Their involvement is critical in developing or adapting an effective population-specific intervention.

There is a dearth of published research findings on specific prevention with positives interventions. Some interventions have been designed specifically for PLWHA, but the need for additional models to meet their prevention needs in the field is substantial. Existing interventions were highlighted in this document. As prevention service providers continue implementing these interventions, attention must be paid to adaptation while maintaining fidelity to the elements that make an intervention effective. Lessons learned as well as evaluation results should be shared on a continual basis to those groups implementing them. This document provided guidance on developing and implementing prevention programs with positives, based on the best available research and programmatic experience. It is recommended that staff and decision makers in health departments and community-based organizations use the findings from this document to stimulate thinking and offer guidance in developing and implementing effective and ethical prevention with positives interventions.

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Glossary

AIDS (Acquired Immunodeficiency Syndrome): a disease caused by the human immunodeficiency virus. For public health surveillance, the CDC defines AIDS as the diagnosis of one or more specified indicator conditions, CD4+ T-cells less than 200/ml, or less than 14% of total lymphocytes and a positive HIV test or absence of other cause of immune deficiency.

Barebacking: a sexual trend with MSM defined by men intentionally engaging in unprotected anal sex.

Behavioral Interventions: programs to designed to change individual behaviors without an explicit or direct attempt to change the norms (social or peer) of the community (e.g., geographically defined area) or the target population (e.g., IDUs or MSM). Example: risk reduction counseling.

Centers for Disease Control and Prevention (CDC): the federal agency responsible for monitoring diseases and conditions that endanger public health and for coordinating programs to prevent and control the spread of these diseases. Based in Atlanta, GA, it is an agency of the U.S. Department of Health and Human Services.

Community-based organization (CBO): an organization offering services to a specific group of people in a defined area. Usually a non-profit, CBOs are governed by a board of directors and staffed by a combination of employees and volunteers.

Community-level interventions (CLI): programs designed to reach a defined community and to increase community support of the behaviors known to reduce the risk for HIV infection and

transmission by working with the social norms or shared beliefs and values held by members of the community. CLIs aim to reduce risky behaviors by changing attitudes, norm, and practices through community mobilization and organization, including community-wide events.

Convenience sample: when the researcher selects participants for the sample at his convenience. The researcher makes no attempt, or only a limited attempt, to ensure that the sample is an accurate representation of some larger group or population.

Correlates: when entities are brought into a causal, complementary, parallel, or reciprocal relation. This term can also refer to when two entities establish or demonstrate that they have a correlation: *Unprotected sex among PLWHA and decreased concerns about HIV transmission with the availability of HAART or lower perceived control over condom use.*

Counseling and testing: the voluntary process of client-centered, interactive information sharing in which an individual learns basic information about HIV/AIDS, testing procedures, how to prevent the transmission and acquisition of HIV infection, and takes a test.

Counseling, testing, referral, and partner notification (CTRPN): voluntary HIV/AIDS counseling and testing, referral to appropriate medical and social services, and anonymous or confidential notification of sex or needle-sharing partners by health department staff.

Cultural competence: the knowledge, understanding, and skills to work effectively with individuals from differing cultural backgrounds.

Disclosure: defined as the act or process of revealing or uncovering something. In the case of HIV/AIDS, this refers to an individual revealing whether he/she is HIV positive.

Discrimination: HIV/AIDS-related discrimination is characterized by prejudiced or prejudicial outlook, action or treatment of people infected and affected by, and at risk for, the virus.

Epidemic: the spread of an infectious disease through a population or geographic area.

Epidemiologic profile: a description of the current status, distribution, and impact of an infectious disease or other health-related condition in a specified geographic area.

Epidemiology: the study of factors associated with health and disease and their distribution in the population.

Group-level interventions (GLI): health education and risk-reduction counseling that shifts the delivery of service from the individual to groups of varying sizes. These use peer and non-peer models involving a wide-range of skills, information, education, and support.

Health education and risk reduction interventions (HE/RR): organized efforts to reach people at increased risk of becoming HIV-infected or, if already infected, of transmitting the virus to others. The goal is to reduce the risk of infection. Activities range from individual HIV prevention case management to broad community-based interventions.

Highly Active Antiretroviral Therapy (HAART): the name given to treatment regimens to aggressively suppress viral replication and progress of HIV disease. The usual HAART regimen

combines three or more different drugs in various combinations. These treatment regimens have been shown to reduce the amount of virus so that it becomes undetectable in a patient's blood.

Human Immunodeficiency Virus (HIV): HIV is the virus that causes AIDS. Persons with HIV in their system are referred to as HIV infected or HIV positive.

Implementation: putting into effect a precise plan or procedure (e.g., collecting information about the interventions identified in the HIV prevention comprehensive plan).

Incidence: the number of new cases of a disease diagnosed in a defined population in a specified period, often a year.

Incidence rate: the number of diagnoses of new cases of a disease diagnosed in a defined population in a specified period, divided by that population. It is often expressed per 100,000 population.

Individual-level interventions (ILI): health education and risk-reduction counseling provided to one person at a time. ILIs assist clients in making plans to change individual behavior and to appraise regularly their own behavior. These interventions also facilitate linkages to services in both clinic and community settings (i.e., substance abuse treatment settings) in support of behaviors and practices that prevent transmission of HIV. Interventions also help clients plan to obtain these services.

Injection drug users (IDU): people who are at risk for HIV infection through the shared use of equipment used to inject drugs with an HIV-infected person (e.g., syringes, needles, cookers, spoons).

Key informant interview: an information collection method involving in-depth interviews with a few individuals carefully selected because of their personal experiences and/or knowledge. An interview guide or checklist guides the discussion.

Men who have sex with men (MSM): men who have sexual contact with other men (i.e., homosexual contact or bisexual contact).

Morbidity: the condition of being diseased or sick; also the incidence of disease or rate of sickness.

Mortality: the ratio of deaths in an area to the population of that area; commonly expressed per 1000 per year.

Non-Sterile Injection: refers to re-using and sharing needles, syringes or other equipment for preparing and injecting drugs. This form of drug injection represents a highly efficient way of HIV transmission.

Outcome evaluation: the use of rigorous methods to assess whether the prevention program has affected the predetermined set of goals. This rules out factors that might otherwise appear responsible for the changes. For example, outcome evaluation determines whether a particular intervention had a desired effect on the targeted population's behavior — typically whether the intervention made a difference in knowledge, skills, attitudes, beliefs, behaviors, or health outcomes.

Outreach: HIV/AIDS educational interventions generally conducted by peer or paraprofessional educators face-to-face with high-risk individuals in the clients' neighborhoods or other areas where clients typically congregate. Outreach usually includes distribution of condoms, bleach, sexual responsibility kits, and educational materials.

Partner counseling and referral services (PCRS): a systematic approach to notifying sex and needle-sharing partners of HIV-positive people of possible exposure to HIV so the partners can avoid infection or, if already infected, can prevent transmission to others. PCRS help partners gain early access to individualized counseling, HIV testing, medical evaluation, treatment, and other prevention services.

Perinatal: refers to events that occur at or around the time of birth (i.e., transmission of HIV/AIDS between mother and child at birth).

Prevention burnout: refers to the difficulty that individuals have in maintaining safe behaviors over a lifetime. In the context of HIV/AIDS, failing to practice safe sexual behaviors increases the risk of HIV transmission.

Prevention case management (PCM): client-centered HIV prevention activity with the fundamental goal of promoting the adoption of HIV risk-reduction behaviors by clients with multiple, complex problems and risk-reduction needs. PCM is a hybrid of HIV risk-reduction counseling and traditional case management that provides intensive, ongoing, and individualized prevention counseling, support, and service brokerage.

Prevention with positives: refers to the use of any of these strategies with persons already infected with HIV in order to prevent transmission to others and to support HIV-positive individuals in living safely.

Process monitoring: a descriptive assessment of the implementation of program activities — what was done, to whom, how when, and where. It involves assessing such things as an intervention's conformity to program design, how it was implemented, and the extent to which it reached the intended audience.

Prophylaxis: treatment to prevent the onset of a particular disease or the recurrence of symptoms in an existing infection that has been brought under control.

Public health surveillance: the continuous, systematic collection, analysis, and interpretation of data essential to the planning, implementation, and evaluation of public health practice; closely integrated with the timely dissemination of these data to those responsible for prevention and control.

Qualitative data: data presented in narrative form, describing and interpreting the experience of individuals or groups. Example: a focus group report relating the experience of Hispanic teens in getting HIV prevention services.

Quantitative data: data reported in numerical form. Example: the numbers of reported AIDS cases by population group and method of transmission, provided by CDC in its AIDS Surveillance reports.

Rapid Testing: a rapid test for detecting antibody to HIV is a screening test that produces very quick results, usually in 20 minutes.

Referral: a process by which an individual or client is connected with a provider who can serve that person's need (usually in a different agency). For example, individuals with high-risk behaviors and those infected with HIV are guided towards prevention, psychosocial, and medical resources needed to meet their primary and secondary HIV prevention needs.

Re-infection: refers to the possibility of an HIV positive individual becoming re-infected with the virus, sometimes a different strain of HIV, through high-risk behavior.

Relapse: refers to a falling back into a “former state”, especially after apparent improvement. For example, demonstrating high-risk behaviors, such as injection drug use, after a period of not injecting drugs.

Risk factor or risk behavior: whatever places a person at risk for disease. For HIV/AIDS, this includes such factors as sharing injection drug use equipment, unprotected male-to-male sexual contact, and commercial unprotected sex.

Seroconversion: the development of antibodies to a particular antigen. When people develop antibodies to HIV, they seroconvert from antibody-negative to antibody-positive. It may take from as little as one week to several months or more after infection with HIV for antibodies to the virus to develop. After antibodies to HIV appear in the blood, a person should test positive on antibody tests.

Serodiscordant: being a couple in which one partner has tested positive for HIV and the other has not.

Serostatus: results of a blood test for specific antibodies; testing either seropositive or seronegative to HIV antibody test.

Social Marketing: seeks to “sell ideas” and influence social behaviors to benefit the target audience and the general society. Commonly used in public health and other social change campaigns.

Sociometric Risk Networks: refers to large social networks among individuals who practice high-risk behaviors. These networks and the relationships of members can affect both the spread of HIV (and other infections) and influence behaviors.

Stigma: refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV/AIDS, and the individuals, groups, and communities with which they are associated.

Syphilis: a sexually transmitted disease resulting from infection with the spirochete (a bacterium), *Treponema pallidum*.

Target populations: groups of people who are the focus of HIV prevention efforts because they have high rates of HIV infection and high levels of risky behavior. Groups are often identified using a combination of behavioral risk factors and demographic characteristics.

Transmission categories: in describing HIV/AIDS cases, same as exposure categories; how an individual may have been exposed to HIV, such as injection drug use, MSM, and heterosexual contact.

