

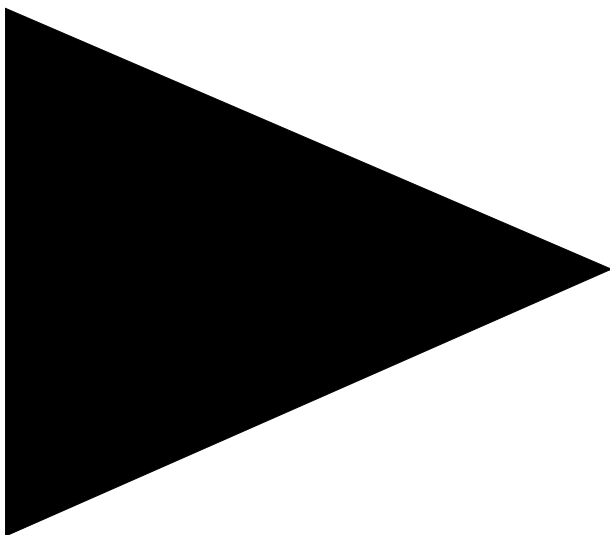
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# *HIV PREVENTION CASE MANAGEMENT*

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## **Guidance**

**September 1997**



**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
**Public Health Service**  
Centers for Disease Control and Prevention  
National Center for HIV, STD, and TB Prevention





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**Centers for Disease Control and  
Prevention**

**Department of Health and  
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## **ABBREVIATIONS AND ACRONYMS**

|               |   |
|---------------|---|
| <b>AIDS</b>   | Acquired immunodeficiency syndrome              |
| <b>CBO</b>    | Community-based organization                    |
| <b>CDC</b>    | Centers for Disease Control and Prevention      |
| <b>HIV</b>    | Human immunodeficiency virus                    |
| <b>HRSA</b>   | Health Resources and Services Administration    |
| <b>MSM</b>    | Men who have sex with men                       |
| <b>NCHSTP</b> | National Center for HIV, STD, and TB Prevention |
| <b>PCM</b>    | Prevention case management                      |
| <b>STD</b>    | Sexually transmitted disease                    |
| <b>TB</b>     | Tuberculosis                                    |



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# 1.0 INTRODUCTION

## 1.1 HISTORY

This guidance is offered to assist state and local health department human immunodeficiency virus (HIV) prevention cooperative agreement grantees and directly funded community-based organization (CBO) grantees in planning, implementing, and evaluating HIV prevention case management (PCM). The Centers for Disease Control and Prevention (CDC) provides funding for individual-level, health education and risk-reduction activities, which include PCM. Previous guidelines for PCM are published in *Guidelines for Health Education and Risk-Reduction Activities*, U.S. Department of Health and Human Services, April 1995. This revised guidance supersedes the 1995 PCM guidelines by further detailing essential components and protocols for PCM programs. (A glossary of terms is provided in Appendix A to assist the reader.)

HIV PCM is a client-centered prevention activity, which assists HIV seropositive and seronegative persons in adopting risk-reduction behaviors. PCM is intended for persons having or likely to have difficulty initiating or sustaining practices that reduce or prevent HIV transmission and acquisition. PCM provides intensive one-on-one prevention counseling and support. In addition, PCM provides assistance in accessing needed medical, psychological, and social services that affect clients' health and ability to change HIV-related risk-taking behavior.

Important issues have emerged from the experiences of those implementing the first PCM programs. As a result of questions about

the range of services appropriate for PCM, the type and extent of counseling, and staffing qualifications, CDC staff believe revising programmatic guidance for this activity is important. This guidance provides minimum standards for PCM programs. Individual jurisdictions may develop more specific PCM standards for their own locale that go beyond the minimum standards specified in this document.

These standards and guidance for PCM were established after consultation among experts from HIV prevention programs, academia, and CDC. This revised guidance is also based on a literature review of the existing research (CDC 1997) and a systematic review of PCM programs [Purcell, DeGroff, and Wolitski, Submitted for Publication]. The experiences of organizations implementing PCM over the past three to five years have provided valuable information on which to base this revised guidance. Little outcome evaluation of PCM has been conducted; therefore, CDC bases this guidance, in part, on the review of research of other case management models.

## 1.2 TENETS OF PCM

This guidance is based on the following tenets and assumptions:

- HIV primary prevention – preventing the transmission or acquisition of HIV – is the fundamental goal of PCM.
- Early identification of HIV infection enables individuals to make informed decisions about their own health.

- Self-determination and self-sufficiency are primary goals when working with clients.
- High standards for PCM will improve the outcomes for clients.
- PCM is guided by the same broadly accepted professional standards adhered to by other human service professionals such as social workers, counselors, and clinical psychologists.

### 1.3 STANDARDS AND GUIDANCE

The standards and guidance in this document describe the core elements that are essential for success in planning, implementing, and evaluating a PCM program. They are provided to assist program planners in enhancing their PCM programs and state and local health department personnel who are funding PCM programs. Agencies receiving CDC funds to support PCM program(s) should follow the standards and guidance contained within this document. Agency staff interested in diverting from this guidance should first seek the advice of their state or local health department or CDC project officer. Organizations using funds other than CDC monies to support PCM activities should consider using this document as a guide.

The two levels of recommendations this document provides are as follows:

**Standards** Specific standards are provided in several sections (boxed text). These standards are intended to be consistently applied to the delivery of PCM services. They must be followed in virtually all cases. Appendix B pro-

vides a comprehensive listing of all PCM standards.

**Guidance** The main text of this document provides overall program guidance in developing, implementing, and evaluating PCM programs. The overall guidance is intended to be more flexible and should be followed in most cases. CDC recognizes that, depending on the client population, setting, and other factors, the overall guidance can and should be tailored to fit individual program needs.

### 1.4 GOALS OF PCM

The goals of a PCM program are as follows:

- To provide specialized assistance to persons with multiple and complex HIV risk-reduction needs;
- To provide individualized, multiple-session HIV risk-reduction counseling to help initiate and maintain behavior change to prevent the transmission or acquisition of HIV;
- To assess risks of other sexually transmitted diseases (STDs) and ensure appropriate diagnosis and adequate treatment;
- To facilitate referral services for clients' medical and psychosocial needs that affect their health and ability to change HIV-related risk-taking behavior; and
- To provide information and referrals for HIV secondary prevention needs of persons living with HIV or acquired immunodeficiency syndrome (AIDS).

## 2.0 DEFINING PCM

### 2.1 WORKING DEFINITION OF PCM

PCM is a client-centered HIV prevention activity with the fundamental goal of promoting the adoption and maintenance of HIV risk-reduction behaviors by clients with multiple, complex problems and risk-reduction needs. PCM is intended for persons having or likely to have difficulty initiating or sustaining practices that reduce or prevent HIV acquisition, transmission, or reinfection. As a hybrid of HIV risk-reduction counseling and traditional case management, PCM provides intensive, on-going, individualized prevention counseling, support, and service brokerage. This HIV prevention activity addresses the relationship between HIV risk and other issues such as substance abuse, STD treatment, mental health, and social and cultural factors.

Priority for PCM services should be given to HIV seropositive persons having or likely to have difficulty initiating or sustaining practices that reduce or prevent HIV transmission and reinfection. For HIV seropositive persons, PCM involves the coordination of primary and secondary prevention interventions in close collaboration with Ryan White CARE Act case management providers (See Appendix C for fact sheet on Ryan White CARE Act). Further, PCM ensures the provision of other medical and psychosocial services affecting risk behavior, including STD and substance abuse treatment services.

HIV seronegative persons, or those of unknown HIV serostatus – either (1) engaging in high-risk behavior within communities with moderate to high seroprevalence rates of HIV

infection or (2) otherwise at heightened risk of infection – may also be appropriate for PCM.

PCM includes the following seven essential components (See Section 4.2 for further details):

1. Client recruitment and engagement;
2. Screening and assessment (comprehensive assessment of HIV and STD risks, medical and psychosocial service needs – including STD evaluation and treatment, and substance abuse treatment);
3. Development of a client-centered “Prevention Plan;”
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.

### 2.2 DIFFERENTIATING PCM FROM OTHER HIV RISK-REDUCTION ACTIVITIES

PCM is conceptualized as a highly individualized and intensive HIV risk-reduction strategy. PCM is intended for persons at greatest risk of transmitting or acquiring HIV whose needs **are not** being effectively served

and whose behavior **is not** influenced by less intensive HIV prevention interventions, such as street outreach, group-level strategies, or HIV counseling and testing. PCM is considered an individual-level HIV prevention activity and does not typically include group or community-level strategies. Characteristics of PCM differentiate it from these other prevention activities. PCM characteristics include the following:

- The formal enrollment of “clients” into an on-going service guided by professional standards.
- The development of a formal relationship between a prevention case manager and a client, a relationship that is characterized by active, cooperative prevention planning, problem solving, counseling, and referral provision.
- In-depth, on-going, risk-reduction counseling that addresses specified behavioral objectives.

- The need for professional staff skills to conduct most functions of PCM, including assessment, prevention planning, and risk-reduction counseling.

These characteristics of PCM are in contrast to other prevention activities such as street and community outreach and risk-reduction groups in which staff or volunteers, often peers or paraprofessionals, may interact on a brief or limited basis with high-risk individuals. The relationship of PCM to other individual-level HIV prevention activities is illustrated in Figure 1.

Finally, PCM is likely to be more costly than most other HIV prevention activities that employ peers or paraprofessionals to reach larger numbers of people with less time-intensive, staff-intensive risk-reduction strategies (See Section 4.3 for more detail about staff qualifications). However, PCM is likely to be cost beneficial because it emphasizes serving persons with particular difficulty changing behavior and most likely to transmit or acquire HIV.





| Street Outreach                                 | HIV Counseling and Testing                    | Prevention Case Management           |
|---|---|--------------------------------------|
| <i>Low Intensity</i>                            | <i>Moderate Intensity</i>                     | <i>High Intensity</i>                |
| <i>Short Duration</i>                           | <i>Short Duration</i>                         | <i>Long Duration</i>                 |
| <i>Potential to Reach High Number of People</i> | <i>Reaches Moderate Number of People</i>      | <i>Reaches Low Number of Clients</i> |
| <i>Low Cost per Person</i>                      | <i>Moderate Cost per Person</i>               | <i>High Cost per Client</i>          |
| <i>Peers or Praparprofessional Staff</i>        | <i>Paraprofessional or Professional Staff</i> | <i>Primarily Professional Staff</i>  |

Figure 1. Relationship of PCM to other Individual-level HIV prevention activities.

### 2.3 DIFFERENTIATING PCM FROM OTHER FORMS OF CASE MANAGEMENT

Case management is widely acknowledged to be an important psychosocial strategy with potential for addressing a wide range of social ills (Rothman 1992). **The fundamental principles underlying case management services are that case managers (1) facilitate linking clients to the complex delivery system and (2) help to enable clients, through psychosocial interventions, to benefit from appropriate services.** For persons living with HIV and AIDS, case management has emerged as the prominent strategy for coordinating the wide range of needed health care, psychiatric,

psychosocial, and practical support services (Mor, Piette, and Fleishman 1989). Although researchers and clinicians have been unable to agree on one widely accepted definition of case management (Baldwin and Woods 1994; Graham and Birchmore-Timney 1990; and Piette, Fleishman, Mor, and Dill 1990), most might agree with the following broad definition of case management:

"... the provision for some greater continuity of care through periodic contact between case manager(s) and the client that provides greater (or longer) coordination and brokerage of services than the client could be expected to obtain without case management" (Orwin et al. 1994, p. 154).

Although PCM also provides greater continuity of care, it is specifically focused on HIV-related behavior change. **PCM involves the identification of HIV risk behaviors and medical and psychosocial needs that influence HIV risk taking followed by the development of a client-centered Prevention Plan with specific behavioral objectives for HIV risk reduction.** Through both direct and facilitative service provision, PCM provides primary and secondary HIV prevention services and facilitates the provision of other medical and psychosocial services affecting risk behavior, including STD evaluation and treatment and substance abuse treatment. HIV primary prevention aims to reduce the transmission and acquisition of HIV infection, whereas HIV secondary prevention aims to prevent a person

living with HIV from becoming ill or dying as a result of HIV-related illness and opportunistic infections (Last and Wallace 1992).

The foundation of PCM involves multiple-session risk-reduction counseling in which a variety of strategies are applied by the prevention case manager to influence HIV risk behavior change. Like case management, prevention case managers broker needed medical and psychosocial services, specifically those that influence HIV risk-taking such as STD and substance abuse treatment, thereby providing more efficient coordination of services. For example, an injecting drug user may have difficulty benefiting from HIV risk-reduction counseling without receiving substance abuse treatment.

## 3.0 DEVELOPING AND PLANNING A PCM PROGRAM

### 3.1 ORGANIZATIONAL CONTEXT AND CAPACITY

Factors related to organizational context and capacity may influence the potential effectiveness of a PCM program. These factors include the organization's physical setting, staffing capacity and skills, referral tracking capabilities, and the availability of, and access to, local referral sources.

PCM may be implemented from a variety of institutional or community-based settings. A review of PCM programs suggests, however, that “stand-alone” PCM programs – those programs **independent** of other preventive, medical, or social services, for example, health care, substance abuse treatment, and residential housing – have had more difficulty recruiting and retaining PCM clients [Purcell, DeGroff, Wolitski, Submitted for Publication]. PCM programs that are well integrated within a larger continuum of drug treatment, STD treatment, health care, or other social services may be more effective in recruiting and retaining clients. Thus, agencies that provide a spectrum of services and have strong relationships and/or alliances with outside providers in the community may be well positioned to support a PCM program, whereas **“stand-alone” programs – those independent from other preventive, medical, or social services – are discouraged from considering a PCM program.**

Second, the skills and capacity of staff are especially important for many of the services

PCM programs provide. Prevention case managers require a broad array of sophisticated skills including assessment, prevention service planning, risk-reduction counseling, and crisis counseling. PCM targets those individuals with multiple, complex problems and risk-reduction needs; consequently, sophisticated skills are required of staff for some tasks (See Section 4.3 for more detail about staff qualifications).

Third, referral tracking systems, computerized or otherwise, should be implemented to evaluate the effectiveness of a PCM program's referral system. This implies a level of organizational capacity to establish and confidentially maintain such a system.

Finally, the case management literature suggests that giving consideration to the available network of community support programs is important (Rubin 1992). The effectiveness of case management in general is related to both the availability of referral sources in the community and to supportive structural factors in the agency itself and the larger community system (Rothman 1992). Therefore, agencies considering a PCM program should first assess the availability of community services relevant to the target population and then evaluate their ability to develop and implement referral systems.

All these factors should be considered in determining whether or not your agency and community has the capacity to effectively support a PCM program.

## 3.2 DEVELOPING AN ORGANIZATION'S PROGRAM PLAN FOR PCM

### 3.2.1 HIV Prevention Community Planning

In 1994, the 65 state and local health departments that received CDC federal funds for HIV prevention began a participatory HIV prevention planning process. The goal of HIV prevention community planning is to improve the effectiveness of HIV prevention programs by strengthening the scientific basis, targeting, and community relevance of HIV prevention interventions. Together, representatives of affected populations, epidemiologists, behavioral scientists, HIV/AIDS prevention service providers, health department staff, and others analyze the course of the epidemic in their jurisdiction, determine their priority prevention needs, and identify HIV prevention interventions to meet those needs. Community planning groups are responsible for developing comprehensive HIV prevention plans that are directly responsive to the epidemics in their jurisdictions.

To proceed in developing a PCM program, the intended target population and PCM as an intervention should be consistent with the HIV prevention priorities identified in a jurisdiction's comprehensive HIV prevention plan.

### 3.2.2 Needs Assessment

In developing and planning a PCM program, a needs assessment is an essential first step. The needs assessment will assist in (1) establishing

appropriate goals and objectives; (2) defining the purpose and scope of the program; (3) identifying social and behavioral attitudes, behaviors, and perceptions of the target community; (4) providing the basis for evaluation; and (5) establishing community-based support for the PCM program. This assessment should augment the epidemiologic profile and needs assessment described in the jurisdiction's comprehensive HIV prevention plan by providing additional, specific information needed for program design and implementation. These population characteristics will influence the range of PCM activities provided, the case manager's caseload, and recruitment and delivery strategies for a program. [More detailed information on conducting a needs assessment can be found in "Chapter 5: Assessing and Setting Priorities for Community Needs," *Handbook for HIV Prevention Community Planning*, Academy for Educational Development, April 1994. State and local health department program managers will also find information on conducting needs assessment in *Planning and Evaluating HIV/AIDS Prevention Programs in State and Local Health Departments: A Companion to Program Announcement 300*, Centers for Disease Control and Prevention, Reissued October 1996.]

### 3.2.3 Assessment of Community Resources

An assessment of community resources, including other HIV prevention programs and diagnosis and treatment services for substance abuse and for other STDs, is also essential – Results may influence the range of services provided by a PCM program and the skills needed by program staff. For instance, if a program is serving injecting drug users and few



substance abuse treatment and prevention services are available, having program staff who are well trained in a variety of harm-reduction strategies is important. In other words, a PCM program should be tailored to the needs and characteristics of the population to be reached as well as to the available community services.

### **3.2.4 Goals and Objectives**

A detailed program plan should be written that includes specific, time-phased, and measurable objectives for the PCM program. This plan should clearly define the goals and boundaries of the PCM program, including the roles to be assumed by prevention case managers. This has implications for staff training and resources. The plan should detail all parts of the PCM program including quality assurance and process evaluation measures.



## 4.0 IMPLEMENTING A PCM PROGRAM

### 4.1 CLIENT ELIGIBILITY

PCM is primarily intended for persons with multiple, complex problems and risk-reduction needs who are having or likely to have difficulty initiating or sustaining practices that reduce or prevent HIV acquisition, transmission, or reinfection. Priority for PCM services should be given to HIV seropositive persons. An agency may also serve HIV seronegative persons or those of unknown HIV serostatus if the individual identified for PCM is (1) a member of a community with moderate to high seroprevalence rates of HIV infection or (2) otherwise at heightened risk of HIV infection.

The following population groups are examples of those who may be appropriate for PCM, providing they meet the eligibility criteria just detailed (NOTE: This list is not exclusive nor exhaustive):

1. Persons recently identified as HIV-infected by counseling and testing sites or partner notification services;
2. Partners of HIV-infected persons identified through referral or partner notification services;
3. Clients in substance abuse treatment or injecting drug users out of treatment who are accessing syringe exchange or harm-reduction programs.
4. Men who have sex with men (MSM), including young MSM;

5. Adults and teens repeatedly infected with STDs, especially HIV-positive persons, identified at health or STD clinics;
6. Clients of tuberculous (TB) clinics;
7. Adults recently released from corrections facilities with a history of substance abuse; and
8. Discordant couples with inconsistent condom use.

PCM program staff should emphasize the benefits of participation to potential clients, including assistance in identifying and addressing barriers to HIV risk reduction and assistance in accessing health and social services. Although some persons may present with a variety of acute medical and psychosocial needs, **PCM is a voluntary service and should be reserved for individuals with a willingness to discuss their personal risk for HIV and to participate in HIV risk-reduction counseling on a regular basis.** A review of PCM programs suggests that HIV seropositive persons may have stronger interest in participating in PCM programs. This review also finds that engaging high-need clients in HIV prevention activities, regardless of HIV serostatus, is difficult [Purcell, DeGroff, Wolitski, Submitted for Publication].

### 4.2 ESSENTIAL COMPONENTS OF A PCM PROGRAM

Each of the seven essential components of a PCM program are described in detail in the following sections.

### 4.2.1 Client Recruitment and Engagement

Each PCM program must have a comprehensive plan that contains explicit protocols to recruit and engage clients for PCM. Making a PCM program well-known and visible for those persons the program intends to serve is important. Recruitment strategies might include (1) enlisting the assistance of a street outreach program serving a similar target population to identify potential PCM clients; (2) recruiting recently identified HIV seropositive persons from a counseling and testing site or partner notification service; or (3) recruiting clients from other programs such as an STD clinic, a women's health clinic, or a drug treatment pro-

gram. In some cases, programs have used various incentives (for example, bus tokens, hygiene kits, tee shirts, and so on) to enhance recruiting efforts [Purcell, DeGroff, Wolitski, Submitted for Publication].

Acting quickly and early in the PCM process is important. Research shows that effective outreach and intake efforts are associated with a quick response time and assertive follow-up, a fact that has important implications for successful client recruitment in case management (Rothman 1992). For example, to ensure initial engagement in PCM, a program may require staff to follow up with each client a minimum of three or four times within the first 30 days, two of which must be in person.

#### ***STANDARD FOR CLIENT RECRUITMENT AND ENGAGEMENT***

Protocols for client engagement and related follow-up must be developed, such as requiring a minimum number of follow-up contacts within a specified time period.

### 4.2.2 Screening and Assessment

To maximize staff resources, potential PCM clients must be initially screened to ensure their eligibility for the service. Screening may include assessing risk behavior, intention, or readiness to change risk behavior (Prochaska and DiClemente 1992; Ajzen and Fishbein 1980). Case managers should also assess, over the course of the first three to four PCM sessions, a client's willingness and ability to participate in HIV risk-reduction counseling. If

a potential client is found ineligible for PCM services, counseling and referrals relevant to their needs must be provided.

The need for a thorough assessment of clients' HIV, STD, and substance abuse risks, along with their medical and psychosocial needs, is essential for PCM. Assessment should identify behavioral factors that increase the risk for infection or transmission of HIV and other STDs. Assessment should also include the determination of whether or not the client has





been HIV antibody tested and the client's knowledge of his or her HIV serostatus. The case manager should engage the client in a discussion that enables the client to recognize and accept personal risk for HIV. A client-centered approach to assessment is essential – the approach should be thorough and individualized for each client. Case managers should develop effective interactive methods to involve the client in identifying risk behaviors.

To provide the case manager with a more complete understanding of each client's medical and psychosocial needs and the overall context in which HIV risk behavior occurs, the following items should be assessed: health; adherence to HIV-related treatment; STD history; substance and alcohol use; mental health; sexual history; social and environmental support; skills to reduce HIV risk; intentions and motivations; barriers to safer behaviors; protective factors, strengths, and competencies; and demographic information. When combined, assessment activities should yield a comprehensive picture of the client's HIV prevention needs (PROCEED, Inc. 1997).

Case managers must provide clients a copy of a voluntary informed consent document for signature at the time of assessment. This document must assure the client of confidentiality (See Section 6.0, Ethical and Legal Issues).

Potential areas for assessment include the following:

**Health** This assessment should address access to medical care; current or chronic health conditions; HIV serostatus; date of last HIV antibody test; history of HIV-related opportu-

nistic infections; date of last TB test; TB status; and, for women, date of last gynecological exam, birth control methods, and pregnancy history.

**Adherence to HIV-Related Treatment** For persons living with HIV and receiving drug treatment, the assessment should address issues related to adherence to HIV-related treatment. Although new antiretroviral therapies have shown tremendous clinical benefit, ongoing concerns about adherence to complicated drug regimens and the likelihood of antiretroviral drug resistance are serious issues that must be actively addressed by prevention case managers. Areas for assessment within this category include adherence to antiretroviral therapies, adherence to treatments for opportunistic infections, barriers to adherence, factors facilitating adherence, and ability and intention to follow complex treatment regimens.

**STD History** The prevention, diagnosis, and treatment of STDs other than HIV is an essential component of any PCM program. The sequelae of untreated STDs can be serious. Untreated chlamydia and gonorrhea are two major contributors to preventable tubal infertility. Furthermore, acute STDs, particularly those involving lesions on the skin or mucous membrane, facilitate the transmission of HIV. Therefore, clients' history and treatment of STDs should be assessed as well as the date of their last STD medical evaluation.

**Substance and Alcohol Use** A number of factors related to substance and alcohol use should be assessed including the following: history of injecting drugs, alcohol use, and other non-injecting drug use; drug(s) of choice;

frequency of use; route of administration; length of time using drugs/alcohol; frequency of needle sharing; treatment history; psychosocial context of drug/alcohol use; and affect of drug/alcohol use on sexual behavior. The potential relationship between substance use and unsafe sexual behaviors highlight the need for a comprehensive assessment of both injecting and non-injecting drugs.

**Mental Health** Several factors related to mental health should be considered including the following: family and personal mental health history; history of treatment, therapy, and hospitalization; adherence to treatment; suicidal ideation and history; and psychotropic medication history.

**Sexual History** A comprehensive sexual history is necessary to fully assess sexual risk behavior and related factors. Areas for assessment include number of sex partners; current partners (nature of relationships); HIV serostatus of partners; sexual behaviors practiced and frequency of behaviors; history of sexual abuse; role of alcohol and drugs during sex; involvement in sex in exchange for drugs/money/and so on; risk behaviors of partners; condom use, including barriers and facilitating factors for condom use; and knowledge of safer sex practices.

**Social and Environmental Support** Assessing key factors related to social and environmental support will provide a prevention case manager a more comprehensive picture of the context within which a client engages in risk behavior and of external factors potentially influencing risk behavior. Areas for assessment include the

following: living situation; economic status; sources of income; employment; in or out of school, if youth; emotional support sources; history of incarceration; significant others; and connections to the community, for example, friends, family, church, and service providers.

**Skills to Reduce HIV Risk** Prevention case managers should assess the level of client skills in areas such as the following: use of condoms; sexual assertiveness; use of needle and syringe sterilization methods; use of safer injecting skills; and communication and negotiation skills.

**Barriers to Safer Behavior** A careful assessment of clients' perceived barriers to safer behavior is essential. Potential barriers include the following: knowledge of risk associated with unprotected intercourse and using unclean shared filters, cookers, and rinse and diluent water; availability of, and willingness to use, condoms and sterile syringes and injection equipment; potential for violence; legal concerns; cognitive or perceptual barriers; and personal and/or cultural barriers – values and norms around sexuality, drug use, or gender roles that affect risk behavior.

**Protective Factors, Strengths, and Competencies** Resources and factors that facilitate client's ability to stay healthy and practice safer behaviors should be assessed.

**Demographic Information** Basic demographic information should be collected including age, gender, race/ethnicity, sexual orientation, and education.



### **STANDARDS FOR SCREENING AND ASSESSMENT**

PCM program staff must develop screening procedures to identify persons at highest risk for acquiring or transmitting HIV and who are appropriate for PCM.

All persons screened for PCM, including those who are not considered to be appropriate clients for PCM, must be offered counseling by the prevention case manager and referrals relevant to their needs.

Thorough and comprehensive assessment instrument(s) must be obtained or developed to assess HIV, STD, and substance abuse risks along with related medical and psychosocial needs.

All PCM clients must participate in a thorough client-centered assessment of their HIV, STD, and substance abuse risks and their medical and psychosocial needs.

Case managers must provide clients a copy of a voluntary informed consent document for signature at the time of assessment. This document must assure the client of confidentiality.

#### **4.2.3 Development of a Client-Centered Prevention Plan**

A written client-centered Prevention Plan, based on information compiled from the assessment, must be developed. **This plan should identify behavioral objectives to reduce the risk of acquiring or transmitting HIV that are time-phased, specific, and achievable.** Both short- and long-term goals should be established by the client with the assistance of the case manager. Client participation is key because many clients are well aware of their goals and what would help them meet those goals (Rothman 1992). A client-centered approach will ensure that the Prevention Plan is

responsive to the individual client's needs and circumstances. Therefore, prevention case managers should actively engage the client in setting behavioral objectives and identifying change strategies.

The Prevention Plan should identify effective change strategies that are reasonable and manageable for the client given his or her skills and circumstances. The Prevention Plan should specify **who** will be responsible for **what** and **when** (PROCEED, Inc. 1997). A high degree of specificity about the behaviors targeted for change, the interventions needed to implement change, and the expected outcomes should be included in the Prevention Plan.

For persons living with HIV and receiving medical treatments, secondary prevention interventions must focus on ensuring adherence to treatment for opportunistic infections and adherence to complex antiretroviral combination therapies. Secondary prevention interventions should also focus on maintaining the health of the client by ensuring the procurement of needed legal and entitlement services, treatment education, information on clinical care, and mental health services. The PCM Prevention Plan should detail the client's involvement, if eligible, in Ryan White CARE Act case management services along with other related programs or services. Further, the Prevention Plan should document efforts to ensure coordination and/or integration of PCM and Ryan White CARE Act case management.

The Prevention Plan must also outline efforts to ensure that a PCM client is medically evaluated for STDs at regular intervals regardless of symptom status. This will require that PCM programs establish a strong relationship and re-

ferred mechanism with local STD service providers. As noted earlier in this document, the sequelae of untreated STDs can be serious and include infertility.

For clients with substance abuse problems, the Prevention Plan must address referral to appropriate drug and/or alcohol treatment. This will require that PCM programs establish strong relationships with local substance abuse providers if these services are not provided in-house. As discussed earlier in this document, the relationship between substance use and unsafe sexual behavior highlights the importance for securing appropriate treatment for those who need it. Furthermore, a substance-abusing client benefiting from HIV risk-reduction counseling without having received substance abuse treatment is unlikely.

Finally, client files that include individual Prevention Plans must be maintained in a locked file cabinet to ensure confidentiality.



### **STANDARDS FOR DEVELOPMENT OF A CLIENT-CENTERED PREVENTION PLAN**

For each PCM client, a written Prevention Plan must be developed, with client participation, which specifically defines HIV risk-reduction behavioral objectives and strategies for change.

For persons living with HIV and receiving antiretroviral or other drug therapies, the Prevention Plan must address issues of adherence.

The Prevention Plan must address efforts to ensure that a PCM client is medically evaluated for STDs at regular intervals regardless of symptom status.

For clients with substance abuse problems, the Prevention Plan must address referral to appropriate drug and/or alcohol treatment.

Clients must sign-off on the mutually negotiated Prevention Plan to ensure their participation and commitment.

Client files that include individual Prevention Plans must be maintained in a locked file cabinet to ensure confidentiality.

#### **4.2.4 HIV Risk-Reduction Counseling**

##### **4.2.4.1 Client-Centered Counseling**

Client-centered HIV risk-reduction counseling (that is, reducing the risk of acquiring or transmitting HIV) is the foundation of PCM. Client-centered counseling refers to counseling conducted in an interactive manner responsive to individual client needs (U.S. Department of Health and Human Services, May 1994). With a focus on meeting the identified behavioral objectives specified in the Prevention Plan,

case managers must work with the client and apply a variety of strategies over multiple sessions to influence HIV risk behavior change. Depending on a client's readiness to change (Prochaska and DiClemente 1992), case managers should intervene to influence knowledge, perceived risk and vulnerability, intentions to change behavior, self-efficacy, skill levels, environmental barriers, relapse, and social support. Specific interventions for clients, regardless of HIV serostatus, may include skills building, individual counseling, couples counseling, crisis management, resource procurement, and preparation for referral of partners.

Counseling should be specifically tailored to the risk-reduction needs of each client. Table 1 summarizes factors that influence HIV risk behavior change (PROCEED, Inc. 1997 and Kelly 1992).

For persons of unknown HIV serostatus, interventions to prepare the client for HIV antibody testing may be appropriate. All clients must receive information regarding the potential benefits of knowing one's HIV serostatus. Counseling should explore barriers to testing faced by the client and seek to identify strategies to overcome these barriers. For individuals to make informed decisions about their health, early identification of HIV infection is important.

As part of client-centered counseling, PCM clients must be provided education about the increased risk of HIV transmission associated with other STDs and about the prevention of these other STDs. This counseling should also address the need for regular medical evaluation for STDs.

Finally, for seropositive clients, prevention case managers must discuss the notification of sex and needle-sharing partners who have been exposed to HIV. The purpose of notifying partners is to make them aware of their exposure to HIV and assist them in gaining access to counseling, testing, and other prevention and treatment services, including PCM, earlier in the course of infection (West and Stark 1997).

PCM program staff must develop a protocol for assisting seropositive clients in confidentially notifying partners and referring them to PCM and/or counseling and testing services. Two

major approaches to partner notification have traditionally been applied by STD and HIV programs. Patient referral, when the patient or client notifies and refers his or her own sex and/or needle-sharing partners for testing, and provider referral, when health professionals, usually from the health department, notify the patient's partners of their exposure. Protocols for partner notification, within the context of PCM, should address the need for this service and be implemented at PCM enrollment or at any time clients potentially expose others while participating in the PCM program.

When clients choose to notify their own partners, prevention case managers should provide them with needed counseling, support, and skill building to ensure the successful confidential notification and referral of partners. Prevention case managers may invite clients to bring their partners to a PCM session, once notified, to provide partner counseling and ensure appropriate referrals to testing. Referral for medical evaluation and treatment of other STDs should be offered to all partners.

If the PCM client is unable or unwilling to notify partners himself/herself, the prevention case manager may facilitate notification by eliciting partner names and locating information and then, with the client's permission, requesting health department officials to confidentially notify partners. This approach requires that PCM programs establish an explicit relationship with health department officials to jointly carry out partner notification services. PCM program staff should be familiar with the health department's procedures for confidentially notifying partners and explain this process to clients. Finally, PCM programs may

**Table 1. Factors That Influence HIV Risk Behavior Change**

| Factor  | Description   | Elements of Effective Intervention  |
|---|---|---|
| <b>Knowledge About Risk</b>                     | Accurate understanding of behaviors that confer risk, behavior changes needed to reduce risk, and the rationale underlying risk-reduction changes   | Clear identification of behavior practices that create risk; practical advice on behavior changes needed to reduce risk, taking into account the realities of the client’s lifestyle and relationships            |
| <b>Perceived Personal Vulnerability</b>         | Personalization of risk; believing oneself to be potentially vulnerable for contracting HIV/AIDS  | Discussion that accurately communicates the client’s risk level, encourages the client’s self-appraisal of risk, and induces realistic perception of threat   |
| <b>Behavior Change Intention</b>                | Readiness for change and committing oneself to risk-reduction effort  | Assessing, together with the client, his or her readiness for change and setting achievable risk-reduction goals through counseling and/or contracting  |
| <b>Self-Efficacy</b>                            | Believing oneself capable of successfully making risk-reduction behavior changes and perceiving that this change will protect against HIV/AIDS  | Assigning incremental risk-reduction “tasks” that can easily be accomplished to establish a sense of competency and a success record; counseling that challenges a client’s sense of fatalism                     |
| <b>Skill Level</b>                              | Behavioral competence in areas necessary for change implementation including condom use or other safer sex practices; sexual assertiveness skills to refuse risk pressures; safer sex negotiation skills; not sharing needles; use of clean needles; etc. | Skills training and practice; self-management or identification of patterns, habits, or activities that increase vulnerability to risk and development of alternative plan to address these behavioral “triggers” |
| <b>Reinforcement of Behavior Change Efforts</b> | Positive rather than negative outcomes associated with behavior change efforts, including positive partner response, self-praise, and reinforcement; belief that behavior change is consistent with peer group norms                                      | Follow-up counseling contracts that suggest and reinforce change efforts, discussion of problems encountered, and encouragement of self-praise of risk-reduction change   |
| <b>Environmental Barriers</b>                   | Experience fewer environmental constraints to perform a behavior rather than not to perform it  | Discussion of barriers to performing risk-reduction behaviors; development of strategies to overcome those barriers and to create easier access to the resources required to enact change                         |

Original table published by J. A. Kelly, “AIDS Prevention: Strategies That Work,” *AIDS Reader*, July/August 1992, pp. 135–141; adapted with permission from version published by PROCEED, Inc., *Standards and Considerations for Establishing HIV Prevention Case Management*, 1997.

refer the client directly to the health department for assistance. Regardless of the approach used, partners identified may benefit from PCM services and should be assessed to determine their eligibility for the service.

#### 4.2.4.2 Partner Counseling

Including the client's partner in risk-reduction counseling sessions is appropriate within the context of PCM.

#### 4.2.4.3 Secondary Prevention Counseling

Although PCM always involves primary prevention risk-reduction counseling, counseling related to secondary prevention for persons living with HIV is also appropriate within PCM. For instance, clients may need counseling support for accessing medical care and treatment. For persons receiving treatment for opportunistic infections and/or antiretroviral therapy(ies), counseling to support adherence to these treatments/therapies must be provided.

#### 4.2.4.4 Substance Abuse and Mental Health Counseling

Although the emphasis of PCM is on HIV risk-reduction counseling, in some instances, some substance abuse and/or mental health counseling may need to be provided. In fact, counseling about strategies to avoid or modify substance abuse behaviors can be a form of HIV risk-reduction counseling. Such counseling should only be provided by staff skilled in these areas. Referring clients with these counseling needs to agencies with specific expertise in substance abuse and mental health counseling is optimal. However, if such services are unavailable and PCM staff have appropriate skills, short-term counseling focused on immediate living problems may be appropriate. Rothman (1992) found that counseling provided within case management is more effective when focused on information sharing, problem solving, reality testing, and socialization skills. **PCM should not substitute for long-term therapy focused on long-standing personality issues or serious mental illness.**





### **STANDARDS FOR HIV RISK-REDUCTION COUNSELING**

Multiple-session HIV risk-reduction counseling aimed at meeting identified behavioral objectives must be provided to all PCM clients.

Training and quality assurance for staff must be provided to ensure effective identification of HIV risk behaviors and appropriate application of risk-reduction strategies.

Clients who are not aware of their HIV antibody status must receive information regarding the potential benefits of knowing their HIV serostatus.

Clients must be provided education about the increased risk of HIV transmission associated with other STDs and about the prevention of these other STDs.

PCM program staff must develop a protocol for assisting HIV seropositive clients in confidentially notifying partners and referring them to PCM and/or counseling and testing services.

For persons receiving treatment for opportunistic infections and/or antiretroviral therapy(ies), counseling to support adherence to treatments/therapies must be provided.

#### **4.2.5 Coordination of Services with Active Follow-Up**

The PCM program must establish a procedure for referring persons in a timely, efficient, and professional manner to sites providing services that may facilitate a client's ability to address and reduce his or her HIV risk behavior (for example, medical services, psychological treatment, substance abuse treatment, STD treatment, social services, and other HIV prevention services). Collaborative relationships

should be established with appropriate representatives of referral sites. PCM staff should **actively** assist clients in securing services at referral sites. Such assistance may include accompanying a client to an appointment, providing transportation services or bus/rail tokens, ensuring the provision of child-care services, ensuring translation or interpretation services, and providing client skills-building to support his/her ability to effectively advocate on behalf of himself/herself with other providers.

Effective coordination of services necessitates that PCM programs have current, accurate community provider information on hand. This information should include hours of operation, addresses, phone numbers, accessibility to public transportation, eligibility requirements, and information regarding materials required at application such as bringing a driver's license, birth certificate, and so forth.

Most PCM clients may be already receiving services from other providers. Therefore, coordination of services also involves collaboration with an individual client's other case managers

or counselors (for example, substance abuse counselor, Ryan White CARE Act case manager, probation officer, or housing or shelter supervisor). Such collaboration benefits the client and avoids duplication of services. Communication about an individual client with other providers is dependent upon the obtainment of **written, informed consent** from the client.

Finally, PCM program staff must have methods in place to follow up on referrals to assess the outcome, for example, whether or not the client received the needed service.



### ***STANDARDS FOR COORDINATION OF SERVICES WITH ACTIVE FOLLOW-UP***

Formal and informal agreements, such as memoranda of understanding, must be established with relevant service providers to ensure availability and access to key service referrals.

A standardized written referral process for the PCM program must be established.

Explicit protocols for structuring relationships and communication between case managers or counselors in different organizations is required to avoid duplication of services, for example, how to transfer or co-manage PCM clients with Ryan White CARE Act case management.

Communication about an individual client with other providers is dependent upon the obtainment of written, informed consent from the client.

A referral tracking system must be maintained.

Annual assessment of relevant community providers with current referral and access information must be maintained.

A mechanism to provide clients with emergency psychological or medical services must be established.

#### **4.2.6 Monitoring and Reassessing Clients' Needs and Progress**

Regular, structured meetings must be carried out between the prevention case manager and the client to assess the client's changing needs, monitor progress, and revise the Prevention Plan accordingly. In addition, HIV risk-reduction counseling must be provided at all appropriate opportunities. As mentioned previously, case managers should regularly inquire

about recent sex and needle-sharing partners of seropositive clients.

If partners were potentially exposed to HIV, steps should be taken as outlined in Section 4.2.5 to inform them and encourage their participation in PCM and/or counseling and testing services. Assessment of progress in meeting the Prevention Plan objectives should be communicated to the client for review and discussion. Home visits, if appropriate, may provide a valu-

able opportunity for case managers to gain a comprehensive impression of the client's social and environmental support. Individual meetings with a client must be reflected in the client's progress notes.

As individual client's progress in a PCM program and psychosocial needs are met, their needs may become less acute. Piette et al. (1992) describes the use of "high-" and "low-need" client categories with separate protocols for frequency and type of interaction to manage caseloads. Assigning individual prevention case managers a balance of new PCM clients (presumably higher need) and continuing clients

(lower need) may also reduce staff burn-out. Regardless of the staffing or triage system applied, monitoring ability is enhanced with a manageable caseload and adequate case records (Piette et al. 1992).

Retention of PCM clients is a concern (CDC 1997) [Purcell, DeGroff, Wolitski, Submitted for Publication]; therefore, program staff must define minimum levels of effort to reach clients for follow-up. For instance, a program should determine how many attempts – telephone calls, field visits, and so on – will be made before a client is made "inactive."

***STANDARDS FOR MONITORING AND REASSESSING  
CLIENTS' NEEDS AND PROGRESS***

Prevention case managers must meet on a regular basis with clients to monitor their changing needs and their progress in meeting HIV behavioral risk-reduction objectives. Individual meetings with a client must be reflected in the client's confidential progress notes.

A protocol must be established defining minimum, active efforts to retain clients. That protocol should specify when clients are to be made "inactive."

#### 4.2.7 Discharge from PCM Upon Attainment and Maintenance of Risk-Reduction Goals

In establishing a Prevention Plan, the prevention case manager and client will determine the appropriate time commitment for completing the plan. This will be based on client characteristics, needs, stated Prevention Plan objectives, and PCM activities provided.

PCM is a time-limited prevention activity intended to meet achievable behavioral objectives – identified by assessment and prevention planning – through counseling, service brokerage, and monitoring. **PCM is not intended to substitute for extended social services or psychological care.** Once the client has accomplished the behavioral objectives set forth in the

Prevention Plan, a determination must be made by the client and prevention case manager that the client is ready for discharge (for example, a client is made “inactive” or “graduates,” and PCM services are terminated). At the time of discharge, the prevention case manager, together with the client, should make every effort to ensure that the client is connected to needed resources and services.

In cases when the client has achieved his or her behavioral objectives, but actively experiences **relapse** to unsafe behaviors and faces on-going barriers to risk reduction, continuation of PCM services may be warranted. For these clients, PCM services may emphasize continued risk-reduction counseling.

**STANDARD FOR DISCHARGE FROM PCM UPON ATTAINMENT AND MAINTENANCE OF RISK-REDUCTION GOALS**

A protocol for client discharge must be established.

#### 4.3 STAFF QUALIFICATIONS

In considering staff qualifications, detailing the related PCM activities, such as assessment, prevention planning, and risk-reduction counseling, and defining appropriate levels of staff training and skills for each, may be valuable. Agency managers may choose to have professionally trained staff serve as prevention case

managers and carry out all PCM activities from recruitment and engagement through discharge. Other agency managers may apply a team approach to PCM, using both professionals and paraprofessionals. Paraprofessionals, under the supervision of a case manager, may be effective in assisting with functions such as recruitment, screening, and follow-up assistance to ensure coordination of care. Professionals may be

more appropriate for performing the functions of PCM requiring more sophisticated skills such as assessment, prevention planning, and HIV risk-reduction counseling. If a team approach is used, an explicit, structured means for professionals, paraprofessionals, and volunteers to communicate must exist. Staff qualifications, then, should be based on the skills required to complete the various PCM functions or activities. All staff must be knowledgeable of confidentiality laws and agency confidentiality policies and procedures.

The essential components of a PCM program along with **suggested minimum staff qualifications** can be grouped into the following two main categories:

1. **Essential Components** Client recruitment and engagement, screening, and coordination of services.

**Suggested Minimum Staff Qualifications**

Knowledge of target population; cultural and linguistic competence; knowledge of HIV, AIDS, and other STDs; knowledge of available community services; and effective communication skills.

2. **Essential Components** Assessment, development of a Prevention Plan, HIV risk-reduction counseling, monitoring and reas-

essment, on-going support and relapse prevention, graduation and discharge planning.

**Suggested Minimum Staff Qualifications**

A bachelor's degree or extensive experience in a human-services-related field, such as social work, psychology, nursing, counseling, or health education; skilled in case management and assessment techniques; skill in counseling; ability to develop and maintain written documentation (case notes); skill in crisis intervention; knowledgeable of HIV risk behaviors, human sexuality, substance abuse, STDs, the target population, and HIV behavior change principles and strategies; and cultural and linguistic competence.

PCM supervisors need the academic training and/or experience to adequately develop an overall PCM program, including PCM program goals and objectives, PCM protocols, and quality assurance and evaluation measures. PCM supervisors should also have management skills and experience overseeing case management staff. PCM program managers should provide an orientation to the PCM program for new workers and on-going supervision to ensure that the PCM intervention is clearly understood. On-going staff training and development is essential to build staff skills.



### STANDARDS FOR STAFF QUALIFICATIONS

Staff must be provided written job descriptions and opportunities for regular, constructive feedback. In addition, staff must be provided opportunities for regular training and development.

Organizations must hire case managers with the appropriate training and skills to complete the PCM activities within their job description.

All staff must be knowledgeable of confidentiality laws and agency confidentiality policies and procedures.

## 4.4 CASELOAD

Depending on client characteristics, needs, and PCM activities provided, an ideal caseload for a full-time prevention case manager may range from 20 to 35 clients (Rubin 1992). Caseload will vary based on the complexities of individual cases and the length of time clients are served. In service areas where fewer resources are available, prevention case managers may be expected to go beyond the HIV risk-reduction counseling and resource-linking roles and become providers of other direct services, if they have the appropriate skills. Such circumstances will decrease the number of clients each case manager can effectively serve.

When case managers deliver many direct services and/or when clients are younger, harder to engage in treatment, or more vulnerable to negative social forces such as poverty or homelessness, smaller caseloads are expected (Rubin 1992). Also, with smaller, more intensive caseloads, case managers may develop a more

therapeutic relationship with the client. In contrast, if case managers are working primarily with low-need clients, the caseload would be expected to be higher.

## 4.5 COORDINATION OF PCM WITH RYAN WHITE CARE ACT CASE MANAGEMENT

The Ryan White CARE Act funds case management services for persons living with HIV or AIDS to ensure coordination and continuity of needed entitlement, medical care and treatment, housing, and other social services (See Appendix C). Eligibility for Ryan White CARE Act case management services are established at the local level by Ryan White planning councils. Because of the obvious potential for service duplication between PCM and Ryan White CARE Act case management, explicit attention to coordination of these services is essential.

Foremost, PCM is intended as an HIV primary prevention activity (to reduce the transmission and acquisition of HIV infection) and must never duplicate Ryan White CARE Act case management services. However, PCM services may be integrated into Ryan White CARE Act case management. The integration of these two services will be influenced by the eligibility requirements for Ryan White CARE Act case management in a given community, the extent of primary HIV prevention provided by Ryan White CARE Act case managers, and the range of services provided by both case management

services. Together, a Ryan White Care Act case manager and a prevention case manager can determine which services are most appropriate to be provided by each. To ensure effective coordination between these two services, PCM program staff must establish explicit relationships for coordination and/or integration with Ryan White CARE Act case management providers in their jurisdiction and be knowledgeable of local Ryan White CARE Act case management eligibility criteria. Effective coordination of Ryan White case management and PCM services will benefit the client.

**STANDARDS FOR COORDINATION OF PCM  
WITH RYAN WHITE CARE ACT CASE MANAGEMENT**

An explicit protocol for structuring relationships with Ryan White CARE Act case management providers must be established and should detail how to transfer and/or share clients.

PCM must not duplicate Ryan White CARE Act case management for persons living with HIV, but PCM may be integrated into these services.



## 5.0 EVALUATION

### 5.1 QUALITY ASSURANCE

Quality assurance is essential to make certain that delivery of quality PCM services are consistent and to ensure that interventions are delivered in accordance with established standards. Project RESPECT, a study of HIV prevention counseling, emphasized quality assurance measures to maintain high performance expectations of staff and ensure consistent and comprehensive delivery of the counseling interventions (Kamb, Dillon, Fishbein, Willis, and Project RESPECT Study Group 1996).

For PCM, clear procedure and protocol manuals are necessary to ensure effective delivery of services and minimum standards of care. These manuals should address all the standards contained in this document (See Appendix B for concise list) and should be available to all staff. Written quality assurance protocols must be developed by PCM programs and should be included in procedure and protocol manuals. Client feedback should be routinely used as a factor in assessing the quality assurance of PCM services provided. Quality assurance mechanisms include the following:

- **Written Protocols** Descriptions of specific communication-related activities, such as protocols for client engagement and follow-up, screening, risk-reduction counseling, partner notification, and so forth.
- **Training** Training for supervisors and staff to ensure appropriate skills to complete the PCM activities within their job descriptions.
- **Individual Supervision** Regular review of each staff member's performance, productivity level, and quality of services provided.
- **Chart Reviews** Regular review of individual client's PCM assessment, Prevention Plan, and progress notes by the case management supervisor to ensure clear documentation and appropriate intervention.
- **Case Conferences and Presentations** Regular presentation of cases, especially those that are complex and difficult, by case managers to peers and supervisors to discuss a client's progress and strategies for intervention.
- **Peer Review** Regular review by a convened panel or peer group of performance and quality of services being delivered.
- **Client Satisfaction Surveys or Interviews** Routine feedback from clients about their satisfaction with the service, their concerns, and their ideas for improvement.
- **Independent Program Audits** Reviews and evaluations from panels of professionals from outside the agency on the quality of the program, including assurance that the program is delivering the services it is promoting. Special attention must be given to ensuring the confidentiality of clients when independent program audits are conducted.

### STANDARDS FOR QUALITY ASSURANCE

Clear procedure and protocol manuals for the PCM program must be developed to ensure effective delivery of PCM services and minimum standards of care.

Written quality assurance protocols must be developed and included in procedure and protocol manuals.

Client PCM records must contain a copy of the voluntary informed consent document and the Prevention Plan showing the client's signature.

## 5.2 PROGRAM EVALUATION

**All PCM programs should conduct process evaluation.** Process evaluation provides a descriptive assessment of a program's actual operation and the level of effort taken to reach desired results (that is, what was done, to whom, and how, when, and where). Process evaluation is intended for program improvement. Process evaluation measures may be both quantitative and qualitative in nature. Possible process evaluation measures for a PCM program include the following:

- Demographic information of clients,
- Risk profiles of clients,
- Health status of clients,
- Service referrals offered and followed through,
- Number and length of PCM sessions provided,

- Client satisfaction surveys, and
- Review of quality assurance measures.

Some programs may have the capacity to conduct outcome evaluation, the assessment of the immediate or direct effects of a program on the program participants (for example, the degree to which the program increased knowledge of HIV/AIDS, perceived risk of infection, and/or decreased intent of engaging in risk behaviors related to HIV transmission). Outcome evaluation also assesses the extent to which a program attains its objectives related to intended short- and long-term change for a target population. Agencies interested in conducting outcome evaluation are encouraged to involve program evaluation experts. To date, PCM programs generally have not been required or funded to conduct outcome evaluation.

[Additional information about program evaluation may be found in Chapter 8 of *Handbook for HIV Prevention Community Planning*, Academy for Educational Development, 1994. State and



local health department program managers may also consult "Planning and Evaluating HIV/AIDS Prevention Programs in State and

Local Health Departments: A Companion to Program Announcement 300," CDC, Reissued October 1996.]



## 6.0 ETHICAL AND LEGAL ISSUES

All of the following issues have critical ethical and legal implications for PCM programs.

### STANDARDS FOR ETHICAL AND LEGAL ISSUES

**Confidentiality** Organizations must have well-established policies and procedures for handling and maintaining HIV-related confidential information that conform to state and federal laws. These policies and procedures must ensure that strict confidentiality is maintained for all persons who are screened, assessed, and/or participate in PCM. Most states have well-established and stringent confidentiality laws specifically related to information about HIV/AIDS.

**Voluntary and Informed Consent** A client's participation must always be voluntary and with the client's informed consent. Documentation of voluntary, informed consent must be maintained in the client's file. In addition, a client's informed consent is required before a prevention case manager may contact another provider serving that same client.

**Cultural Competence** Organizations must make every effort to uphold a high standard for cultural competence, that is, programs and services provided in a style and format respectful of the cultural norms, values, and traditions that are endorsed by community leaders and accepted by the target population. Cultural appropriateness and relevance are critical to the success of any HIV prevention activity.

**Professional Ethics** PCM must be governed by the same general professional ethics that govern most human service fields such as social work, counseling, and clinical psychology (For example, Hepworth, D. H. and Larsen, J. 1986).

**Discharge Planning** Organizations must make efforts to ensure that clients have received appropriate referrals and are adequately receiving needed services at the time of discharge (graduation).

**Duty to Warn** Organizations must be familiar with state and local procedures/requirements related to duty to warn other individuals at risk or in physical danger.



## 7.0 TECHNICAL ASSISTANCE

CDC project officers in the Division of HIV/AIDS Prevention – Intervention Research and Support, National Center for HIV, STD,

and TB Prevention are available to provide technical assistance to grantees in interpreting and applying these guidance and standards.





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# APPENDIX A

## GLOSSARY

### **Client-Centered Counseling**

Client-centered counseling refers to counseling conducted in an interactive manner responsive to individual client needs. The focus is on developing prevention objectives and strategies with the client rather than simply providing information. An understanding of the unique circumstances of the client is required – behaviors, sexual identity, race/ethnicity, culture, knowledge, and social and economic status.

### **Cultural Competence**

In the context of PCM, services provided in a style and format respectful of the cultural norms, values, and traditions that are endorsed by community leaders and accepted by the target population.

### **Patient Referral**

In the context of notifying sex and needle-sharing partners, when the patient, that is client, notifies and refers his or her own partners for testing.

### **Provider Referral**

In the context of notifying sex and needle-sharing partners, when health professionals, usually from the health department, notify the patient’s partners of their exposure.

### **Medical and Psychosocial**

In the context of PCM, “medical” and “psychosocial” encompasses the medical, psychological, and social domains of an individual.

### **Outcome Evaluation**

Outcome evaluation involves the assessment of the immediate or direct effects of a program on the program participants, for example, the degree to which the program increased knowledge of HIV/AIDS, perceived risk of infection, and/or decreased intent of engaging in risk behaviors related to HIV transmission. Outcome evaluation also assesses the extent to which a program attains its objectives related to intended short- and long-term change for a target population.

|                                   |   |
|-----------------------------------|---|
| <b>Prevention Case Management</b> | PCM is a 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, on-going, and individualized prevention counseling, support, and service brokerage. |
| <b>Primary Prevention</b>         | The aim of primary prevention is to reduce the incidence of disease and injury (Last and Wallace 1992). As related to HIV prevention, the aim of primary prevention is to reduce the transmission and acquisition of HIV infection through a variety of strategies, activities, interventions, and services.  |
| <b>Process Evaluation</b>         | Process evaluation provides a descriptive assessment of a program's actual operation and the level of effort taken to reach desired results, that is, what was done, to whom, and how, when, and where.   |
| <b>Secondary Prevention</b>       | The aim of secondary prevention is to reduce the prevalence of disease and disability (Last and Wallace 1992). As related to HIV prevention, the aim of secondary prevention is to prevent a person living with HIV from becoming ill or dying as a result of HIV, opportunistic infections, or AIDS through a variety of strategies, activities, interventions, and services.                          |

# APPENDIX B

## STANDARDS FOR PCM PROGRAMS

### CLIENT RECRUITMENT AND ENGAGEMENT

- Protocols for client engagement and related follow-up must be developed, such as requiring a minimum number of follow-up contacts within a specified time period.

### SCREENING AND ASSESSMENT

- PCM program staff must develop screening procedures to identify persons at highest risk for acquiring or transmitting HIV and who are appropriate clients for PCM.
- All persons screened for PCM, including those who are not considered to be appropriate for PCM, must be offered counseling by the prevention case manager and referrals relevant to their needs.
- Thorough and comprehensive assessment instrument(s) must be obtained or developed to assess HIV, STD, and substance abuse risks along with related medical and psychosocial needs.
- All PCM clients must participate in a thorough client-centered assessment of their HIV, STD, and substance abuse risks and their medical and psychosocial needs.
- Case managers must provide clients a copy of a voluntary informed consent document for signature at the time of assessment. This document must assure the client of confidentiality.

### DEVELOPMENT OF A CLIENT-CENTERED PREVENTION PLAN

- For each PCM client, a written Prevention Plan must be developed, with client participation, which specifically defines HIV risk-reduction behavioral objectives and strategies for change.
- For persons living with HIV and receiving antiretroviral or other drug therapies, the Prevention Plan must address issues of adherence.
- The Prevention Plan must address efforts to ensure that a PCM client is medically evaluated for STDs at regular intervals regardless of symptom status.

- For clients with substance abuse problems, the Prevention Plan must address referral to appropriate drug and/or alcohol treatment.
- Clients must sign-off on the mutually negotiated Prevention Plan to ensure their participation and commitment.
- Client files that include individual Prevention Plans must be maintained in a locked file cabinet to ensure confidentiality.

### **HIV RISK-REDUCTION COUNSELING**

- Multiple-session HIV risk-reduction counseling aimed at meeting identified behavioral objectives must be provided to all PCM clients.
- Training and quality assurance for staff must be provided to ensure effective identification of HIV risk behaviors and appropriate application of risk-reduction strategies.
- Clients who are not aware of their HIV antibody status must receive information regarding the potential benefits of knowing their HIV serostatus.
- Clients must be provided education about the increased risk of HIV transmission associated with other STDs and about the prevention of these other STDs.
- PCM program staff must develop a protocol for assisting HIV seropositive clients in confidentially notifying partners and referring them to PCM and/or counseling and testing services.
- For persons receiving treatment for opportunistic infections and/or antiretroviral therapy(ies), counseling to support adherence to treatments/therapies must be provided.

### **COORDINATION OF SERVICES WITH ACTIVE FOLLOW-UP**

- Formal and informal agreements, such as memoranda of understanding, must be established with relevant service providers to ensure availability and access to key service referrals.
- A standardized written referral process for the PCM program must be established.





- Explicit protocols for structuring relationships and communication between case managers or counselors in different organizations is required to avoid duplication of services, for example, how to transfer or co-manage PCM clients with Ryan White CARE Act case management.
- Communication about an individual client with other providers is dependent upon the obtainment of written, informed consent from the client.
- A referral tracking system must be maintained.
- Annual assessment of relevant community providers with current referral and access information must be maintained.
- A mechanism to provide clients with emergency psychological or medical services must be established.

### **MONITORING AND REASSESSMENT OF CLIENTS' NEEDS AND PROGRESS**

- Prevention case managers must meet on a regular basis with clients to monitor their changing needs and their progress in meeting HIV behavioral risk-reduction objectives. Individual meetings with a client must be reflected in the client's confidential progress notes.
- A protocol must be established defining minimum, active efforts to retain clients. That protocol should specify when clients are to be made "inactive."

### **DISCHARGE FROM PCM UPON ATTAINMENT AND MAINTENANCE OF RISK-REDUCTION GOALS**

- A protocol for client discharge must be established.

### **STAFF QUALIFICATIONS**

- Staff must be provided written job descriptions and opportunities for regular, constructive feedback. In addition, staff must be provided opportunities for regular training and development.

- Organizations must hire case managers with the appropriate training and skills to complete the PCM activities within their job description.
- All staff must be knowledgeable of confidentiality laws and agency confidentiality policies and procedures.

### **COORDINATION OF PCM WITH RYAN WHITE CARE ACT CASE MANAGEMENT**

- An explicit protocol for structuring relationships with Ryan White CARE Act case management providers must be established and should detail how to transfer and/or share clients.
- PCM must not duplicate Ryan White CARE Act case management for persons living with HIV, but PCM may be integrated into these services.

### **QUALITY ASSURANCE**

- Clear procedure and protocol manuals for the PCM program must be developed to ensure effective delivery of PCM services and minimum standards of care.
- Written quality assurance protocols must be developed and included in procedure and protocol manuals.
- Client PCM records must contain a copy of the voluntary informed consent document and the Prevention Plan showing the client's signature.

### **ETHICAL AND LEGAL ISSUES**

- **Confidentiality**
  - ▶ Organizations must have well-established policies and procedures for handling and maintaining HIV-related confidential information that conform to state and federal laws.
  - ▶ These policies and procedures must ensure that strict confidentiality is maintained for all persons who are screened, assessed, and/or participate in PCM.



- ▶ Most states have well-established and stringent confidentiality laws specifically related to information about HIV/AIDS.

- **Voluntary and Informed Consent**

- ▶ A client's participation must always be voluntary and with the client's informed consent.
- ▶ Documentation of voluntary, informed consent must be maintained in the client's file.
- ▶ In addition, a client's informed consent is required before a prevention case manager may contact another provider serving that same client.

- **Cultural Competence**

- ▶ Organizations must make every effort to uphold a high standard for cultural competence, that is, programs and services provided in a style and format respectful of the cultural norms, values, and traditions that are endorsed by community leaders and accepted by the target population.
- ▶ Cultural appropriateness and relevance are critical to the success of any HIV prevention activity.

- **Professional Ethics**

- ▶ PCM must be governed by the same general professional ethics that govern most human service fields such as social work, counseling, and clinical psychology.

- **Discharge Planning**

- ▶ Organizations must make efforts to ensure that clients have received appropriate referrals and are adequately receiving needed services at the time of discharge (graduation).

- **Duty to Warn**

- ▶ Organizations must be familiar with state and local procedures/requirements related to duty to warn other individuals at risk or in physical danger.



# APPENDIX C

## RYAN WHITE CARE ACT PROGRAMS<sup>1</sup>

The Health Resources and Services Administration (HRSA) is one of eight agencies in the U.S. Department of Health and Human Services. Within HRSA four bureaus provide funding for the delivery of HIV/AIDS care, services (including case management), and training – the Bureau of Health Resources Development (BHRD), Bureau of Primary Health Care (BPHC), Bureau of Maternal and Child Health (MCHB), and Bureau of Health Professions (BHP).

Each of the four HRSA bureaus conducts programs to benefit low-income, uninsured, and underinsured individuals and families affected by HIV/AIDS through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. HRSA's AIDS Program Office (1) provides direction; (2) coordinates HIV/AIDS health care-related activities across the bureaus; and (3) works with other federal and state agencies, providers, and constituent groups to identify emerging issues and needs and to facilitate integrated, client-oriented HIV/AIDS services.

Signed into law on August 18, 1990, the Ryan White CARE Act was named after the Indiana teenager, Ryan White, who became an active public educator on HIV/AIDS after he contracted the disease. He died that same year. The act, which was amended in May 1996, provides assistance to improve the quality and availability of care for people with HIV/AIDS and their families.

HRSA administers HIV/AIDS programs under four titles and Part F of the act, which are described as follows:

**Title I – HIV Emergency Relief Grant Program for Eligible Metropolitan Areas** Title I is administered by BHRD's Division of HIV Services. This program provides formula and supplemental grants to Eligible Metropolitan Areas (EMAs) that are disproportionately affected by the HIV epidemic. For an area to be eligible, it must have a population of 500,000 or more and have reported more than 2,000 AIDS cases in the preceding 5 years.

**Title II – HIV Care Grants to States** Title II is also administered by BHRD's Division of HIV Services and provides formula grants to states, U.S. territories, the District of Columbia, and Puerto Rico to provide health care and support services for people with HIV/AIDS. Grants are awarded based on (1) the estimated number of living AIDS cases in the state or territory; and (2) the estimated number of living AIDS cases within the state or territory but outside of Title I EMAs (that is, outside an area with 500,000+ population and 2,000+ AIDS cases/previous 5 years). Additionally, grantees must provide therapeutics to treat HIV/AIDS under the AIDS Drug Assistance Program (ADAP).

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<sup>1</sup>Adapted, with permission, from HRSA's AIDS Program Office, "HRSA Fact Sheet," March 1997.

**Title III(b) – HIV Early Intervention Services** BPHC’s Division of Programs for Special Populations administers Title III(b) of the act through the Early Intervention Services Program. This program supports outpatient HIV early intervention services for low-income, medically underserved people in existing primary care systems. Medical, educational, and psychosocial services are designed to prevent the further spread of HIV/AIDS, delay the onset of illness, facilitate access to services, and provide psychosocial support to people with HIV/AIDS.

**Title IV – Coordinated HIV Services and Access to Research for Children, Youth, Women, and Families** Title IV is a special grant program directed by MCHB to coordinate HIV services and access to research for children, youth, women, and families in a comprehensive, community-based, family-centered system of care.

**Part F – Special Projects of National Significance Program** BHRD’s Office of Science and Epidemiology administers the Special Projects of National Significance (SPNS) Program to support the development of innovative models of HIV/AIDS care. These models are designed to address special care needs of individuals with HIV/AIDS in minority and hard-to-reach populations. Additionally, they are expected to be replicable and have a strong evaluation component. Integrated service delivery models were funded in Fiscal Year 1996 to create formal linkages to integrate health and support services.

**Part F – AIDS Education and Training Centers** Fifteen AIDS Education and Training Centers (AETCs) have been established under BHP. The AETCs are a national network of centers that conduct targeted, multidisciplinary education and training programs for health care providers in designated geographic areas. The AETCs increase the number of health care providers who are educated and motivated to counsel, diagnose, treat, and manage care for individuals with HIV/AIDS and to help prevent high risk behaviors that may lead to further HIV transmission.

**Part F – AIDS Dental Reimbursement Program** BHP also administers the AIDS Dental Reimbursement Program. This grant program assists accredited dental schools and post-doctoral dental programs with uncompensated costs incurred in providing oral health treatment to HIV-positive patients.

For additional information on the Ryan White CARE Act, contact

HRSA AIDS Program Office  
5600 Fishers Lane, Room 14A-21  
Rockville, MD 20857  
Phone: 301-443-4588  
Fax: 301-443-1551