
HIV PREVENTION CASE MANAGEMENT



Literature Review and Current Practice

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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**Department of Health and
Human Services**

Atlanta, Georgia

ACKNOWLEDGMENTS

We thank the CDC staff in the National Center for HIV, STD, and TB Prevention (NCHSTP) who have participated on the working group for this project.

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Jo Valentine, Epidemiology and Surveillance Branch, Division of Sexually Transmitted Disease Prevention

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Rich Wolitski, Behavioral Intervention Research Branch, DHAP

We also thank the 25 community-based organizations who graciously participated in interviews and shared their experiences, valuable insights, and ideas about the implementation of PCM programs. Thanks also go to the National Alliance of State and Territorial AIDS Directors (NASTAD), who assisted CDC by issuing a survey to 65 AIDS directors across the United States and its territories and to those states and cities that responded to the survey. Finally, we thank all the program consultants in the Community Assistance, Planning, and National Partnerships Branch, DHAP, NCHSTP, at CDC.

ABBREVIATIONS AND ACRONYMS

AIDS	Acquired immunodeficiency syndrome
AHSP	AIDS Health Services Program
CBO	Community-based organization
CDC	Centers for Disease Control and Prevention
DHAP	Division of HIV/AIDS Prevention
HERR	Health education and risk-reduction
HIV	Human immunodeficiency virus
HRSA	Health Resources and Services Administration
NASTAD	National Alliance of State and Territorial AIDS Directors
NCHSTP	National Center for HIV, STD, and TB Prevention
PCM	Prevention case management
STD	Sexually transmitted disease
TB	Tuberculosis

CONTENTS

<u>Item</u>	<u>Page</u>
1.0 INTRODUCTION	1
2.0 LITERATURE REVIEW	3
2.1 Case Management	3
2.1.1 Definitional Issues	4
2.1.2 Models	4
2.1.3 Core Components	5
2.1.4 Broad Services Provided by Case Managers	7
2.1.5 Key Questions	9
2.1.6 Education and Training of Case Managers	11
2.1.7 Evaluation	11
2.1.8 Conclusions	13
2.2 Ryan White or AIDS Case Management	14
2.2.1 Practice	15
2.2.2 Evaluation	16
2.2.3 Conclusions	17
2.3 Prevention Case Management	18
2.3.1 Published Literature	18
2.3.2 Conclusions	20
3.0 SUMMARY OF PCM PRACTICES IN 1996	23
4.0 SUMMARY	25
REFERENCES	27

ILLUSTRATION

1. Schematic Model of Intervention	6
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1.0 INTRODUCTION

Prevention case management (PCM) for human immunodeficiency virus (HIV) was funded originally by Centers for Disease Control and Prevention (CDC) in 1992 through cooperative agreements with community-based organizations (CBOs) (CDC, 1992). That same year, PCM was included for the first time as a health education and risk-reduction (HERR) activity in CDC's program announcement for state and local health departments. CDC HERR activities include a range of HIV prevention activities designed to motivate behavior change through outreach, counseling, and other approaches. In 1995, CDC published the first programmatic guidelines for PCM (CDC, 1995). In 1997, the National Center for HIV, STD, and TB Prevention, CDC, revised the guidelines for PCM (CDC, 1997).

This report summarizes a review of scientific literature on case management, acquired immunodeficiency syndrome (AIDS) case management, and PCM. The review was undertaken to support the revision of PCM guidelines, and it highlights many important lessons learned from the case management literature that should be considered in planning, implementing, and evaluating PCM programs. This document may help CDC grantees implement the revised PCM guidelines.

PCM is a time-limited behavioral intervention designed to assist HIV-seropositive and HIV-seronegative persons. It is intended for persons having, or likely to have, difficulty initiating and sustaining practices that limit the transmission and the acquisition of HIV. PCM, a hybrid of HIV risk-reduction counseling and case management, provides intensive, individualized support and prevention counseling. PCM comprises several essential components, including the assessment of clients' HIV and STD risk behavior and medical and psychosocial needs, risk-reduction counseling, and service brokerage. PCM is based on the premise

that some people may not be able to prioritize HIV prevention when they face problems perceived to be more important and immediate (Falck, Carlson, Price, & Turner, 1994). Furthermore, developing an ongoing relationship with each client provides an environment of trust and understanding within which prevention counseling can take place.

Because PCM is a relatively new type of HIV prevention activity, important questions emerged from the experiences of those implementing the first programs about the appropriate range of services for this intervention, the type and extent of counseling, staffing patterns and qualifications of staff, quality assurance measures, and evaluation methods. These questions persisted despite the existence of guidelines (CDC, 1995). In 1996, CDC staff began a guideline revision process comprising the following activities:

- Review and synthesis of relevant scientific literature
- Structured interviews with 25 CBOs that conduct PCM
- Survey of 32 health departments about PCM
- Site visits to 7 CBOs with PCM programs
- A meeting with consultants from nongovernment organizations, health departments, and academic institutions

This document complements the new programmatic guidelines for PCM that emerged from these activities (CDC, 1997) and is divided into two sections: Literature Review (Section 2.0) and Summary of PCM Practices in 1996 (Section 3.0). Section 2.1 provides a description of the theoretical underpinnings of case management. Then, AIDS

case management, which is funded primarily by the Health Resources Services Administration (HRSA), is described briefly in Section 2.2. Finally, the available literature on PCM is examined in Section 2.3. In Section 3.0, a brief summary of the results of interviews and site visits with PCM projects directly funded by CDC is provided as well as a summary of survey results from various state, territorial, and city health departments. A more detailed review of the

results of the surveys, interviews, and site visits is provided elsewhere (Purcell, DeGroff and Wolitski, submitted for publication). The literature review and practice data presented here and elsewhere greatly enhanced the guideline revision process. Hopefully, this document also will provide useful background information for agencies implementing PCM programs.

2.0 LITERATURE REVIEW

HIV prevention case management is a hybrid intervention derived from individual HIV risk-reduction interventions and case management. Individual-level HIV interventions have been effective in changing risk behavior (Choi & Coates, 1994; Kalichman, Carey, & Johnson, 1996). Individual interventions have reduced HIV risk behavior in a variety of populations, for example, adolescent and adult heterosexuals, gay and bisexual men, and adults with serious and persistent mental illness. Furthermore, these intervention strategies have worked in a variety of settings such as counseling and testing sites, methadone maintenance clinics, and shelters. For example, a recently completed CDC study of heterosexual STD clinic patients found significant decreases in STD rates for persons receiving either a two-session or a four-session client-focused counseling intervention (Kamb et al., 1997). Behavioral interventions also have facilitated change in areas other than HIV, such as smoking, diet, exercise, and adherence to treatment for tuberculosis and other diseases.

In addition to individual-level HIV interventions, case management is widely acknowledged to be an important intervention with the potential to address a wide range of social ills (Rothman, 1992). Since the 1970s, when case management first became widely used for persons with serious mental illness, it has been applied to an increasingly broad array of populations to address an increasing variety of problems (Falck et al., 1994). By adding a case management component to HIV risk-reduction interventions for persons having, or very likely to have, difficulty initiating and sustaining safer behavior, CDC posited that risk-reduction efforts might be more effective.

Because little research or writing exists on the relatively new prevention activity called PCM, the

literature on case management and AIDS case management is particularly relevant. AIDS case management is an interrelated system of services provided to HIV-seropositive persons to promote adaptive coping and improve their access to medical and other supportive services. The literature reviews of case management and AIDS case management presented here are not intended to be exhaustive. The focus throughout is on research findings most relevant for PCM.

2.1 CASE MANAGEMENT

The concept of case management as a way to coordinate services in a given community came from public health nursing and social work in the early 1900s (Sowell & Meadows, 1994). Over time, case management has become a more refined intervention to address the difficulties posed by the fragmentation and partial funding of services for persons who need long-term support and services (Baldwin & Woods, 1994). Traditionally, case management has been provided to persons who need extended, or even life-long care, such as people with serious mental illnesses or chronic medical conditions, abused and neglected children, the elderly, and those who are developmentally disabled (Rothman, 1992).

Case management has a different implementation history for each of these populations; yet commonalities exist for each group – namely, that case managers face clients with debilitating, long-term difficulties in a fragmented, ever-changing, and increasingly restrictive community service system (Rothman, 1992). For example, from the 1950s to 1970s, when many patients with severe mental illness were deinstitutionalized, case managers were enlisted to coordinate their extended

care needs so that patients could be maintained in the community. However, resources that had maintained patients in the hospital were not transferred to community-based programs, leaving case managers with the difficult task of trying to coordinate the few existing services for these clients and extract services from fiscally strained community agencies (Rothman, 1992).

2.1.1 Definitional Issues

Although case management is an important intervention, case management is “indistinct and amorphous,” and many disagree about the practice of it (Rothman, 1992, p. 1). Researchers and clinicians have been unable to agree on one widely accepted definition of case management (Baldwin & Woods, 1994; Graham & Birchmore Timney, 1990; Piette, Fleishman, Mor, & Dill, 1990). This lack of clarity may be attributed to the two potentially divergent social goals of case management: (1) coordinating and maximizing resources for clients, and (2) containing costs of extended care (Brennan & Kaplan, 1993). Managed health care is a form of case management that focuses primarily on cost control. In contrast, many of the AIDS case management programs that have developed in CBOs across the country focus on maximizing access to resources for their clients, relegating cost control to a secondary goal (Cruise & Liou, 1993). Therefore, an inherent tension seems to exist between the gatekeeper function – ensuring that scarce resources go to the neediest – and the service advocate function – maximizing services for a client, regardless of overall systems needs (Piette, Fleishman, Mor, & Thompson, 1992). These potentially competing goals affect both program implementation and the evaluation of outcomes.

In the absence of a clear definition and protocol, agencies have tended to develop case management

programs or models that address a particular set of local issues or problems (Rothman, 1992). These models are likely to be influenced by organizational culture (Piette et al., 1990). For example, reportedly, if an agency’s goal is continuity of care and responsiveness to clients rather than cost containment, greater variability is observed in how case management is implemented (Graham & Birchmore Timney, 1990). Although the flexible definition of case management makes it an attractive intervention for addressing a variety of social ills, this means that no universally accepted case management models are available. Constructing case management guidelines and evaluating case management interventions are more difficult because of this definitional ambiguity (Graham & Birchmore Timney, 1990).

2.1.2 Models

Without consensus on a definition of case management, the development of a wide variety of case management models is not surprising (Orwin, Sonnefield, Garrison-Mogren, & Smith, 1994). Rubin (1992) listed at least 13 distinct models or variants of models. Other commentators highlight many different models or program features that distinguish the ways in which case management is practiced (Brennan & Kaplan, 1993; Holloway, Oliver, Collins, & Carson, 1995; Korr & Cloninger, 1991; Loomis, 1988; Rothman, 1991, 1992). For example, Thornicroft (1991) defined 12 dimensions along which case management programs might differ, such as type of care (direct care versus brokerage of services), target population, and point of contact (setting). A variety of case management programs or models can be developed by emphasizing different dimensions. However, research has not advanced to the point at which particular models can be said to be better than others (Rothman, 1992), and most researchers agree that



no case management model is appropriate in all settings with all populations.

2.1.3 Core Components

Although there is little consensus on a definition of case management or a single model of case management, a few common themes and core components of case management have emerged. Most commentators would agree with the broad definition of case management as

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)

Most commentators view case management as a “boundary spanning” activity (Rubin, 1987, p. 210) because it involves work with individuals and communities, from micro- to macrosystems (Rothman, 1991). In addition, case management clients are usually defined as those who have severe and chronic disabilities and who require long-term rather than acute treatment, and treatment is focused broadly on the client’s multiple needs. In other words, case management is cross-sectional (providing a broad array of services at one point in time) and longitudinal (striving to ensure that services extend over time to meet the client’s changing needs) (Rothman, 1992).

Generally, case management involves locating and pooling resources, sequencing and coordinating services and resources to respond to assessed needs, and monitoring the service delivery and service needs for a defined group of people (Baldwin & Woods, 1994; Loomis, 1988). No established procedure exists for providing the activities that may be

part of case management (Graham & Birchmore Timney, 1990). Although these activities have been grouped in many ways, the following six core case management tasks seem most relevant for PCM (Brennan & Kaplan, 1993; Intagliata, 1982; Piette et al., 1990; Rothman, 1991, 1992):

1. Client identification, outreach, and engagement
2. Medical and psychosocial assessment of need
3. Development of a service plan or care plan
4. Implementation of the care plan by linking with service delivery systems
5. Monitoring of service delivery and reassessment of needs
6. Advocacy on behalf of the client (including creating, obtaining, or brokering needed client resources)

Note that counseling usually is not considered a core case management task, although this controversy will be discussed further in the Section 2.1.5, “Key Questions.” Rothman (1991; Rothman & Sager, 1998) developed an empirically based model of case management that incorporates these six core functions. Figure 1 is a graphic representation of his model. Case management is represented by a flow diagram, whereas functions that take place intermittently during case management, such as interagency coordination, counseling, therapy, and advocacy, are outside the main flow of the model.

In conjunction with his model, Rothman (1992) developed an extensive set of generalizations and action guidelines for the practice of case management that were based on an extensive review of the research. Figure 1 reflects the first generalization

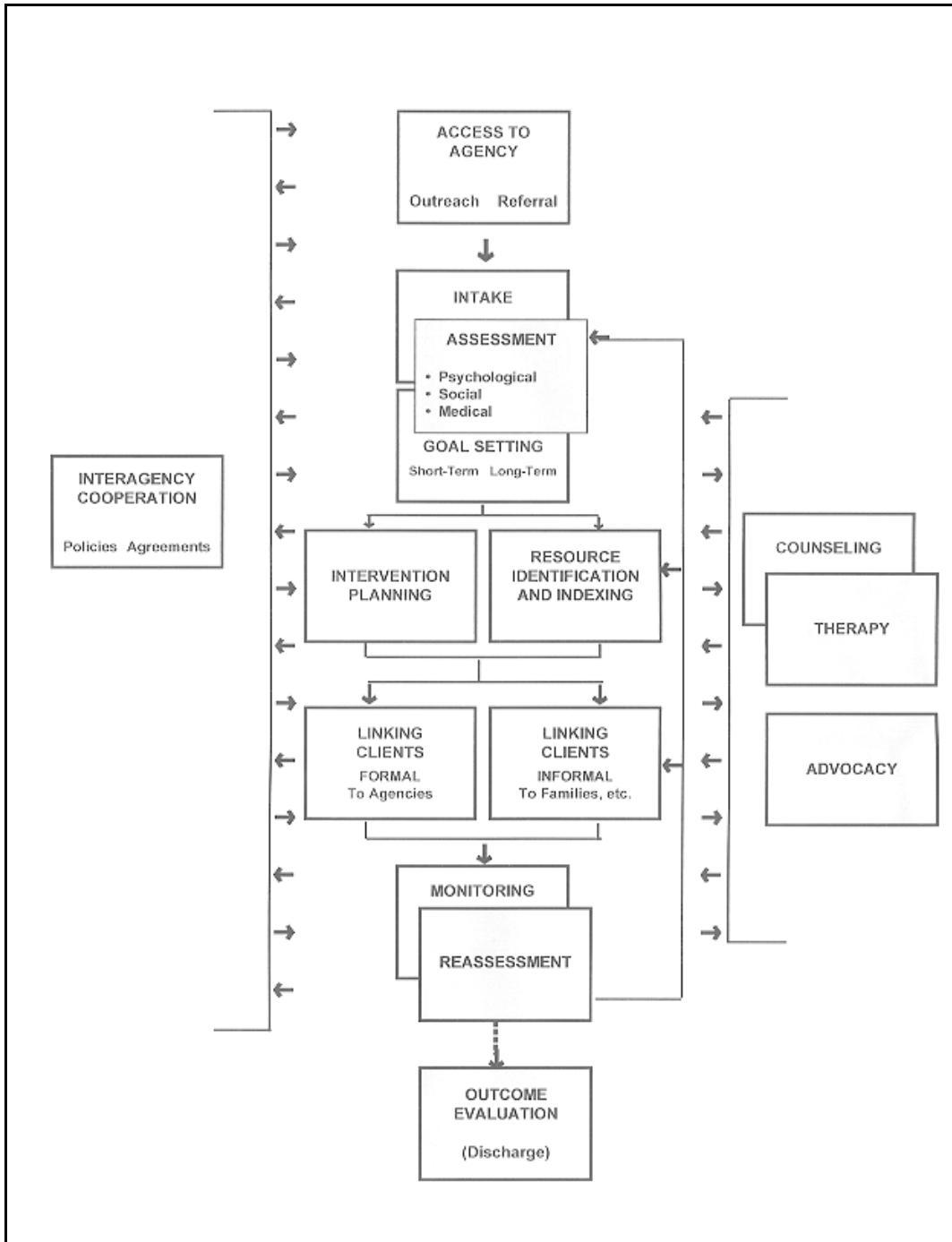


Figure 1. Schematic model of intervention (Rothman, 1991; Rothman & Sager, 1998; Reprinted with permission of Allyn & Bacon).



that emerged from the research: case management is, “a phased process with sequential functions that often overlap” (Rothman, 1992, p. 15). Although Rothman’s generalizations were developed from research and experience with clients who had severe mental illness, they have relevance for PCM as well.

2.1.4 Broad Services Provided by Case Managers

In trying to better understand and categorize the core tasks of case management (what case managers actually do), Lauber (1992) grouped case management tasks empirically by conducting a factor analysis of a questionnaire listing 100 tasks performed by case managers for patients with serious mental illness. The results revealed three primary factors that represent three types of services provided by case managers:

1. Individual-level or primary personal services – assessment, planning, treatment, and monitoring
2. Community-level or secondary personal services – advocacy, support, linkage to services, and networking
3. Interface services – client identification and outreach, administration, public relations, and education and training

Lauber (1992) noted that traditionally trained case managers are schooled in providing individual-level and community-level services, but they receive little training in public relations, organizational theory, and management, which would aid in providing interface services. The fact that case managers must use these types of “management” skills, for which they are seldom trained and that are distinct from individual- and community-level

service, has been emphasized by other commentators (Wolk, Sullivan, & Hartmann, 1994).

2.1.4.1 Case Management as an Individual-Level Activity

Rothman’s (1992) first generalization about case management as an individual-level activity is that “effective outreach and intake efforts are associated with a quick response time and assertive follow up” (p. 17). Thus, time is of the essence early in the process to bring clients into case management. Second, the need for a thorough assessment was found to be essential for case management practice (this has particular implications for the educational level of case managers and for staff development). Third, Rothman’s review found that “effective case management planning includes clients in the process” because many clients are already aware of their goals and what would help them meet those goals (p. 19).

Regarding linking clients to services, Rothman (1992) found that “effective case managers take an active and facilitative practice role in connecting clients with service agencies” (p. 20). As for the content of advice-giving, counseling, or therapy, Rothman found that it is more effective when it focuses on advice and information giving, problem solving, reality testing, and socialization skills rather than traditional intrapsychic therapy (Rothman, 1991, 1992). Because clients who are appropriate for case management programs generally have significant difficulties, it is not surprising that they benefit most from a present-focused, reality-based approach. Finally, Rothman’s guidelines indicate that client monitoring and evaluation are essential parts of case management, “because services are needed on a continuous and indeterminate basis” (1992, p. 22-23). These guide-

lines, developed from Rothman’s review of the research, highlight effective individual-level case management activities and practices.

2.1.4.2 Case Management as a Community-Level Activity

Because case managers often are aware of clients’ needs, they could be individual- and system-level advocates. Many programs, however, focus primarily on the client level (Graham & Birchmore Timney, 1990; Rothman, 1992). Barriers to systems-level advocacy by case managers include lack of power and fear of complaining about the system that employs them. In addition, because the activities of case managers are affected by the service system in which they operate, work setting may facilitate or inhibit community-level activities (Piette et al., 1990).

Rothman (1992) reported on several community-level factors that influence case management:

- Organizational base or setting, for example, case management provided as a free-standing service or a service within another program
- Degree of involvement in direct service provision
- Professional reference group of case managers, for example, mental health, medical, or health education professionals
- Target population
- Authority base, for example, control over funding and services

Although little research has been conducted on the relationship between the first three variables and case management practice, we discuss the last two factors to illustrate the concept of community-level activity.

Authority base is defined as the ways in which an agency and its employees can elicit favorable responses – services – from other agencies for their clients. An authority base can be established through informal or formal agreements, contractual arrangements, or specific legislative enactments (Rothman, 1992). Having an authority base, whether it is administrative, legal, fiscal, clinical, or some combination thereof, allows case managers both to procure services for their clients and to engage in community-level advocacy for improvements in service systems. Rothman (1992) developed a generalization based on the research: “an authority base for case management facilitates the ability to integrate services for clients. Successful integration of services necessitates case managers to have ‘clout’” (p. 26). In other words, case managers more successfully integrate services for clients to the extent that they have the ability or the clout to provide or procure a range of services. Although this point may seem obvious, in some situations, case managers are expected to provide or link clients to services when they do not have the ability, administratively, legally, or through formal interagency agreements, to do so.

Regarding target population, Rothman (1992) found that case management programs were affected by the population served. Population characteristics and needs affect the range of case management tasks provided and the way in which the service is marketed and delivered. The target population also affects caseload size. The suggested ideal caseload



for case managers ranges from 10 to 35 clients, depending on client characteristics (including severity and type of need) and role expectations for the case manager. When case managers deliver many direct services or when the clients are younger, harder to engage in treatment, or more vulnerable to environmental forces (such as poverty), smaller caseloads are expected (Rubin, 1992). Also, case managers with smaller caseloads may be expected to develop a more counseling-like alliance with clients.

2.1.5 Key Questions

Although the case management literature contains some agreement on the six core case management tasks and three types of services, disagreement arises about the boundaries of certain case management tasks and areas. Graham and Birchmore Timney (1990) raised three primary questions about the role of the case manager:

1. Should case managers adopt a broad range of helping roles and proactive interactions with the client?
2. Should case managers be primary therapists?
3. Should case managers be involved in community-level activities such as resource development and class advocacy, including supporting case management services, increasing the supply of services, and improving access to services?

The answers to these questions overlap and highlight some of the difficulties in clearly defining the boundaries of case management.

2.1.5.1 Breadth of the Case Manager's Role

Models of case management differ about the range of tasks the case manager is expected to perform. This range is influenced not only by resources allocated to case management but also by the availability of community resources (Rubin, 1992). For example, in areas with fewer resources, case managers may be expected to go beyond resource-linking roles and become providers of direct services. In such areas, the skills of the case manager may need to be broader and more advanced than in resource-rich areas; in resource-poor areas, the case manager may have to fill many roles (resources are discussed in more detail in Section 2.1.5.3). The case managers' roles also are affected by whether the program uses an individual approach, in which case managers perform many tasks, or a team approach, in which case managers specialize in one or a few tasks. Neither an individual nor a team approach has been found to be superior (Rothman, 1992), and many programs are based on local need and talent rather than on any specific model.

The range of helping roles adopted by the case manager also is influenced in part by whether a particular case management program is implemented to provide services or to ration resources or both. A potential conflict of interest may arise concerning the case managers' roles in procuring services if the goal is also to decrease costs (Baldwin & Woods, 1994). This conflict can be conceptualized by viewing case management activities along a continuum from one extreme, where greater emphasis is placed upon financial responsibility so that case managers are budget-

holding service providers, to the other extreme, where case managers are service brokers who have no responsibility for the rationing of resources. Case management programs should clearly define goals and boundaries for their case managers because they have implications for training and for resources (Baldwin & Woods, 1994).

2.1.5.2 Case Manager as Primary Therapist

A second question about case management concerns the extent to which a case manager should be the primary individual therapist. By providing the broad range of services that are part of the case management process, the case manager becomes the “human link” between the client and the potentially confusing array of services (Piette et al., 1990, p. 746). Even though the development of a relationship between the case manager and the client through periodic personal contact is implicit in case management, these relationships can differ dramatically. Most case managers counsel their clients to some extent as a natural part of relationship development, but role definitions for case managers range from coordinating and facilitating services to extensive, regular, supportive contacts in which the focus is counseling (Graham & Birchmore Timney, 1990).

In the case management context, *therapy* can be divided into short-term, or crisis-oriented, therapy, focused on immediate living problems, and long-term therapy, focused on long-standing personality issues (Rothman, 1991). According to Rothman’s (1992) review case managers’ practices differed widely in the emphasis on therapy. Benefits and problems result when one mixes case management and therapy. Some commentators have argued that the development of a therapeutic relationship is the key to engaging the client in case management.

Therefore, only clinically trained staff are qualified to be case managers (Lamb, 1980). This argument suggests that case managers skilled in counseling might best understand clients’ needs and subsequently link them to appropriate services. On the other hand, case managers with at least a master’s degree may prefer therapeutic interventions to the brokerage of “hard” resources such as housing, food, medical attention, and transportation services (Austin, 1990). Consequently, some case managers may experience a conflict in roles between directly providing services and coordinating services – and in some instances, the case coordination aspects of case management may be ignored in favor of providing direct service (Schwartz, Goldman, & Churgin, 1982).

Therapy-oriented professionals also may be more comfortable working in their offices and may not be willing to perform those tasks necessary to be good case managers such as client outreach, which often is done outside the office (Schwartz et al., 1982). Rothman (1992) found that clinically trained practitioners prefer individual therapy or counseling to case management, and that students in master’s of social work programs expressed this view even at the beginning of training. Finally, counseling by case managers may be influenced by the availability of mental health and substance-abuse resources in the community, an issue we address later.

2.1.5.3 Effect of Community Resources

Commentators disagree whether case managers should advocate only for their particular clients (for the individual), or whether they should be advocates for the class of clients they serve (Graham & Birchmore Timney, 1990). One of the inherent weaknesses of case management is that it is dependent on the availability and accessibility of other medical, social, and psychological resources.



Many case management systems have been established without the benefit of a network of community support programs (Rubin, 1992). Without referral sources, a skilled case manager can assist a client personally, for example, by providing counseling. However, without some additional authority over resources, the case manager cannot address environmental, structural, and political constraints, for example, by changing the local service delivery system, creating services, or improving the quality of services (Austin, 1990). The question remains whether a case manager should do some of these community-level activities. Rubin (1992) summarized this dilemma as follows:

Does it make sense to hire young, inexperienced, and low-paid individuals who lack professional authority; give them few resources and little or no formal organizational clout; and then expect them to work miracles in overcoming serious deficiencies in poorly funded service delivery systems? Is case management nothing more than a seductive notion for those who would like to think that society's care of its needy citizens can markedly improve without more money being spent? (p. 141)

This is an issue that programs can address in advance by knowing what community resources are available and by being clear with case managers about the extent to which they will be expected to engage in community-level activities.

2.1.6 Education and Training of Case Managers

The scope of the case manager's general role, and the extent to which therapy is part of that role, has implications both for educational background and for on-the-job training. The lack of consensus about case managers' roles has contributed to disagreements about appropriate training and

professional background. Not surprisingly, social work guidelines for *social work case management* recommend that all case managers have a bachelor's degree or a master's degree in social work (Brennan & Kaplan, 1993). However, that does not seem to be the reality in general. Rothman (1992) found no optimal level of education for case managers. However, he found that relevant training for case managers was beneficial for case managers and for clients. Rothman's guidelines suggested that case management programs should provide an orientation to case management for new employees and should provide ongoing supervision to ensure that the case management intervention is clearly understood.

Some researchers have suggested that defining the appropriate level of training for the components of case management may be important because appropriate training may differ for activities such as outreach versus assessment or counseling. For example, paraprofessionals may be effective in certain outreach, referral, and follow-up activities. Agency staff should train case managers for the roles they will assume in various programs (Graham & Birchmore Timney, 1990). For example, if paraprofessionals from the community are used, they should be aware of service provision and agency issues. HIV researchers have found that paraprofessionals can implement theory-based interventions (for example, Cabral et al., 1996; Leviton & O'Reilly, 1996), which suggests that they should be able to implement certain, but perhaps not all, case management activities.

2.1.7 Evaluation

Little definitive research exists on the efficacy of case management strategies (Graham & Birchmore Timney, 1990). Although definitional difficulties with case management make it a

complex intervention to implement, they are particularly acute when one attempts to measure the effectiveness of case management. Setting clear boundaries around the activities that do and do not constitute case management is crucial to measuring its effectiveness. For example, when case management was first implemented for the persons with serious mental illness, it was conceptualized as one component of a comprehensive care system, which made evaluating case management alone difficult (Rubin, 1992). Thus, positive results, some of which were attributed to case management, could have been caused by other components of the program or by the program as a whole. Because some people define case management solely as the functions performed by case managers, whereas others believe that case management does not exist without an entire community support program, the challenges in evaluating case management are likely to persist.

One feature of case management that may distinguish it from other interventions, is that, in some instances, the core services provided by the case manager are not sought by the client. This fact affects not only evaluation, but decisions about implementation. People who are eligible for case management are usually those society has decided “need” to be case managed, on the basis of some external criteria such as having a severe mental illness or being unable to change unsafe sexual behaviors. These types of people may be interested in some of the services that the case manager can provide (food, clothing, and shelter) but uninterested in core services such as a structured day program (for patients with severe mental illness) or HIV prevention (for PCM clients). In other words, potential clients rarely come to an agency or health department seeking their core service. Thus, persons to be managed often must be found and recruited for a case management intervention.

In general, outcome studies of case management have been poorly designed and have provided inconsistent results and thus do not strongly support the effectiveness of case management (Orwin et al., 1994; Piette et al., 1990; Rothman, 1992; Rubin, 1992). In fact, much of the case management research has focused on the process of case management rather than on any particular outcome (Rubin, 1992). Differences in community resources affect evaluation because the same program may be effective in a resource-rich community but not in a resource-poor community. If difference in resources are not accounted for when the results are examined, the conclusions may be erroneous. Further, as mentioned earlier, deciding whether the entire system is being evaluated or whether the case management program is being evaluated becomes difficult. Rothman’s (1992) review provides the following generalization about resources: “Practice outcomes are related to both the availability of relevant resources in the community and to supportive structural factors in both the agency itself and within the larger community system” (p. 72).

Although resource issues may obscure the effectiveness of case management programs, the effectiveness of case management also remains unresolved because of two crucial definitional problems: (1) difficulty in defining or placing clear boundaries around case management (discussed earlier), and (2) difficulty in defining appropriate outcome variables to measure the effectiveness of the intervention (Rothman, 1992).

Case management has been used to advance two social goals (coordinate or maximize resources and contain costs); therefore, it is not surprising that studies on the effectiveness of case management have focused on two types of dependent or outcome variables: (1) client, service, or access issues, and (2) cost variables. For example, some studies have



examined how well case management has increased access to care for clients or improved client well-being (Piette et al., 1990). Other studies have focused on financial savings and improved client functioning through decreased patient use of services, such as shortening the average length of hospital stay for psychiatric patients.

Regarding client functioning, three potential classes of dependent variables for case management have been described: (1) social functioning or quality of life, (2) intrapsychic variables, and (3) behavioral variables (Rothman, 1992). In measuring the effectiveness of case management for improving the functioning of seriously mentally ill clients, potential outcome variables have included rehospitalization rates, number of days in the hospital, quality of life, role performance, social functioning, social isolation, occupational functioning, medication compliance, service use, number of contacts with the legal system, and the cost of all services.

Regarding persons with serious mental illness, case management programs generally have affected the client's community adjustment positively and decreased the number of rehospitalizations, although not all studies have supported this positive association (Rothman, 1992). Data on the cost-savings of case management with this population are mixed. Some of the variables that potentially influence the effectiveness of case management are client characteristics, the clarity and scope of a case manager's role, the size of a case manager's caseload, case manager characteristics, quality of supervision, agency support for case management, and the adequacy of the service resources in the community (Rubin, 1992). Unfortunately, many of these variables are poorly measured or not accounted for in research on the effectiveness of

case management. Thus, not only are outcome variables difficult to define but other potentially important variables that might influence the outcome are difficult to measure or are ignored in the research.

2.1.8 Conclusions

These lessons that have emerged from the review of case management literature may have relevance for PCM programs:

- No models of case management are universally accepted, and no case management model is appropriate in all settings with all populations.
- Case management programs should clearly define their goals and boundaries for their case managers (this has implications for training and resources).
- Case management has six core tasks: client identification, outreach, and engagement; assessment of need; development of a service plan; linking with services; monitoring of needs; and advocacy.
- Case manager roles are influenced by the goal of the case management program, resources allocated to case management, and the availability of community resources.
- Effective outreach and intake efforts are associated with quick response time and assertive follow-up, which have important implications in recruiting clients.
- Thorough assessment of clients' psychosocial and medical needs is essential.

- Effective case management planning includes clients, because many clients are aware of their goals and what would help them to meet these goals.
- Effective case managers take an active and facilitative role in connecting clients with service agencies.
- Counseling is more effective when focused on advice giving, information sharing, problem solving, reality testing, and socialization skills, rather than on long-standing personality issues.
- Because case management research has not revealed optimal levels of education for case managers, defining appropriate levels of training for various case management activities may be more useful.
- Agencies should train case managers for the roles they will assume. This training should include intensive orientation to case management for new workers and ongoing supervision to ensure that the case management intervention is clearly understood.
- Characteristics of the target population affect the range of case management tasks, the way services are marketed and delivered, and caseload.
- Depending on client characteristics and case management activities, an ideal active caseload may be 10 to 35 clients.
- Informal or formal agreements, such as memoranda of understanding, contractual agreements, and legislative enactments, are means by which to affect the availability of and access to referrals for services.

2.2 RYAN WHITE OR AIDS CASE MANAGEMENT

AIDS case management is being implemented in virtually all large- and medium-sized cities (Aday, Pounds, Marconi, & Bowen, 1994). A re-view of AIDS case management literature is valuable for understanding PCM because many of the high-risk populations served by AIDS case management are potentially eligible to receive PCM. Thus, client needs for the two services may be similar in some situations.

Case management was used first for people with AIDS in the early to mid-1980s (Aday et al., 1994; Mor, Fleishman, Piette, & Allen, 1993; Piette et al., 1990). In 1986, in response to the rapidly growing epidemic, the Robert Wood Johnson Foundation initiated the AIDS Health Services Program (AHSP) to develop local networks of human service agencies and to coordinate case management services (Mor et al., 1993). The program philosophy was that for AIDS case management to be successful, a central agency should coordinate all services received by an individual (Cruise & Liou, 1993). The program also was based on the "San Francisco model," which focused on providing community-based comprehensive care and was thought to be preferable to clients and more cost-effective.

Today, most AIDS case management is funded by the Ryan White CARE Act (administered by HRSA), which was signed into law in 1990 (Aday et al., 1994). The Ryan White CARE Act supports services to HIV-seropositive persons by directing communities to develop a comprehensive, coordinated system of health care delivery by building on resources in the community (Aday et al., 1994). HIV prevention is often mentioned as a



general goal for Ryan White case management, but detailed descriptions of specific HIV prevention activities undertaken by AIDS case managers are seldom found in program descriptions. Furthermore, given AIDS case managers' usual heavy caseloads and other high-priority activities, HIV prevention is often only a minor part of Ryan White case management in many communities. This may change, however, as the need to provide ongoing support and assistance in the maintenance of safer sex and injection practices becomes clearer because of the new treatments that are extending health.

2.2.1 Practice

Similar to case management in general, some models of AIDS case management focus on decreasing the costs of AIDS care in a given community (Cruise & Liou, 1993), whereas others focus on coordinating care and developing uniform standards of service (Sowell & Meadows, 1994). Many programs also try to balance these two goals.

Historically, AIDS case managers work primarily in two settings – (1) within CBOs or (2) in public hospitals that provide medical care for persons who have many needs and who are HIV-seropositive or have AIDS (Mor et al., 1993; Piette et al., 1990). The activities of AIDS case managers, in terms of structure and content, differ substantially, depending on the work site. This finding is consistent with studies that found that the location of the organization significantly shapes the content of case management services (Intagliata & Baker, 1983). Piette and his colleagues (1990) found that hospital-based case managers served more people who injected drugs as well as clients who needed long-term care, housing, transportation, and psychological counseling. In contrast, CBO case managers

served primarily gay or bisexual clients who more often needed emotional support, usually provided by volunteers, and legal assistance. Furthermore, hospital-based case managers were significantly more likely to provide psychological counseling or therapy, whereas case managers in CBOs were more likely to work to expand or develop services (Piette et al., 1990).

Evaluation of the Robert Wood Johnson AHSP projects found similar results: hospital case managers focused on discharge planning, obtaining entitlements, and making referrals for home care; CBO case managers linked clients with emotional support programs, “buddies,” emergency housing, and financial support (Mor et al., 1993). Piette and his colleagues (1990) also found that case managers in CBOs had significantly less education and less experience with case management than hospital-based case managers. In the early 1980s, because of the stigma surrounding AIDS, CBOs that were already working with the gay and lesbian community were the first to offer support services for people with AIDS, and the initial qualification for case managers was a willingness to work with gay clients. In contrast, most hospital-based case managers had a nursing or a social work background. Interestingly, no differences in sizes of the caseloads were found of hospital- and CBO-based case managers (median, 50 cases). These findings are based on research conducted in the late 1980s; thus, it is unclear whether there continues to be such a sharp difference between hospital- and CBO-based case managers. Three changes in the 1990s may affect these results: an increase in the number of CBO clients who are not gay, better educated case managers in CBOs, and less stigmatization of the organizations and people working in AIDS-related CBOs.

One possible reason for the differences between hospital- and community-based case management is that hospital-based case management is much better defined than community-based case management (Sowell & Meadows, 1994). In other words, expectations and requirements are clearer for hospital-based case management, partly because the case management system is part of a large medical system with strict documentation and qualification requirements and a history of providing social work services. In contrast, the expectations for community-based case management programs are more abstract. Piette and his colleagues (1990) found that cities with hospital- and CBO-based case management systems had few protocols for sharing client information, transferring primary responsibility for clients, and differentiating the roles of the two systems (Piette et al., 1990). To resolve issues of coordination when multiple case managers are involved, Piette and his colleagues (1990, 1992) recommended an explicit protocol for structuring the relationship between case managers. Sowell and Meadows (1994) recently reported on a comprehensive program to integrate CBO case managers into a variety of community settings including local hospitals serving AIDS patients.

2.2.2 Evaluation

The evaluation of AIDS case management programs for people with AIDS is fraught with the difficulties already discussed regarding other case management interventions. In addition, the practice and the evaluation of AIDS case management have been affected by the rapid spread of HIV and the resulting large increases in caseloads. Piette and his colleagues (1992) evaluated 20 AIDS case management programs that were funded by the Robert Wood Johnson Foundation; they examined how well the agencies were performing in five core components of case management – assessment, care

planning, service linkage, monitoring, and advocacy. On an evaluation of agency structure and process, the agencies generally were performing poorly in each of the core components.

For example, few standardized assessment instruments were being used; thus, the assessments of clients differed across sites and across case managers at the same site. Assessment instruments were often simply brief checklists. Need-based triage was virtually nonexistent, meaning that client services could not be decreased if clients' needs lessened, and the most vocal clients received the most services. The few case plans that existed were not useful to anyone but the original case manager. Paperwork was a low priority, and documentation was informal, a situation that works best with a small caseload and few providers. In addition, few agencies had formal monitoring policies, and changes were seldom noted in case records. Finally, client-centered advocacy was valued, but system-level advocacy received little financial support (Piette et al., 1992). The authors cautioned that these results should be interpreted in light of the following facts: (1) data were collected in 1988, when all the participating CBOs were very young organizations, (2) caseloads were growing rapidly, (3) resources were sparse, and (4) the development of a coordinated case management system was just beginning.

Despite the caveats, some of the authors' suggestions seem relevant. The importance of a thorough assessment and proper assignment of clients, or triage, was emphasized. As practiced, AIDS case management was crisis-focused and reactive, leaving case managers to spend most of their time with clients who were most in need or most vocal. The use of "high-need" and "low-need" client categories with separate protocols for frequency and type of interaction was one



suggestion for managing caseloads (Piette et al., 1992). Monitoring client status is crucial to any two-tiered system so that clients can be moved as their needs change. Such monitoring may require structured, regular contact with clients (according to explicit protocols). Monitoring ability is enhanced with a manageable caseload and adequate case records. If a team approach is used, professionals, paraprofessionals, and volunteers must have an explicit, structured way to communicate (for example, case conferences or case notes in a central file used by all staff).

Regarding the level of training required for AIDS case managers, Piette and his colleagues (1992) suggested that bachelor's-level social workers were optimal because they were trained in making the crucial service linkages while remaining sensitive to psychological issues. Master's-level case managers also were effective case managers, but many of them complained that the job did not allow them to use their therapy training. Unfortunately, because of high turnover and burnout, inexperienced people often stepped into case manager positions. Thus, detailed protocols and procedure manuals were suggested to ensure the effective delivery of services and adequate minimum standards of care (Piette et al., 1992). Regarding system-level advocacy, the authors suggested that a specific person be hired to perform this task so that case managers could focus on client-level advocacy. Finally, client advocacy requires that case managers closely monitor their clients' needs and the delivery of services to the client, a skill for which case managers should receive training.

More recently, a framework was proposed for evaluating the community programs funded by the Ryan White CARE Act (Aday et al., 1994). Although these programs encompass more than just

case management, the framework is instructive for the potential evaluation of PCM. In this framework, three criteria were used to evaluate how well the programs met their objective: (1) the structure, or design, of the program; (2) the process, or method, by which goals were achieved; and (3) the outcomes, or effects, of the program on the population served (Aday et al., 1994). Process evaluation may be particularly important in AIDS case management, in which some clients may be functioning more poorly over time in some areas, for example, physical status or the ability to live independently (Sowell & Meadows, 1994). Thus, case managers can meet acceptable standards by following and meeting certain process goals even if client functioning declines in some areas. Sowell and Meadows also specified client satisfaction as an important measure of success for AIDS case management.

2.2.3 Conclusions

Some clear lessons from research on AIDS case management have implications for PCM:

- Thorough assessment and triage are important.
- Monitoring of clients' needs and behavior change is an important part of reassessment.
- Clear documentation is crucial for staff communication and evaluation.
- Client advocacy is an important part of AIDS case management.
- Clear procedure and protocol manuals are necessary to ensure the effective delivery of services and adequate minimum standards of care.

- If multiple case managers or other staff are working with one client, they need a clear communication protocol.
- Bachelor's-level social work training may be best for case management staff.
- A broad evaluation framework seems warranted to include (1) program structure, (2) the case management process, and (3) the outcomes for the population served.
- Client satisfaction can be an important part of process evaluation.

2.3 PREVENTION CASE MANAGEMENT

In the next two sections, the limited literature on PCM will be examined. Note that all of the studies on PCM were completed before CDC published its initial guidelines in 1995.

2.3.1 Published Literature

PCM is a hybrid intervention, attempting to provide time-limited case management and HIV prevention services. PCM is based on the idea that people are unable to prioritize the threat posed by HIV when they face problems they perceive as more important and immediate (Falck et al., 1994). By addressing these acute needs through case management, high-risk persons who would not typically seek other risk-reduction programs might be reached for HIV prevention efforts. For example, a recent study found that poor mental health and drug dependence may undermine the ability and motivation of female sex traders in Harlem to adopt safer sex behavior (El-Bassel et al., 1997). A PCM

intervention for this population would attempt to address the women's psychosocial and mental health needs and provide risk-reduction counseling so that they would be more likely to adopt safer sex practices. As discussed, however, one of the salient features of case management, including PCM, is that the core services provided by the case manager are not sought by every client. In other words, PCM clients may not come to an agency or a health department to seek prevention services, even though HIV prevention is the primary purpose of the program.

Only a few reports on PCM have been published or presented. Three reports focus exclusively on HIV-seropositive persons (CDC, 1993; Schwartz, Dilley, & Sorenson, 1994; Thurnherr, Moore, Bonk, & Strum, 1994), and one focuses mostly on HIV-seronegative individuals (Falck et al., 1994). Two of the studies provide very limited outcome evaluation data.

The CDC (1993) reported outcome data on PCM programs for HIV-seropositive persons in three community health centers. The goal of PCM at these three sites was to assist HIV-seropositive clients in obtaining services that would prevent or reduce behaviors that result in further spread of the virus, delay the onset of symptomatic HIV disease, and improve the client's health. Clients attended a follow-up visit after testing positive, during which the case manager collected data on risk behavior (five items), provided risk-reduction counseling, and developed a care plan for medical and psychosocial services (Time 1). Clients' next scheduled meeting with the case manager was 4 to 6 months after the first visit, and the risk questionnaire was readministered (Time 2). No other PCM activities took place between Time 1 and Time 2. Although 755 clients received PCM serv-



ices at the three sites, because of changes in methodology, only 61 clients completed the same questionnaire at Time 1 and Time 2. At Time 2, significantly more of these clients had not had sex in the past 30 days and reported no current sex partner, than at the beginning of PCM. However, no differences were found in the number of new sex partners or the use of condoms with a regular sex partner.

Even though these findings are somewhat encouraging, they do not provide a very good test of the efficacy of PCM in decreasing high-risk behaviors. Problems include the small sample size, the lack of control for disease progression (which could have caused a decrease in sexual activity), and the failure to collect behavioral data in the time between HIV testing and the first case management appointment (a 2.4-month lag time on average, during which time changes could have occurred). In addition, interpretation of the findings on condom use is difficult because the serostatus of sex partners is not known. Furthermore, the intensity of the PCM services delivered at these program sites is unclear. The PCM intervention in this case seems to have consisted of two meetings with a case manager, although few details were provided.

In a randomized controlled trial of a PCM program in Ohio for injection drug users (most of whom were HIV-seronegative), no differences were found between three groups of participants (case management, health education, and control) with regard to drug use, risky sexual behaviors, or use of human services at 6-month follow-up (Falck et al., 1994). Participants in all three groups reported significantly less drug risk, but no change in high-risk sexual practices at follow-up. Although no evidence of behavioral change was found in this study, the difficulty in retaining participants

suggests that it may not have been an adequate test of the PCM model. To try to increase the number of clients completing the intervention, the researchers changed their initial PCM plan (a minimum of six sessions with the prevention case manager) to one initial office visit and two sessions in the field. Even with this adjustment, retention was difficult. Of the 105 clients randomly assigned to the case management intervention, 66% agreed to further participation after the first office visit; 49% participated in at least one field visit; and only 37% participated in two or more field sessions. Thus, data were available only for the 38 participants who received at least two case management sessions.

These authors focused most of their commentary on the difficulty of getting clients to “engage” in the program (the first step in their six-step case management model) and to remain in the program. They were discouraged by the fact that, “the clients expressed a nearly uniform lack of interest in what the project offered” (Falck et al., 1994, p. 165). Given the intense effort that was needed to engage clients for the first session, Falck and his colleagues were disappointed in the retention rate. They concluded that the effects of drug use worked directly against the engagement and retention of clients in the case management process. Another possibility not mentioned by the authors is that because most clients were HIV-seronegative, they were less interested in primary prevention, and hence, in the HIV PCM program.

Schwartz and her colleagues (1994) reported on a case management model with HIV-seropositive substance-abusing persons that focused on decreasing drug usage, linking clients to services, and decreasing the risk of HIV transmission. Although no outcome data are available yet from this project, Schwartz and her colleagues did

describe some difficulties with addressing prevention issues in the context of case management. She noted that AIDS issues were not primary for many clients and could not be addressed effectively until basic needs were met. They found, however, that meeting basic needs for this substance-abusing population was very difficult because of the number of obstacles faced by clients, including

- lack of money
- lack of child care
- lack of transportation
- lack of a telephone
- lack of necessary documentation (for example, identification or social security card, citizenship papers)
- active substance abuse
- poor physical health
- mental illness
- eviction or criminal history
- long waiting lists or lines for services
- few services for people who were not HIV-seropositive and who were not disabled

To the extent that persons in PCM cannot become engaged in the process (and thereby get their basic needs met), implementing the prevention component of PCM becomes more difficult. Moreover, as seen from this list of obstacles, many

of these barriers are significant. Clearly, long-standing individual or social issues may be difficult to overcome with any social program, let alone an HIV prevention intervention.

The final PCM-like program was a 60-day peer-based program in which clients who had recently tested seropositive were matched with seropositive agency *veterans* (Thurnherr et al., 1994). On the basis of focus groups with new and veteran clients, the agency determined that the biggest obstacles to services for new clients were the complexity of the service system and the clients' feelings of isolation. The clients with recent diagnoses also exhibited substantial confusion about safe sex practices. Thurnherr and his colleagues designed a 60-day, 6-session intervention in which the agency veterans led newcomers through training on safe sex alternatives, correct condom usage, personal responsibility and HIV, choices of early medical intervention, HIV basics, and STD education. The authors did not state whether or not traditional case management activities such as assessment, linking to services, and monitoring were provided. Although the authors called the intervention a peer PCM program, its seems to be more similar to risk-reduction programs and buddy programs for HIV-seropositive persons than to the usual PCM program. No outcome data were presented, and a phone call to the agency revealed that the program has been discontinued.

2.3.2 Conclusions

From the few publications on PCM, several points stand out. First, client engagement and retention are difficult with multiproblem, high-risk clients such as those who abuse substances. This difficulty is important because the goal of PCM is to reach such persons. Second, providing social



services to high-need, multiproblem clients, let alone HIV prevention services, is difficult. Third, many PCM clients do not perceive a need for HIV prevention services, and this might be especially

true for those who are HIV-seronegative. Finally, PCM programs have not been evaluated; thus, conclusions about the effectiveness of PCM are not warranted.

3.0 SUMMARY OF PCM PRACTICES IN 1996

The three literature reviews in this document (case management, AIDS case management, and prevention case management) provided important lessons that helped to direct the revision of PCM guidelines. However, it also was imperative in the revision process to assess the implementation of PCM programs to identify key issues as well as barriers and factors that facilitate PCM programs.

To learn from existing PCM projects, CDC staff conducted one-hour telephone interviews with program managers who oversaw the 25 PCM programs implemented by CBOs directly funded by CDC in 1996. A standard questionnaire was used to assess each program's PCM activities, the extent of their HIV prevention components, staffing patterns and staff qualifications, evaluation activities, and recommendations for revised PCM guidelines. After these interviews, seven programs were selected for site visits. A more detailed description of PCM practices at directly funded CBOs is provided elsewhere (Purcell, DeGross, and Wolitski, submitted for publication).

From an examination of PCM practice at the 25 directly funded CBOs, the following summary emerged:

- PCM was being implemented by CBOs in a variety of settings and with a wide array of populations.
- Most programs were serving both HIV-seropositive and HIV-seronegative clients.
- PCM clients have medical and psychosocial needs, but many do not perceive a need for HIV prevention.
- PCM client recruitment and retention have been difficult.
- Recruitment has been particularly difficult in stand-alone PCM programs – those independent from other preventive, medical, or social services – that do not have an internal source of referrals.
- The quality of assessment and case planning differed from program to program.
- Programs had well-documented case records and treatment plans, but many lacked clearly defined HIV-related behavioral objectives.
- The most common referrals by PCM case managers were for medical treatment, HIV antibody counseling and testing, housing, substance-abuse treatment, and mental health counseling.
- Most PCM programs were providing some substance abuse and mental health counseling, the extent of which seemed influenced by staff skills.
- Sixteen percent of PCM programs used a standardized risk-reduction curriculum; 68% used a client-centered model.
- Many PCM programs had incorporated a group-level intervention, which was used as a support group or as a means of providing risk-reduction information and counseling.

- Protocols for coordination between PCM and Ryan White case management were seldom in place – some duplication of these two services was evident.
- Whether multisession risk-reduction counseling was taking place was unclear – the acute psychosocial needs of clients may have superseded efforts for risk-reduction counseling.
- Staff models and related staff credentials for PCM differed across programs.
- Attention to quality assurance measures differed (this may be particularly important for an intervention for which outcome data is difficult to obtain).

In addition to examining the PCM practices of directly funded CBOs, CDC staff wanted to deter-

mine whether state and local health departments are supporting PCM. To accomplish this, CDC worked with the National Alliance of State and Territorial AIDS Directors (NASTAD), which sent a six-item survey to all AIDS directors about their PCM activities. A total of 32 responses were received (28 states and 4 cities) from the 65 NASTAD members, a 49% response rate. Most of the states with the highest number of AIDS cases responded to the survey. Many of the health departments are involved, in some way, with PCM; 72% (19 states and 4 cities) *fund* PCM activities; and 34% (9 states and 2 cities) *implement* at least one PCM program. When asked how many CBOs they fund to implement PCM, responses ranged from 0 to 17, for a total of 107 CBOs currently funded by the 32 respondents. Fifteen health departments provide PCM-specific training and technical assistance to agencies. Regarding the need for new PCM programmatic guidelines, 81% of the directors thought that new guidelines were needed.

4.0 SUMMARY

PCM is a hybrid intervention for providing both time-limited case management and HIV pre-vention. The premise of PCM is that by helping high-risk persons address their most pressing medical and psychosocial needs in a supportive, case management relationship, (1) they will be able to prioritize and understand HIV prevention, and (2) they may be better able to remove themselves from high-risk situations or environments. CDC originally issued guidance for PCM in 1995 (CDC, 1995). However, because PCM is a relatively new intervention and implementation issues have emerged, revised guidelines have been issued (CDC, 1997). Although extensive outcome evaluation of case management is not yet available, case management remains a widely used approach that is

being applied to an increasingly broad array of populations to address an increasing variety of problems. In addition, HIV and STD individual-level interventions have been effective in changing risk behavior (Kamb et al., 1997; Choi & Coates, 1994; Kalichman, Carey, & Johnson, 1996). The evaluation and research of other types of case management programs provide many lessons that should be useful to PCM programs. In addition, a review of current practices has highlighted barriers to implementation and areas that need attention. These data underscore the need for guidelines for the practice of PCM and indicate the need for research on the structure, implementation, and effectiveness of this hybrid model.

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