

Mental Health Care

for People Living With or Affected by HIV/AIDS:

A PRACTICAL GUIDE



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Bill died of complications associated with HIV on April 23, 1994. He was only 34 years old. All of us who knew him and respected him still feel a tremendous sense of loss and sadness. However, at the same time, we are able to rest comfortably in the knowledge that Bill Bailey’s legacy lives on in every community-based program that provides mental health services at Ryan White-funded facilities. It lives on in mental health-specific HIV programs created by Congress and a broad range of national associations and organizations. It lives on in our memories and our work.

Bill Bailey’s legacy lives on in this Practical Guide.

Without Bill Bailey and his tireless efforts, the Demonstration Program and this Practical Guide would never have existed, and the more than 5,000 people served by the Demonstration Program most likely would have had nowhere to turn for HIV-specific mental health services.

Bill, we are honored and privileged to have been a part of making your vision a reality. It is our deepest hope that this Practical Guide conveys the values and principles to which you dedicated both your career and every aspect of your life.

The Authors

1999

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Preamble

Since the advent of the AIDS epidemic, people living with HIV who also have mental and/or substance use disorders have been forced to navigate complex, fragmented, and uncoordinated health care systems in order to access the services they need. Over time, health and human service providers have begun to recognize that these problems are interwoven and present a broad range of challenges for the service provider on practical, economic, and treatment levels.

To address some of these concerns, the Substance Abuse and Mental Health Services Administration (SAMHSA), the Health Resources and Services Administration (HRSA), and the National Institutes of Health (NIH) launched the HIV/AIDS Mental Health Services Demonstration Program—the first federal initiative to focus on the mental health needs of people living with or affected by HIV. Funded at more than \$4 million per year over four years, the Demonstration was designed to:

- increase access to integrated mental health, primary care, and support services
- develop effective mental health care models that can be replicated elsewhere
- improve quality of life for those living with or affected by HIV
- prevent further transmission by reducing high-risk behaviors
- promote cultural competence in service delivery

...created to generate new knowledge...

This initiative was unique at the time it was conceived because it was intended to accomplish far more than the mere provision of mental health services to people living with or affected by HIV. It also was created to generate new knowledge about the role of mental health services in primary medical treatment for people living with or affected by HIV and to identify characteristics of the clients served, the types of services they used, and other lessons learned in implementing integrated care.

The 11 service delivery projects listed in Appendix A were located in eight states and Puerto Rico. In addition to implementing programs tailored to the unique needs of their target population, **the projects tested a variety of mental health service interventions, including:**

- mental health services co-located with HIV primary care centers
- integrated outreach, case management, and mental health programs
- psychosocial rehabilitation programs
- HIV mental health services integrated into residential drug treatment

More than 5,000 clients received mental health services from the Demonstration projects. Figure 1 provides a demographic breakdown of clients by gender, race/ethnicity, and age. Figures 2 through 4 provide information on a subset of the clients served in the Demonstration projects for which comprehensive data are available. Although there was demographic and socioeconomic diversity among clients, **three characteristics were common across all service sites:**

- 1 Clients served were financially disadvantaged, with poverty and reliance on public sector service systems as the norm. Forty percent of the clients were covered by Medicaid, while another 40 percent had no health insurance coverage at all.
- 2 The racial and gender composition of the clients resembled the changing face of the AIDS epidemic, with racial/ethnic minorities constituting the majority of the clients and substantial proportions of women, heterosexuals, and injecting drug users included. The projects also served a large number of men who have sex with men and a few transgendered individuals.
- 3 Clients presented with high rates of serious mental and substance use disorders. Three out of four clients met criteria for major depression, one in four met criteria for alcohol dependence, and half met criteria for drug dependence. Comorbidity of mental and substance use disorders was common, complicating treatment of both disorders.

Figure 1

Demographic Characteristics of Clients Served in the Demonstration Program

Total Served	% Male	% Female	% African American	% Hispanic	% White * and Other	Mean Age
5583	69.5	30.5	47.3	23.2	29.5	34.6

* "Other" includes Asian Pacific Islander, American Indian/Alaskan Natives, Mixed, and Others

Figure 2

Housing Status of 1,837 Clients Served in the Demonstration Program *

Independent	With family/friends/other	Dependent	Homeless
52.0	31.1	11.9	5.0

* The San Francisco project was excluded from this data set because it is a residential substance abuse treatment program

Figure 3

Monthly Income/Source of Income of 1,837 Clients Served in the Demonstration Program

Median Monthly Income (\$)	% With Employment	% With Public Assistance Only
575	21.0	31.7

Figure 4

Health Insurance Coverage of 1,837 Clients Served in the Demonstration Program

% With Private Insurance/Other	% With Medicaid	% With No Source of Coverage
13.6	42.3	44.1

...this
Practical Guide
is just the
beginning...

From the beginning, Demonstration Program participants expressed a desire to share their cumulative wisdom and experience with individuals and organizations that provide HIV, mental health, and substance abuse services. It is hoped that this knowledge also will be useful to others who are responsible for the organization and financing of HIV and mental health treatment systems and who are positioned to improve the availability and accessibility of HIV, mental health, and substance abuse treatment. With the rapid development of more effective treatments, it is essential that this new knowledge be applied in the clinical setting so that, as people with HIV live longer, service providers are equipped with the know-how and skills they need to assist clients in living happier and healthier lives.

This Practical Guide was developed as a collaborative effort of the 11 projects that participated in the Demonstration Program and is based on experience gained in the clinical setting over a four-

year period. It is designed to assist service providers and others in developing comprehensive and coordinated systems of care for people living with or affected by HIV. The Practical Guide provides information on a broad range of topics, such as how to set up and establish services, how to deliver services, how to evaluate services, and several other important clinical and service delivery concerns.

The writers recognize that this Practical Guide is just the beginning. It is not meant to stand alone. The authors also recognize that no single agency or service organization can realistically put all of these ideas or principles into clinical practice. The reader is encouraged to consider the ideas and principles contained in this publication, to compare his/her own personal and clinical experience with those of the authors, to consider the needs of the target population, and to incorporate these ideas and approaches based on the resources available. As these approaches are implemented, this Practical Guide may serve as a valuable reference for clinicians and program planners, as well as a useful training tool for service staff.

Ultimately, the writers hope that this Guide will inspire a new generation of providers and professionals who are committed to ensuring that all individuals living with or affected by HIV have full and immediate access to a broad range of mental health and support services that will improve both their well-being and their quality of life.

Principles *of* Care

The following principles reflect the experience of the 11 Demonstration projects in delivering primary medical, mental health, substance abuse, and related support services to people living with or affected by HIV. These principles are based on the knowledge gained by the projects during the Demonstration Program and are designed to provide guidance to administrators, program planners, and service providers as they establish and implement HIV-specific mental health care service programs. While not empirically based, these principles represent the ideals of the 11 projects.

...these principles
represent the
ideals
of the 11 projects...

PRINCIPLE 1

- Clients need access to comprehensive primary medical, mental health, substance use, and related support services. Some clients will need access to free or affordable transportation to attend appointments. Others will need assistance obtaining affordable housing, food, child care, permanency planning, HIV risk reduction education services, medications, and supportive residential services.

PRINCIPLE 2

- Services should be flexible and client-centered. Clients will present with a broad range of medical, mental health, substance use, and psychosocial needs. While some clients will benefit from psychotherapy, others may need only support groups or case management. Service plans need to be adapted to meet changing client needs.

PRINCIPLE 3

- HIV, mental health, and substance use treatment services should be adequately coordinated and integrated. Often, service providers from different systems of care do not communicate with one another, even though they may be responsible for delivering care to the same individuals. Service systems should establish formal linkages and networks to enhance service coordination and integration. Likewise, service providers representing multiple disciplines should take a “team” approach to meeting each client’s needs.

PRINCIPLE 4

- Services should be delivered in a way that is consistent with each client’s cultural needs and expectations. This may require that service systems employ multilingual and multicultural staff. Multicultural sensitivity is essential for those staff who are not culturally matched with their clients.

PRINCIPLE 5

- Services should promote individual self-respect and personal dignity. Services can only be delivered effectively when an individual's self-worth and contributions to society are recognized. In addition, people with HIV who also have mental and/or substance use disorders typically have been stigmatized by both society and the traditional health care delivery system. To meet their needs, service systems must take steps to ensure that the system itself does not stigmatize its clients further.

PRINCIPLE 6

- Services should promote healthier behaviors. Providers can work together to promote safe sexual behaviors by clients and to strengthen family relationships. Promoting healthier behaviors involves being comfortable with discussing issues such as risk and harm reduction.

PRINCIPLE 7

- Service delivery programs should work to reduce barriers to care for “hard-to-reach” populations. Some service systems have failed to reach populations that desperately need access to HIV primary medical treatment and mental health services, including people in jails and prisons, people who are homeless, substance abusers, and individuals with severe mental illness.

PRINCIPLE 8

- Programs should develop and deliver services that are clinically informed and research-based. Many programs have developed and conducted evaluations of their clinical services. The knowledge gained from these undertakings, as well as the latest research on HIV-related mental health services, can be used to enhance service delivery and program policy.

PRINCIPLE 9

- Persons living with HIV need to be empowered to make decisions in collaboration with the service provider. In addition, all segments of the community, including consumer and family advocacy groups, should be actively involved in the establishment, delivery, and quality improvement of services.

PRINCIPLE 10

- Programs should work to create an “HIV Community.” Service systems can play a major role in creating a community of individuals, agencies, and organizations that work in partnership to increase access to the broadest, most comprehensive range of services possible and to foster the development of an HIV Community that offers a sophisticated network of support for clients.

Introduction

As HIV invades the body, it creates rippling and profound biological and social consequences for those persons infected. In addition to attacking the body's immune system and causing a broad spectrum of health complications, HIV may present a host of mental and emotional problems by disrupting the infected person's emotional equilibrium, sense of self, relations with others, and purpose in life. HIV also has socioeconomic consequences that affect one's most basic human needs, such as housing, food, financial security, and employment. Substance abuse confounds these issues, leading to deteriorating physical and mental health, and the poor judgment that may result in risk-taking behaviors of both a sexual and criminal nature. When addictions become severe and refractory, every aspect of life is affected.

The very complexity of these biological, psychological, and social needs springing from HIV infection argues in favor of an integrated and coordinated approach to care. Failure to address the needs in any one sphere can lead to a breakdown in the effectiveness of treatment in the others. As HIV approaches its third decade of existence, the changing demographics of HIV infection reinforces the need for service integration and coordination.

EPIDEMIOLOGICAL TRENDS

In the early days of the epidemic, HIV primarily affected gay white males from a broad range of socioeconomic strata. Since 1994, when the HIV/AIDS Mental Health Services Demonstration Program was launched, HIV rates have increased rapidly among disenfranchised ethnic minorities and women. Today, those infected are more often from communities of poverty (i.e., intravenous drug users and their partners, persons who are incarcerated, individuals with serious mental illness, people who are homeless, and the foreign-born) and those engaged in the sex trade. According to the Centers for Disease Control and Prevention's data from 25 states with integrated HIV and AIDS reporting systems, 63 percent of young persons between the ages of 13 and 24 diagnosed between January 1994 and June 1997 were African American (CDC Update, April 23, 1998). Recent estimates indicate that 25 percent of those living with HIV in the U.S. were infected through unsafe injection drug use, while 15 percent became infected through unsafe heterosexual sex (CDC, 1997).

New and effective medical treatments for HIV, including protease inhibitors, have had a profound effect on those living with HIV. The hope that HIV, for some, has become a chronic, treatable condition instead of a fatal one brings with it an energizing optimism—and a host of additional psychosocial complications. At the same time, there are widespread treatment implications for the future. While the death rate from HIV-related

...a changing epidemic...

complications decreased 47 percent between 1996 and 1999, the rate of HIV infection has remained steady for some populations and is increasing in others. With those who are infected living longer, caseloads will increase, and the demand for services supporting adherence to a complex array of medical treatments will climb.

These epidemiological changes, coupled with the complex biological and social needs of a growing number of people living with or affected by HIV, call for a comprehensive, coordinated, and integrated approach to care—one that recognizes the importance of mental health issues in providing services to people living with HIV. A specialized approach to HIV mental health service delivery car-

ries many advantages for the client. Sharing the struggle with others who are living with HIV can provide a sense of mutual support, alleviate the stigma encountered in society, and promote a sense of safety. Issues of confidentiality, risk reduction, advocacy, and medication adherence may be emphasized and effectively addressed with appropriately trained staff. Efforts to reach this alienated and heavily stigmatized population require specialized and targeted approaches that involve close collaboration among a broad range of disciplines and service providers.

As this manual was being developed, three themes repeatedly emerged that bear special significance for the provision of mental health services to people affected by HIV—stigma, multicultural sensitivity, and a biopsychosocial approach to care. Although these themes are woven throughout the Practical Guide, their critical impact upon service delivery warrants highlighting them in this introduction.

...three themes
repeatedly
emerged...

STIGMA

Central to an understanding of the person with HIV who seeks mental health services is an understanding of the concept of stigma and its corrosive and debilitating effects. The archaic definition of stigma is “a mark burned into the skin of a criminal or slave (Webster’s New Riverside University Dictionary, 1139).” The HIV-infected client often finds himself/herself stigmatized in many ways—for having a fatal, transmittable disease; for being “crazy;” for being gay; for being sexual; for being a substance user; for being African American; for being poor; for being Hispanic; for being an illegal immigrant; for being unemployed; for being homeless; or for being an ex-offender. HIV-related stigmatization constitutes an epidemic in itself—an epidemic of fear, prejudice, and discrimination.

The fear of being stigmatized keeps many from seeking services. It also can prevent many clients from remaining in treatment or adhering to a treatment regimen. The feelings resulting from stigmatization may include fear, shame, distrust, rejection, exile, guilt, isolation, hopelessness, helplessness, alienation, lack of self-worth, powerlessness, and aloneness. Empathy for those facing the painful reality of this multiple stigmatization is what propels many to work in the HIV field.

MULTICULTURAL SENSITIVITY

An effective HIV treatment team includes clinical providers who are dedicated to the work and possess a depth of knowledge of HIV, mental health, substance abuse, and community resources. The successful worker possesses a sensitivity to, and understanding of, individual differences, different cultures, and subcultures, as well as a broad understanding of the biopsychosocial effects of HIV infection on the client's everyday life.

The culturally competent provider must be able to interact in a way that demonstrates an openness, understanding, and respect for the experiences, value systems, and beliefs of others. The culturally sensitive provider will convey to the client an appreciation of the varied cultural perceptions of power and control over one's life and an understanding of why and how clients may have learned adaptational skills that seem to promote dependency and social marginalization.

Prejudgments—of how persons should have lived their lives, avoided HIV infection, or adjusted to a majority culture that all too often discriminates, stigmatizes, and oppresses—lead to a breakdown of trust. As a result, the therapeutic alliance that is the bedrock of effective intervention may be severely compromised. HIV infection has different meanings in different cultures, communities, and families. A person's internal perceptions of his/her external life is unique and evolves in large part from the individual's cultural roots. Cultures and subcultures have contrasting interpretations of what constitutes

pathology, and the culturally competent provider must tread carefully in making a diagnosis and prescribing treatment.

Providers should be comfortable with diverse educational levels, sexual orientations, physical and mental disabilities, substance use, class, and other psychosocial variables. Staff competence and sensitivity results from ongoing self-reflection that diminishes judgmental thinking and promotes tolerance and a sensitive curiosity toward care. By accompanying clients to public agencies to access services, providers gain an appreciation of power and control differentials. Developing a sensitivity to certain marginalized subcultures requires a willingness to enter a "virtual reality" that sees events and attitudes from the client's perspective.

A SPECIALIZED BIOPSYCHOSOCIAL APPROACH TO CARE

In 1990, AIDS was described as a paradigm of an illness requiring a biopsychosocial approach. With the advent of new and effective medications, such a designation is increasingly apt. HIV infection is a medical illness caused by a virus often transmitted through socially stigmatized behaviors—unprotected sex and injection drug use—that biologically affects the brain and the immune system. At the same time, a diagnosis of HIV creates a series of immense psychological burdens that occur within a larger, more complex psychosocial arena. As the importance of adhering to complex antiretroviral medication regimens gains acceptance, the spotlight focuses increasingly on the whole person and his/her capacity for medication adherence.

To increase the likelihood of treatment adherence and to promote wellness, the provider must address client-specific concerns on many levels:

- **Social and Environmental Circumstances.** These include poverty, access to care, family relationships, housing, financial needs, food, child care, transportation, and legal status. Such concerns may be further complicated by homelessness, incarceration, and prostitution.
- **Psychological Factors.** These include stress; depression; anxiety; cognitive impairments due to HIV-associated dementia; psychosis; mania; pre-existing serious mental illness, including schizophrenia and bipolar disorder; and poor judgment and impulsivity associated with personality disorders. Defense mechanisms, such as avoidance and denial, also may interfere with seeking and accepting treatment.
- **Biological Aspects.** The health issues associated with HIV include the client's medical condition; health of the immune system; symptoms and common opportunistic infections (e.g., of the brain); medications prescribed both prophylactically and for symptom relief; and co-existing chronic illnesses, such as diabetes, renal and liver disease, and high blood pressure.

...social,
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The biopsychosocial framework is a useful guide in assembling a specialized HIV mental health delivery system. The model helps the treatment provider to remain alert to the interactivity of disorders and stressors, to frame a complete diagnostic picture of the client, and to construct an appropriate and comprehensive treatment plan.

To provide examples of how this biopsychosocial approach to service delivery may be implemented throughout different stages in the treatment process, the authors will share the experiences of clients served by the Demonstration Program. (Case material has been disguised to protect client confidentiality.) Their stories, as told throughout this manual, will enable the reader to better understand how the social, psychological, and biological factors described in this introduction interact with one another and define the approach to treatment.

CREATING PROGRAMS

CHAPTER 1:

Establishing Services

From the early years of the HIV pandemic, clinicians and program planners have recognized that HIV can exact an enormous toll on an individual's emotional health. Over the years, some AIDS service organizations (ASOs) and community-based organizations (CBOs) have tried to make mental health a service priority. However, since most of these organizations lack the necessary resources to meet the mental health needs of their clients, mental health services largely have been restricted to providing referrals to other community programs (e.g., community mental health centers) or offering limited on-site counseling for people living with or affected by HIV.

One of the lessons learned by the 11 sites that participated in the Demonstration Program was that programs interested in serving HIV-infected and -affected individuals need to augment their traditional mental health approaches with a biopsychosocial perspective. They also need to be responsive to persons who are hard-to-reach and have multiple service needs. This chapter presents steps for programs to consider and pursue in establishing services to address the HIV-specific mental health needs of their communities.

DETERMINING THE NEED FOR SERVICES

The types of services offered by a program should encompass the range of service alternatives required to meet the needs of the program's target population. Program planners and clinicians should recognize the need for mental health services when clients are not adhering to treatment, having interpersonal difficulties with medical service providers, missing appointments, or presenting with indicators of depression or anxiety. There are other indicators that can help administrators and clinicians determine what types of services should be provided. For example, changes in the demographics of persons affected by HIV underscore the need for "refined" or "different" services.

The first step in establishing services is to determine the need for HIV-specific mental health services. This may be done through:

- **Holding focus groups.** Invite the sharing of ideas and experiences by people living with or affected by HIV, medical providers, substance abuse treatment providers, mental health providers, program planners from ASOs and CBOs, and other local experts.
- **Seeking client input.** Set up suggestion boxes at the facilities where HIV-positive clients go for services. Periodically ask clients to fill out surveys. Invite persons living with HIV to participate on an advisory group. In addition to asking them to articulate their service needs, these venues provide an opportunity to gather information on service utilization patterns, program evaluations from a client perspective, and other information that can provide insight into how services can be improved and enhanced. Throughout these processes, program administrators and staff should keep an open mind. It may appear that the services being offered by a particular program are effective and operating in a smooth fashion, but some clients served by a program may not feel the same way. Program administrators and staff should be receptive to new ideas and consider all suggestions carefully and thoughtfully.
- **Conducting a needs assessment.** It may be wise to conduct a formal evaluation of service needs, to review recently published literature on needs assessments conducted with a similar population, and to distribute the needs assessment to key members in the community. A needs assessment will likely uncover unmet service needs in the community, as well as identify organizations and agencies that may be interested in collaborating in the establishment of HIV-specific mental health services.
- **Observing trends.** Program staff should continue to monitor local epidemiological data, as well as data from other areas that are ethnically, geographically, or socioeconomically similar for emerging trends in service needs and utilization patterns.
- **Listening to anecdotal information.** Service providers who work with HIV-infected and -affected individuals often talk in loose terms about the number of "mental health," "psychological," "family-related," or "depression/anxiety" complaints presented by clients. This type of anecdotal information may be useful in determining specific service needs that are not being addressed.

DESIGNING A RESPONSIVE PROGRAM

Once specific population needs are identified and documented, program planners and service providers can begin developing an action plan designed to meet the needs of a specifically defined target population or geographic service area. An action plan should identify how the program can address unmet needs. Designing a program and determining the feasibility of actually providing services happens almost simultaneously. (See the following section on "Determining Feasibility" in this chapter). Figure 5 presents examples of unmet mental health needs and possible treatment models/services.

Figure 5

Matching Client Services with the Target Population

Population/Unmet Need	Treatment Model/Services
Single mothers in advanced stages of HIV	Permanency planning Intensive case management Individual counseling in the home
Injection drug users	Traditional case management Relapse prevention Methadone maintenance Harm reduction Detoxification
Clients in advanced stages of HIV infection	Neurologic and psychiatric services Family education Support groups Psychiatric hospitalization case management Pastoral care Home services Telephone contacts
HIV testing	Individual counseling Case management Risk reduction services (psychotherapy and counseling)
Marginalized populations	Support groups Intensive case management Advocacy
Homeless	Aggressive outreach Field visits
HIV-infected women	Child care Parenting support/education groups Individual counseling
HIV-affected children	Family counseling and education

Service Delivery Approaches Used in the Demonstration:

Traditional services with psychiatric evaluations, psychotherapy, and psychopharmacological management

Traditional services that integrated proactive community outreach and case management

Psychosocial rehabilitation and support services as the primary treatment modality

SELECTING THE SERVICE MODEL

In addition to considering the needs of the target population, program planners need to consider what the most appropriate services are and where they will be located within the existing service delivery model. Each of the 11 Demonstration sites devised a service model that was based on local needs, the capacity for community linkages, and funding allocations. Although each site provided a unique constellation of services, the mental health service delivery approaches fell into three broad categories:

- **Traditional mental health service models that offered psychiatric evaluations, psychotherapy, and psychopharmacological management** (Atlanta, Chicago, Los Angeles, New York, Richmond, San Francisco, and San Juan). While each of these projects implemented similar service models, there was significant diversity in the populations served. For example, the Special Needs Clinic, located at Presbyterian Hospital in New York, primarily served children and families. Walden House in San Francisco served a predominantly substance using population. The Puerto Rico HIV/AIDS Mental Health Services Demonstration Project served a Latino population. The other projects implemented a traditional mental health service model that served large numbers of ethnic minorities, women, substance abusers, persons with severe mental illness, homeless individuals, men who have sex with men, and a few transgendered individuals. This diverse range of clients provided an opportunity to test the effectiveness of the traditional mental health service model across different target populations.

- **Traditional mental health service models that integrated proactive community outreach and case management** (Alexandria and Elizabeth). Both of these projects served typically hard-to-reach populations. For example, the Alexandria Mental Health HIV/AIDS Project focused on people with serious mental illness and substance use disorders, as well as homeless and incarcerated individuals. Kinship Connection in Elizabeth, New Jersey, identified women with HIV, their affected children and caregivers, and their reconfigured families as its target population. Given the composition of the target populations, these projects provided an excellent opportunity to identify effective ways to integrate assertive community outreach and case management into a traditional mental health service model.
- **Psychosocial rehabilitation and support services as the primary treatment modality** (Omaha and Philadelphia). The Harambee Project in Omaha targeted a diverse range of African Americans, including homeless individuals, women, injection drug users, and men who have sex with men. Consequently, the Harambee model emphasized group support and culturally relevant services as the primary means of treatment. Similarly, the Community Living Room in Philadelphia, which served an ethnically and socially diverse inner-city population, implemented a psychosocial rehabilitation model that emphasized peer support, social and support networks, education and empowerment, and helping clients acquire the knowledge and skills they need to live independently in the community.

A critical factor influencing the treatment approach for HIV-specific mental health service models is the location of services. The sites represented in the Demonstration Program reflect the creativity required to successfully match service delivery with client needs. Examples of site locations for HIV-specific mental health service models include:

- **Models co-located with HIV primary care facilities** (Atlanta, Chicago, Los Angeles, New York, Richmond, and San Juan). These projects typically focused on integrating mental health and HIV primary medical care to the greatest extent possible. For example, Atlanta's Center for HIV/AIDS Mental Health Services and the Los Angeles SPECTRUM Project created consortia of academic, state, and community-based ASOs to coordinate mental health services for people living with HIV throughout Atlanta and South Central Los Angeles. Chicago's HIV Health and Psychological Support Project replicated an integrated model of primary medical and mental health care at three community-based health centers, while the Mini Mental Health Center at the Medical College of Virginia in Richmond provided services in a university-based medical setting.
- **Models co-located with general mental health treatment facilities** (Alexandria and Philadelphia). The Alexandria project, an outpatient program within a community mental health center, provided traditional mental health treatment along with community outreach and close coordination with the city health clinic. Mental health and intensive case management services were offered in client homes, shelters, jails, and in the African American church. The Philadelphia project is a satellite program of a comprehensive community mental health center.
- **Models co-located with residential substance abuse treatment facilities** (San Francisco). The Walden House program in San Francisco provided mental health services for people with HIV in a structured substance abuse treatment setting. Depending on the client's needs, he/she had access to mental health counseling, substance abuse treatment, HIV counseling, housing, financial and legal assistance, medical treatment, education services, and vocational training.
- **Models that are free-standing in the community** (Elizabeth and Omaha). These two projects were unique in that they operated as their own entities within their respective communities and were not closely affiliated with a larger community organization or service program.

While factors such as funding and existing linkages within one's health care system are practical considerations guiding the approach and location of service models, one of the key lessons learned as a result of the Demonstration Program was the role of support structures. Developing or participating on existing advisory boards, networks, and consortia can put program staff in touch with others who may have confronted similar issues in the past and who can provide technical assistance on how to develop workable and effective solutions to unexpected and unanticipated challenges. Some of the support structures found to be helpful include:

...put program
staff
in touch
with
others...

- **Consumer Advisory Boards.** Typically comprised of clients, their significant others, and interested service providers, consumer advisory boards can provide program planners with the benefits of consumer input and perspectives on developing, monitoring, and improving service delivery. Meetings should be held regularly, and specific agendas should be established for each meeting. Program managers, administrators, clinicians, and other staff who keep an open mind when working with a consumer advisory board can gain valuable insight and ideas for achieving their program goals.
- **Collaborative Networks.** A collaborative network is composed of a series of formal or informal relationships among service providers and organizations with the purpose of furthering programmatic goals and objectives, and improving overall client care. Among other features, collaborative networks can also ensure that services are available and accessible to clients. (See Chapter 2 on Collaborative Networks.)
- **Consortia.** Similar to networks, a consortia usually evolves out of formal agreements among service providers from different organizations who pledge to coordinate services. The difference between consortia and networks, however, is that members of a consortia also share and distribute funding resources. Many HIV-specific consortia were established in response to the requirements of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. In fact, most states and territories have at least one consortia in place. These consortia have administrative structures and procedures designed to increase client access to care and to equitably distribute funding among participating organizations. As a general rule, any "new" service would benefit from establishing a formal linkage with local consortia.

DETERMINING THE FEASIBILITY OF THE PROGRAM

Once service needs are concretely identified and possible service model solutions are drafted, program planners can consider the feasibility of offering HIV-specific mental health services. Numerous questions may arise regarding such issues as implementation, cost, staffing, and the political environment. Some of the most critical areas identified by the Demonstration Program are described below.

Existing organization. Adding a new, HIV-specific mental health program to an existing administrative structure can have both advantages and disadvantages. Personnel at all levels of an organization may be affected by the challenge of changing an existing service delivery structure. Program administrators may want to conduct a careful analysis of these pros and cons prior to proposing such a dramatic change in an organization's scope of services. Some key areas to consider regarding the organizational factors are:

- **Historical responses to change.** How has the organization changed to adapt to client needs in the past? Do staff or administrators view change negatively? Is organizational change usually a random occurrence, causing anxiety among staff and clients? Or is change a routine and ongoing process? It is important to define change as a positive action and to set an agenda for regular review and revision of organizational and programmatic efforts. This approach can help staff anticipate and prepare for the possible outcomes of change.
- **Mission and vision.** Does the organization have a clearly stated and clearly articulated mission? Does the program itself have a realistic vision for the kind of positive impact it can have on the lives of clients? Do existing staff, administrators, board members, and other relevant personnel support the program's vision and share a commitment to making the vision a reality? If the answer to any of these questions is "no," then the program's ability to meet the needs of its clients in a unified fashion may be severely compromised.
- **Philosophical approach to working with clients.** Too often, health care professionals assume that everyone in the field is equally committed to the general goal of doing what is best for the client. In reality, however, there are many ways to serve clients effectively, and different professionals may have different values or perspectives when it comes to delivering services.
- **Flexibility around established procedures.** Will staff in the new program be required to complete organizational paperwork that does not pertain to their work with clients? What are the costs to the organization if established procedures are not undertaken by staff? It is important to weigh the costs and benefits of requiring program staff to perform established procedures, especially since they will have the additional task of serving HIV-infected and -affected individuals that other organizational staff may not have.

Funding (short-term and long-term). Funding for services is the fuel that enables a program to run efficiently and effectively. Far too often, service planners underestimate the costs associated with providing certain services. To avoid this problem, program staff should carefully consider the range of services that are essential to meet client needs, the number and type of service providers available to the program, necessary equipment and materials, overhead, and indirect costs. An old-fashioned and carefully crafted budget is still the best way to determine if the available financial resources are sufficient to meet the program's service goals.

This budget may include:

- **Sources of reimbursement**, such as client payment for services, Medicare and Medicaid, and private health insurance
- **Outside funding sources**, such as federal, state, county and city governments, private foundations, charitable organizations, and United Way funds
- **Ryan White CARE Act** funding
- **In-kind contributions**, such as staff, office space, utilities, furniture, or equipment

Once funding sources are identified, program planners and administrators can become better positioned to determine the economic feasibility of providing the range of services that were originally planned.

Sources of reimbursement:

Outside funding sources

Ryan White CARE Act

In-kind contributions

Political climate. The level of support for a new HIV-mental health program may be closely tied to, or dependent upon, the current political climate in which the program will operate. Some program efforts (e.g., needle exchange or condom distribution programs) may not receive support from certain parts of the community. Many political leaders have different points of view about funding priorities (e.g., whether limited resources should be allocated to local, county, or state levels). Programs that opt to provide a certain service may find themselves in competition for funds with other organizations providing similar services. Administrators will want to discuss plans for new services with representatives of other community or state organizations to determine if new services will be supported and embraced by state and local political leaders.

IMPLEMENTING THE PROGRAM

After funding has been secured, the organizational factors have been considered and managed, and the program design has been established, it is time to put the program into action. Once the program begins the implementation phase, staff may find that there is a greater demand for services than the program is able to provide. To manage funding, human, and service resources effectively, program planners and administrators will have to establish priorities.

Triage plan. Most programs would like to provide services to everyone who needs them, but trying to meet everyone's needs will probably result in depleting already limited resources sooner than expected. Before things get to this point, it is wise to establish a detailed, yet flexible, triage procedure that outlines specific inclusion and exclusion criteria.

Space. The provision of mental health services requires a safe, confidential atmosphere. Offices in which clients will receive services need to be enclosed to prevent others from eavesdropping on conversations between the service provider and the client. In designing or planning the use of office space, reception areas, and waiting rooms, consideration needs to be given to ensuring confidentiality, equal treatment, and handicapped access.

Staff. The recruitment of trained and motivated staff is critical to establishing new services. Administrators need to determine if an adequate supply of

human resources is already available or if additional staff need to be recruited. (For additional discussion about staffing issues, see Chapter 3.)

Service Intensity. Different persons not only need different services, but they also need varying "doses" of services. Too many agencies establish a service model that expects the services offered to be sufficient for all clients who walk through the door. The fact is that no single organization can provide all the possible combinations of services needed by persons living with HIV. Programs need to consider the following questions:

- Will the program provide support services in addition to mental health services?
- To what extent is the program able to meet the transportation needs of clients, such as giving clients bus tickets or taxi vouchers, so they can attend their sessions and other health-related appointments?
- What kind of formal and informal linkages will the program have with other providers who serve people living with or affected by HIV?

Resources for staff. In addition to having an enclosed, private space to meet with clients, staff may need access to password-secured computers and locked file cabinets for storing confidential materials. Staff who conduct work outside of an office setting (e.g., outreach workers) may need pagers or cellular telephones to maintain contact with clients and other service providers. If a program intends to provide transportation, agency cars or vans are needed.

...service, training, and evaluation...

Publicity and marketing. Existing service organizations cannot assume that clients will simply hear about new services and request them. Services need to be marketed to clients and other service providers. Service providers and potential clients need to know what mental health services are and how clients can benefit from them.

Clients and service providers also need to be educated about the warning signs of diagnosable and treatable mental disorders. For example, many individuals living with or affected by HIV often may feel "sad," not realizing that they may be experiencing a depressive disorder. How a program informs and educates potential clients and referral sources about mental health issues and new services is a key challenge. Inviting service providers and potential clients to educational workshops that explain what mental health services are and how they can help people living with or affected by HIV is one suggestion. Publicizing services can be done by handing out flyers at a local grocery store or

sending a one-page description of the program to other service providers in the community.

Staff training. Program administrators have to provide awareness training to all personnel within their facility to make sure they understand what the newly established services are, when a potential client should be referred for mental health services, and what the benefits are for the clients. In addition, existing staff need to know how these new services may change the scope of their duties. Staff may express anxiety or anger about taking on new responsibilities, or they may fear that they will lose their jobs when new (and perhaps more experienced) staff are hired. (See Chapter 3 on Staffing.)

Policy and procedures manual. It may be useful and beneficial to develop a "Policy and Procedures Manual" that can be modified as new situations arise. The manual may include up-to-date copies of all organizational and program forms, such as intakes and assessments. New procedures can be reviewed frequently by appropriate staff early in the program implementation process.

Program evaluation. An important lesson learned from the Demonstration Program was that the evaluation of services should be considered early on in the program development process. Program administrators need to set aside funding for evaluation and for educating staff about the importance of evaluation in informing program decisions and policies. (For a more comprehensive presentation of these issues, see Chapter 14 on Evaluation.)

SUSTAINING THE PROGRAM

Sustaining an HIV-specific mental health program is about much more than funding. It is also about recruiting and retaining staff; providing staff training; engaging and retaining clients; coordinating services within the network of available services; keeping providers informed of emerging clinical issues and procedural changes; and preventing or reducing provider burnout. These program development issues are discussed in more detail later in the Practical Guide and are critical to the program implementation process.

CHAPTER 2:

Collaborative Networks

Because HIV affects a person along the entire biopsychosocial spectrum, clients need access to a variety of systems of care. One of the key lessons learned by the Demonstration projects was that collaborative networks can be vehicles to help ensure that service provision systems are responsive and effective in meeting the multiple, complex needs of people living with or affected by HIV.

A collaborative network is a series of formal or informal relationships between and among individuals and organizations designed to further programmatic goals and objectives. While it is difficult to establish high-quality and effective services independent of existing services, collaborative networks allow providers and administrators to benefit from the experience of other organizations in the community that share a commitment to serving people living with or affected by HIV. Most importantly, collaborative networks can dramatically enhance the range and accessibility of services available to clients.

What Types of Service Organizations Can Benefit From Collaborative Networks?

- primary medical care organizations
 - AIDS service organizations
- academic institutions
 - cultural and ethnic service organizations
 - hospitals
 - dental clinics
 - food banks
 - religious organizations
 - job placement agencies
 - city, state, and federal agencies

The biggest winner in the network approach is the client. New programs also can benefit from collaborative networks. For example, involvement in collaborative networks can:

- increase client access to care
- eliminate barriers to care by providing a broader range of supports for clients, such as transportation, child care, medical services, housing, education, and food
- facilitate the sharing of information, knowledge, experience, and resources between individuals and organizations
- improve the coordination of multiple services across multiple systems
- prevent duplication of services
- reduce or eliminate service gaps
- create new opportunities for funding
- improve communication between front-line staff, service providers, and representatives of different agencies
- increase opportunities among service providers for referrals
- promote a strong sense of “community” among providers
- reduce competition between and among service agencies

WHAT A COLLABORATIVE NETWORK MAY LOOK LIKE

Networks often begin between individual service providers who share a client. These networks can develop into teams that evaluate treatment on an ongoing basis. It is important to maintain a client focus in these teams and to come to an agreement about who does what. It also is imperative to identify confidentiality standards and appropriate boundaries. Most importantly, since the most disenfranchised clients will be the first to get lost between service providers, special care must be taken to ensure that these clients do not fall between the cracks.

Collaborative networks can become more formalized through letters of agreement between two or more organizations, such as when an HIV/mental health program contracts with a local group to do street outreach. These letters should identify the specific services, information, and resources to be shared between the organizations.

What is a Collaborative Network Worth?

In Los Angeles and Atlanta, local funding is determined by a program's ability to demonstrate linkages and networks with other service providers in the community. Some collaborative networks seek funding as a single source to fund their various programs.

Federal Resource Contact Information

CDC National AIDS/HIV Hotline	800.342.AIDS
CDC National AIDS Clearinghouse	800.458.5231
Center for Mental Health Services	http://www.mentalhealth.org/
Substance Abuse and Mental Health Services Administration	http://www.samhsa.gov/
Health Resources and Services Administration	http://www.hrsa.dhhs.gov/
National Institute of Mental Health	http://www.nimh.nih.gov/

...planning, funding, and information-sharing structures...

How to Find Local Planning Councils

Local Ryan White planning councils can be an excellent resource for establishing collaborative networks. Information about local planning councils can be found on the Internet at www.hrsa.dhhs.gov/hab or by calling the Health Resources and Services Administration, Office of the Director, at 301.443.1993.

Many communities already have formal networks in place. It is important for new programs to be aware of existing networks in the community and the resources they can offer. For example, on a local level, Ryan White CARE Act money is distributed through planning councils. New programs may want to build relationships with representatives on the council or seek representation on the council—either of which can help foster program sustainability. Both the Los Angeles and Chicago programs have been able to continue to offer services directly as a result of networking efforts with their local planning councils. In Atlanta, the collaborative network formalized into the Ryan White Mental Health Task Force to guide HIV-related mental health funding.

Hierarchically, there also are existing structures at the state and federal level. These planning, funding, and information-sharing structures serve as valuable resources in initiating and developing service programs and collaborative networks, as well as providing education and prevention materials.

Common Issues That Arose When Demonstration Projects Created Collaborative Networks

ISSUE POSSIBLE SOLUTION

Identifying participants

Seek a blend of different administrative and functional levels (e.g., a mixture of line staff, clients, administrators, and evaluators). They must all share one characteristic—they are key people to disseminate information within their own constituent groups and return to the table with feedback.

Selecting the meeting location

Select the easiest and most accessible site for most members. Consider rotating locations.

Addressing turf issues (funding, clients)

Openly discuss instances when members are going to be competitive and cooperative, especially around seeking Ryan White funding and providing client services.

Maintaining interest and participation

Find members who will take their participation seriously. Rotate responsibility for sustaining the network. Orient new members (especially clients) to the value of networks and how they work.

Making participation worth the members' time

Clarify the purpose of the network and what members can “get” from their participation. Consider holding topic-centered meetings or workshops (e.g., on shelter resources) so that members can know in advance what they are going to do and gain. The purpose and content of the meeting should justify the network.

Maintaining confidentiality

Privacy of personal information of participants and/or shared clients must be respected. Consider establishing “ground rules” that deal with this issue, as well as other issues of respect and privacy.

Addressing tension between members about the mission of the network and service provision issues

Allow members with differing missions and ideas about service provision to offer training to other members as a way of outlining their points of view. Invite other members to their respective places of work to show their missions in action. Agree to disagree in some instances.

Responding to change in leadership in the network or within member organizations

The importance of maintaining the network supercedes changes in leadership. If the leader leaves or becomes de-funded, some other agency/representative needs to take the initiative to guarantee the ongoing vitality of the network. When leadership changes within organizations, seek the support of new administrators and leaders to allow staff time to participate in networks. Ask the predecessor to underscore the value of the network to his/her successor.

Dealing with disagreements about individual client care in formalized client centered networks (case conferencing, etc.)

Maintain an open dialogue about various approaches to care. Agree early on to discuss differences. Members of the team who clearly understand the importance of confidentiality and boundaries in the therapeutic relationship can educate other members about maintaining these boundaries. Agree to disagree.

DEVELOPING, MAINTAINING, AND EVALUATING NETWORKS

Although formal networks may already exist in a community, some programs may find it necessary to forge new networks to meet service goals for their population. For example, a program may discover that its mechanism for referring clients to primary medical care, substance abuse treatment, housing programs, and case management needs to be strengthened. To address this need, a program director could convene a meeting of local service providers in these areas to create a mutually beneficial referral network, to address and decrease barriers to services, and to prevent duplication among partner organizations. Ultimately, these meetings may lay the foundation for an ongoing network that continues to meet regularly, working in close partnership for many years to come.

When establishing networks, it is important to carefully consider the composition of the network. It has been the experience of some of the Demonstration projects, however, that the membership may simply come down to those who keep showing up. This process can be viewed as natural selection. The members who return are those who are most vital to the continuation of the network.

Evaluating a collaborative network can provide valuable information about program and client outcomes. For instance, an evaluator can help collaborative networks better understand the value of forming networks and their effectiveness in increasing standards of care, how the network addresses service gaps, how the network strengthens ongoing inter-organizational relationships, and how the network affects client outcomes. The processes for evaluating a network are similar to those for evaluating a program. (See Chapter 14 on Program Evaluation.)

As noted throughout this Practical Guide, HIV infection is a dynamic illness, so individuals and organizations must be flexible in adapting to the changing needs of clients. Collaborative networks can serve as a vehicle to stay current and provide appropriate responses to change.

CHAPTER 3:

Staffing

Staffing a program to serve the mental health needs of HIV-infected and -affected individuals can be a lengthy and time consuming process. Program directors need to do the most they can up front to hire or train the “right” staff to address the multiple issues confronting persons living with HIV. Before undertaking such an endeavor, it is crucial to have certain organizational and program elements in place. (See Chapter 1 on Establishing Services.) The most significant factors to examine and act upon when hiring or re-assigning staff for an HIV-specific mental health program are found in this chapter.

STAFF COMPOSITION

The staff composition of the 11 Demonstration projects included social service case managers, social workers, psychologists, psychiatrists, psychiatric nurses, substance abuse treatment counselors, medical doctors, medical case managers, nurse practitioners, physician assistants, outreach workers, pastoral care providers, HIV-positive peer providers, and other paraprofessionals. A program's staff composition depended on the program's focus, and the needs and service utilization patterns of the target population. (See Chapter 1 on Establishing Services.)

STAFF CHARACTERISTICS

Certain staff characteristics are highly desirable when it comes to meeting the mental health, substance abuse, and case management needs of people living with or affected by HIV. Some key traits to look for include those identified below.

Commitment to the program's mission, vision, and philosophy. It is important to get a sense of how staff see themselves applying the program's mission, vision, and philosophy in client interactions. For instance, several Demonstration sites experienced difficulty in finding staff who not only understood their program's philosophy and model but also knew how to operationalize its concepts. For the sites who overcame these difficulties, staff adapted and integrated their professional training and field experiences and/or their personal recovery strategies in order to fully carry out the mission, vision, and philosophy of their programs.

Cross-cutting competencies and skills. It is important to have the following knowledge and skills represented in a program's staff:

- Mental health treatment practices and modalities, such as individual, group, family, and peer-led therapy and counseling, as well as neuropsychiatric and psychiatric services and neuropsychological testing
- Substance abuse treatment practices, such as harm reduction and 12-step programs
- Biomedical practices in the ever-changing treatment of HIV, such as the evolution of the virus itself, new medications, their side effects, and new opportunistic infections
- Holistic approaches to treating the complications of HIV, such as aromatherapy, acupuncture, or herbal therapies
- Awareness of the service system and its political context
- Knowledge of local resources
- Experience in using evaluation tools to measure client outcomes

Diversity. Staff need to be demographically similar or relate easily to the target population in terms of ethnicity, age, gender, class, sexual orientation, language, culture, life experiences, and HIV status. However, demographic matching is not always possible, nor does it necessarily guarantee the best "fit" between staff, clients, and the program's mission. Program planners also need to look for providers who share similar values and beliefs with clients, as well as providers who have the most appropriate skills to meet the client's needs. Demographic matching, value matching, and skill matching are equally important.

Flexibility with clients. Since people living with or affected by HIV present with multiple and dynamic needs, staff may need to adapt traditional ways of working to meet clients “where they are.” For example, some clients will benefit from after-hours appointments or make unscheduled visits. Within the therapeutic relationship, staff likely will be called upon to change their approach from time to time. Whether it be assuming case management responsibilities or altering the format and goals of treatment so that they are more relevant and appropriate for the unique needs of each client, flexibility is an essential characteristic for service providers.

Sensitivity. Clients often present with values, beliefs, and behaviors that conflict with the worker’s values, beliefs, and behaviors. Staff must have the capacity to remain nonjudgmental and avoid any hint of “moral superiority.”

Empathy. Living with HIV and its accompanying uncertainties, stigma, demanding medication regimens, and emotional stressors is a challenge, especially when HIV occurs in tandem with mental health, substance abuse, and other physical disorders. Staff who are able to understand these issues from the client’s perspective are better equipped to engage and retain clients in treatment.

HIV-Specific Mental Health Training Opportunities

The Mental Health Care Provider Education In HIV/AIDS Program II, funded by the Center for Mental Health Services, is an interdisciplinary program that promotes training opportunities for the full cadre of mental health care providers who serve people affected by HIV, including traditional mental health care providers, such as psychiatrists, psychologists, nurses, social workers, counselors, marriage and family counselors; other front-line providers of mental health services, such as medical students and primary care physicians; and nontraditional providers, such as clergy, other spiritual providers, and alternative health care workers. The program supports seven grants to universities across the nation that provide HIV/mental health-specific training opportunities to professionals in their communities. In addition, the American Psychiatric Association, the American Psychological Association, and the National Association of Social Workers provide training and education opportunities for mental health professionals who are members of, or affiliated with, these three national organizations.

For more information about possible training opportunities, call 1-800-789-CMHS (2647) or go to <http://www.mentalhealth.org/> on the Internet.

In-Vivo Training at the Los Angeles Project

At the Los Angeles project, social work interns observe staff clinicians as they conduct psychosocial intakes (with the client's prior permission). Interns then complete the next round of intakes with a staff clinician observing and intervening when necessary. Since direct observation of individual therapy sessions often is impossible (unless a facility is equipped with two-way mirrors), process recordings can be an effective way of teaching clinicians how a session should be conducted. (See Appendix B for the form that the Los Angeles project uses for process recordings.) In addition, the use of audio recordings provides instant feedback for clinicians and supervisors.

Comfort with difficult issues. Addressing death and dying issues—both in the abstract and on a personal level—is extremely important. Comfort with sexual issues on several levels, including being comfortable with one's own sexual identity, thoughts, and behaviors; accepting differences in clients around sexual promiscuity, experimentation, and expression; and being comfortable talking about sex, sexual abuse, incest, and death issues concurrently with clients also is important.

Determination. Staff likely will face barriers from clients, co-workers, systems, and other service providers. After fighting many such battles, staff may become discouraged. With support from supervisors, staff must persevere and seek help when they experience low morale and burnout. (Burnout issues are discussed later in this chapter.)

Ability to be a team player. To meet the diverse needs of clients, staff need to work closely and cooperatively with other service providers. Learning from one another, sharing responsibility, and reaching consensus are key staff attributes.

Ability to adapt to the changing nature of the epidemic. As the epidemic changes and as new research and treatment approaches continue to emerge, staff need to continually adapt their thinking and approach to how services are delivered. If staff do not have the knowledge or skills required to provide HIV-specific mental health treatment, it is important that they are open to learning about these areas so they can become better equipped to serve the target population.

Perseverance. With some clients, it takes a lot of energy and patience on the part of staff to initiate, stabilize, and maintain relationships and keep clients engaged in services. While the client may relapse or want to discontinue services, staff need to reach out and press onward so that clients can accept the help they need.

Sheila's Story

In addition to mood swings stemming from her bipolar disorder, Sheila was naturally drawn to dramatic and attention-seeking behaviors that got her into trouble. Monitoring the lithium adherence, the crack abstinence, and the natural peaks and valleys of Sheila's volatile relationships kept Dottie in a state of concerned vigilance. Over a three-year period, Dottie provided a wide range of case management services, including reinstating Sheila's Social Security disability check, helping her find progressively independent housing, securing emergency financial assistance, counseling and coaching her for court appearances and job interviews, and accompanying her during painful gynecological procedures.

The order was predictable. Sheila would skip her lithium, develop manic symptoms, relapse into crack use, and then re-enter detoxification—a cycle she repeated three times. The precipitant would be an upsetting event—a physical assault by her boyfriend, an appearance in court as a witness to a shooting, the incarceration of a younger brother, or a sharp drop in her T-cell count. Much of Dottie's energy was spent calming and reasoning, taking Sheila step by step through the consequences of her threatened actions.

Sheila handed Dottie her walking papers on many an occasion. Threats of suicide and homicide (toward a boyfriend) required at least one psychiatric hospitalization. Dottie remained steadfast, tenacious, available, non-judgmental, and persistent. When Dottie returned to the office, out of breath after a high-heeled chase through an alley to the crack house, even her supervisor cautioned against "excessive pursuit."

From their first meeting at the jail, through a shelter placement, a residential group home, and finally Sheila's own place and a part-time job, Dottie demonstrated the intensive case management, outreach, careful monitoring of medication adherence, and consistent follow-through necessary for Sheila to come to grips with her triple diagnoses. Above all, Dottie made evident through her actions her unflinching belief in Sheila's worth and her ability to significantly improve the quality of her life.

Dottie, a psychiatric nurse, demonstrated some of the staff characteristics put to effective use in working with Sheila, a triply diagnosed client.

STAFF TRAINING

Staff training should be driven by a program's staff composition, the services offered, and the needs of the target population. Ideally, staff training should incorporate the following elements.

Orientation to the organization, the program, the work, and the clients. All staff should receive training about the organization's and program's mission and vision, as well as its functions and operations. Staff also need to know where they "fit" in the program and the roles and responsibilities expected of them.

Continuous and ongoing training opportunities. Training should be updated to reflect changes at the macro-level (e.g., changes in the epidemic, psychotropic medications, and local resources) and the field's response to such changes. In addition, staff need to be trained when these changes affect day-to-day program operations and procedures.

Experiential and didactic formats. Training has the best effects when it is both experiential and didactic. If possible, conducting direct observations of staff as they perform their jobs can be an important part of training and quality assurance.

Multidisciplinary training conducted by other staff. Training curricula can be developed and delivered by staff from different backgrounds and orientations—including staff from other agencies and

...training from
multiple
perspectives...

programs. Training from multiple perspectives helps staff better understand the role of different providers in the service delivery process. It also can provide staff with ideas on how to work with other providers.

Match the needs of staff to changes in the epidemic. Training opportunities can address individual staff and team needs, as well as areas of weakness. A training needs assessment, conducted with the input of staff, can be an effective way to identify training needs and areas of weakness. Another way to assess training needs is to interview clinical supervisors. Individual staff training may be necessary for individuals who have greater needs or areas of weaknesses.

TRAINING INITIATIVES CONDUCTED BY DEMONSTRATION PROJECTS

Throughout the Demonstration Program, the 11 projects implemented a broad range of training initiatives related to HIV, mental health, substance abuse, and case management. (See Figure 6.) The projects also conducted trainings on many other topics, including the following areas.

Desirable staff characteristics. Not every staff member can possess the characteristics described previously in this chapter. Training should be provided to ensure that these characteristics and skills are discussed and conveyed to staff as being vital to their work with clients.

Group interventions. For programs that offer group treatment, the following staff training topics were found to be useful by the Demonstration sites:

- Learning about group facilitation and skills (e.g., role plays)
- Understanding clients' information-processing styles
- Learning about the different ways to educate clients
- Understanding the issues that may arise from integrating clients with different life experiences (i.e., social, class, and cultural differences) in group situations
- Understanding the issues that may arise when clients with varying degrees of mental health problems participate in the same group

Safety issues. Clinics that provide HIV-specific mental health services should have a viable safety plan in place if a client becomes aggressive or loses control. This plan can be communicated to each employee through a series of trainings. Local county departments of mental health often provide Management of Assaultive Behavior training, and every staff member should be trained under such a program.

Special populations. Specialized training may be required to increase staff awareness of and sensitivity to issues predominant in special populations (e.g., HIV-positive women and their children; people who are transgendered; and ethnic and cultural minorities). Training can help staff recognize multicultural nuances of service delivery and provide a framework for working effectively with these special populations.

Legal issues. There are many legal issues associated with providing services to people living with or affected by HIV. For example, there may be restrictions on the kinds of services a program may offer (e.g., needle exchange programs) or on service providers themselves (e.g., duty to warn or confidentiality laws). In addition, staff need to know about a client's legal rights, such as his/her eligibility for entitlements. Specific training on these issues can help ensure that programs operate within the confines of the law and assist staff in providing high-quality services, including access to HIV-specific legal assistance.

Figure 6

Examples of Training Topics Used in the Demonstration Program**Substance Abuse Issues:**

- Different theories and interventions, including harm reduction vs. abstinence orientation
- Relationship between substance abuse and HIV
- Interaction between legal and illegal psychoactive substances and medication
- Similarities between marinol and marijuana, and cocaine and anti-depressants

Mental Health Issues:

- Categories of mental illnesses, especially those associated with HIV
- Current psychotropic medications and treatment modalities
- How to incorporate HIV-specific and primary medical needs into the clinical assessment of clients
- Working with clinicians from multiple disciplines, including medical care providers
- Exploring death and dying issues
- Addressing ambivalence associated with sexual expression
- Integrating HIV as a chronic illness into assessment and psychotherapy
- Interactions of psychotropic medications with HIV medications

Primary Care Issues:

- Basic training on HIV and how it attacks the immune system
- Current medication and treatment regimens
- Basic information on HIV and opportunistic infections
- How to help clients adhere to medical regimens
- New developments in HIV and its effect on medication and treatment

Case Management Issues:

- The existing service delivery environment and the contacts within each system
- Existing linkages (informal, or formal) between the organization and other service providers
- How clients and/or the program can access federal, state, and local services and entitlements
- Ways to empower clients so they can navigate numerous systems effectively
- Confidentiality issues, such as state reporting requirements and partner notification standards

supervision... an important component

SUPERVISION

Staff supervision is an important component of programs delivering HIV-specific mental health services. The goal of supervision is to train, lead, motivate, and support staff around clinical and programmatic issues. Supervision also helps ensure that clinical services reflect the program's commitment to quality assurance. Areas of focus for supervision may include the supervisee's:

- therapeutic relationships with clients
- professional relationships with the supervisor and other staff
- fidelity to the program's mission and philosophy
- application of desirable characteristics in his/her work with and on behalf of clients

Desirable Characteristics in a Supervisor

The 11 Demonstration projects identified the following qualities beneficial in a good supervisor:

- sound clinical judgment
- unflappability
- creative problem-solving
- knowing when and how to lay down the law
- ability to contain anxiety
- a therapeutic approach grounded in research and experience
- a fair, even-handed approach to the work
- willingness to include staff in decision-making
- motivation and the ability to motivate others
- a sense of humor
- a non-shaming and non-blaming approach to his/her work
- sensitivity to burnout and the emotional toll associated with serving people with HIV
- a capacity for nurturing that fosters independence
- good listening skills
- a willingness to consider and try new approaches to service delivery

SPECIAL STAFFING ISSUES

Transference and countertransference. Transference and countertransference are concepts from psychoanalytic theory that are used broadly by mental health practitioners and are particularly useful to understand when providing mental health services to people living with or affected by HIV. Basically, transference is the phenomenon of the client projecting his/her feelings, thoughts, and wishes onto the therapist who has come to represent someone from the client's past. Transference may be either positive or negative (e.g., the client overvalues or undervalues the therapist without basis in reality). In working with HIV-positive persons, some clients will re-experience unresolved past issues. It is therefore helpful for therapists to be aware of transference and the particularly rich frame it provides for therapeutic work.

Some client concerns that led to transference reactions at the Demonstration projects were:

- past experiences with helping professionals
- thoughts and feelings toward illness and dependency
- past experience in intimate and familial relationships
- thoughts and feelings about HIV
- beliefs about sexuality, homosexuality, and substance abuse

It also is important for therapists to be aware of countertransference and how it may arise in the provision of HIV-specific mental

health services. Countertransference refers to the phenomenon of the therapist projecting past feelings and wishes onto the patient who has come to represent someone from the therapist's past. Because this is an unconscious phenomenon, therapists must be alert to what is occurring in the therapeutic process. Often, supervision is helpful in identifying countertransference issues. If countertransference continues unrecognized, it can obstruct a clinician's understanding of the client's situation or needs and may have a detrimental effect on the success of treatment.

Some therapist concerns that led to countertransference reactions at the Demonstration projects were:

- fear about "being contaminated" by the virus
- values, beliefs, and judgments about sexuality and homosexuality
- thoughts and feelings about meeting dependency needs of others
- relief in not being HIV-positive
- past experiences in intimate and familial relationships

Burnout. When staff have difficulty balancing their commitment and motivation with the stresses in their work, the result may sometimes be an onset of symptoms suggestive of burnout. The word "burnout" refers broadly to an individual's response to work-related stressors that have not been successfully managed or resolved (Macks & Abrams, 1992).

The process of burnout for HIV-specific mental health providers operates within a multi-layered context of adverse sociocultural issues (e.g., discrimination, fear, and stigma), harsh medical realities (e.g., multiple course of HIV and the lack of a cure), and difficult psychological circumstances (e.g., continued confrontation with hopelessness and helplessness, death, and dying). An understanding of this context and its influence on staff burnout will help program directors respond better to staff who begin to show signs of burnout (McDaniel et al, 1996). Burnout may be manifested in a variety of ways, including:

- **Physical symptoms**, such as chronic fatigue, changes in appetite, gastrointestinal problems, tension headaches, and sleep disturbance
- **Psychological symptoms**, such as alienation, depression, anxiety, irritability, loss of concern, negativism about self and others, and anger toward clients
- **Behavioral symptoms**, such as avoiding responsibilities, decreased productivity, under/overeating, lethargy, and increased alcohol or drug use

In some instances of burnout, program directors may be forced to accept the fact that some staff simply do not belong in an HIV service delivery setting. Perhaps they do not have the necessary coping skills, have worked too long and too hard to remain in this line of work, or HIV has taken its toll in their personal lives as well. Staff may need to take a respite from the work until they have restored balance in their lives.

Ways to Prevent Staff Burnout

The 11 Demonstration projects found the following efforts to be helpful in preventing staff burnout:

- Providing ongoing staff support
- Helping staff learn new skills and techniques so they remain interested in their work
- Revamping or eliminating cumbersome or unnecessary procedures, such as paperwork and reporting requirements
- Using different strategies to motivate staff
- Promoting team building by doing activities together, such as holding staff retreats
- Balancing caseloads
- Delegating authority so that staff feel a greater sense of control over their work
- Supporting and nurturing staff members' special interests
- Frequently acknowledging and rewarding staff contributions
- Giving staff "mental health days" off
- Asking staff to assume a variety of assignments so they are not dealing with the same difficult tasks every day
- Assisting staff in developing positive and healthy coping skills

Turnover. Any HIV-specific mental health program inevitably will encounter the challenge of managing staff turnover. Staff turnover is not necessarily a negative event. However, clients and staff may experience it as an additional loss. The following issues contributed to staff turnover at the 11 Demonstration projects:

- The pressures inherent in work with HIV-infected and -affected clients
- The emotional ramifications that can emerge when trying to help a client who does not want to be helped
- Experiencing the death of clients
- Inflexibility on the part of program directors to help staff meet the changing needs of HIV-positive clients
- Poor matching of staff with clients
- An historic and persistent shortage of resources to serve clients effectively
- Neglectful leadership
- Poorly operationalized program goals
- Ignoring the “red flags” that often lead to burnout
- Inadequate and non-responsive supervision
- Low pay and the lack of promotional opportunities

How a program intends to prevent high staff turnover should be articulated when the program is being established. In addition, organizational leaders must pay constant attention to the “warning signs” identified above. Otherwise, the program’s ability to serve clients effectively and consistently may be severely jeopardized.

DELIVERING SERVICES

CHAPTER 4:

Mental Health Services

People living with or affected by HIV need access to a broad range of mental health services. Some services may be more widely available, particularly traditional mental health services, while others have been developed in response to the unique needs of persons affected by HIV. This section of the Practical Guide describes the range of mental health services offered by the Demonstration sites in response to the ever-changing impact of HIV infection on the biomedical, psychological, social, cultural, and spiritual dimensions of each client's life and experience.

...a flexible approach to engaging clients.

ENTERING THE MENTAL HEALTH SYSTEM

People living with HIV may enter the mental health system through a variety of means:

- Referrals from medical and allied health staff of hospitals, both from general medical units and from inpatient psychiatric units
- Community-based public health clinics, including Sexually Transmitted Disease/HIV testing programs
- Non-governmental organizations providing community-based HIV-related services
- Public and private providers of substance abuse treatment
- Various levels of the legal and court system, including prison/jail discharge planners, parole and probation offices, community-based ex-offenders' groups, and child protective services
- Peer-led HIV service and support organizations
- "Word of mouth" referrals
- Social services staff at local government levels
- Community-based providers of services to people who are homeless
- General mental health service systems, both publicly and privately based, that do not possess the capacity to provide HIV-specific mental health care

Clients with HIV infection who enter the mental health service system may have long-standing mental and/or addictive disorders that were present prior to HIV infection. Some may develop symptoms of a mental disorder—such as a mood or adjustment disorder—in response to learning of their HIV status, while others may develop more serious symptoms of psychosis or mania due to the progression of HIV infection itself. Regardless of the severity or duration of mental and/or substance abuse problems, some people living with HIV experience powerful feelings of loss, shame, and guilt related to HIV infection and may cope through deeply held denial or avoidance.

Clients can benefit from a broad range of HIV-specific mental health interventions. However, for some, it may be very difficult to acknowledge a personal need for mental health services. The mental health service system needs to take a flexible approach to engaging clients. For example, a client may not attend one or several scheduled intake appointments. Service providers need to accept this and be willing to reach out to and engage the client. A section discussing approaches to enhance the engagement of clients follows the overview of services described below.

SERVICES OFFERED

The following services, either alone or in combination, comprise the foundation of mental health treatment offered by the Demonstration projects. Some of these services will be described in more detail later in this chapter. Determining the package of services that will be clinically useful involves an accurate and comprehensive assessment of clients' functioning so that the link to appropriate treatment and services can be made successfully. For instance, a client recently released from prison who had been receiving psychotropic treatment for bipolar disorder and recently began Highly Advanced Anti-retroviral Treatment (HAART) to slow the progression of HIV will need a formal biopsychosocial assessment that may prompt linkages to case management, psychiatric evaluation, medication management, psychotherapy, residential services, or psychosocial rehabilitation, when indicated.

As a component of each service, it is important to incorporate a discussion of risk reduction strategies, specifically ways for clients to promote safer sexual behavior and safer drug use for those clients who use drugs. As more advanced medications become available to prevent the progression of HIV, it is critical that mental health clinicians use their unique perspectives to assist clients in adhering to complex medication regimens. Becoming aware of the psychological and social barriers that may inhibit client adherence to such life-extending medications needs to be addressed in the helping relationship between clinician and client.

Psychotherapy and counseling. Sometimes referred to as “the talking cure,” psychotherapy or counseling with a person with HIV infection can occur at many levels, through diverse modalities, and from different theoretical perspectives. Some clients are only interested in looking at their immediate situation, resolving issues that may cause present pain, ongoing relationship struggles, coping with HIV infection, or sorting out job options. Others may move toward a deeper examination of their past and the early childhood alliances and formative experiences that may have shaped their sense of self, their current relationships, or their functioning.

Clients with a history of sexual abuse often discover that working through aspects of childhood trauma can be both a liberating and necessary step in moving toward a commitment to self-care and risk reduction. Psychotherapy can help clients develop greater self-awareness, stronger coping skills, and greater motivation to engage in meaningful and productive activities. Clients with a history of substance use often discover and begin to heal—through counseling or psychotherapy—the underlying pain against which they have long sought to medicate themselves. (See Chapter 8 on Psychotherapy and Counseling for a discussion of psychotherapy treatment modalities and theoretical approaches used by the 11 Demonstration projects. See Chapter 9 for more information on counseling themes.)

Case management. Past experience in serving people with serious and persistent mental illness in community mental health centers led to the development of case management as a supportive approach that provides clients with case managers who link and refer clients to needed services—such as additional mental health treatment, entitlements, housing, clothing, and financial assistance—and advocate on behalf of the client to other agencies and organizations. As trust develops, case managers may be able to introduce more traditional mental health services. Seeking change in a supportive case management relationship in which there are mutually identified service goals may lead to greater empowerment for clients. Ultimately, clients may gain skill and comfort seeking additional services for themselves. (See Chapter 7 on Case Management.)

Psychiatric evaluation. Completed as part of a formal and comprehensive biopsychosocial assessment, the psychiatric evaluation involves assessing clients' presenting mental health symptoms, past psychiatric treatment, current mental health status, and the appropriateness of a psychotropic medication evaluation. Psychiatric evaluations also may be helpful in obtaining a consultation related to diagnoses or further evaluation of neuropsychiatric symptoms. Clients with a history of psychotic mental illness or those with past or current diagnoses of mood disorders (e.g., depression and bipolar disorder) and anxiety disorders may benefit from taking medications that alleviate their symptoms.

Medication management. Once medications have been provided by the prescribing clinician, follow-up is required to ensure that clients understand medication dosing and side effects, to monitor medication effectiveness and adherence, and to watch for possible adverse effects. There is a heightened need for sensitivity regarding adverse drug effects when working with those with HIV due to possible interactions between psychotropic drugs prescribed simultaneously with HIV-related medications. In addition, close monitoring of organ functioning and blood levels is needed, given the presence of HIV infection and other chronic medical complications.

Inpatient psychiatric hospitalization. Stabilizing a client's psychiatric symptoms may not always be possible in an outpatient setting. Staff often will recommend inpatient psychiatric hospitalization. Clients may voluntarily agree to such hospitalization, recognizing the need for greater structure and supervision. However, there may be a need for involuntary commitment and detention to an inpatient psychiatric setting for those whose threats of harm to self or others have been assessed as acutely dangerous and whose symptoms or behaviors interfere with accepting help. Psychiatric hospitalization involves a thorough biomedical and psychiatric assessment that may lead to changes or improvements in psychotropic treatments. These efforts are supplemented with group treatment, occupational therapies, and multidisciplinary inpatient care.

Emergency services. Working with persons who have mental disorders requires the availability of emergency and crisis intervention/stabilization services, as well as the programmatic flexibility to accommodate “drop-in” visits when needed. The re-emergence of psychotic symptoms, or decompensation, requires immediate assessment and intervention. Similarly, threats of suicide and/or homicide must be assessed to determine a client’s intent, history, plan, and means to act. The stress of living with HIV may require heightened monitoring of those most at risk for harming themselves or others.

Psychosocial rehabilitation, partial hospitalization, and psychiatric day treatment. For those with serious and persistent mental illness, psychosocial rehabilitation programs offer day support to enhance self-care and social functioning, and to stimulate a sense of self that incorporates and internalizes the ability to manage oneself (See Chapter 13 on Psychosocial Rehabilitation). Partial hospitalization programs provide more intensive outpatient treatment for those whose mental health symptoms seem too deeply entrenched to be alleviated by outpatient psychotherapy. These approaches include more frequent, often daily, monitoring of medication adherence and greater support, including the use of group work. Partial hospitalization and psychiatric day treatment may be a short-term intervention during times of intensified symptomatic distress and risk.

Residential services and treatment. For those for whom independent living may be too unstructured, residential services may offer placements with varying levels of staff support that seek to maximize medication adherence, social living skills, and self-care, and to introduce tasks of independent living in a consciously stepped fashion so that clients may find success in their efforts toward greater independence. A more structured environment, specifically as it relates to medication adherence, may improve medical and physical outcomes for persons with HIV infection who have lived in more chaotic circumstances, those who have cognitive impairments, and those who have not successfully adhered to their medication regimen. Residential treatment also is often a long-term and intensive intervention that may prove successful in helping clients maintain sobriety.

Expressive therapies. Art, music, dance, psychodrama, bibliotherapy, and other expressive therapies can provide a means to access and express emotional experiences that otherwise may not arise in talk-driven psychotherapy. Frequently, for those living with HIV, certain defense mechanisms, like denial and sublimation, serve to protect clients from overwhelming anxiety and fear related to HIV infection and its progression. Expressive therapies seek to uncover such distress in a non-threatening and non-confrontational manner so that the client may gain mastery over it.

COMPLEMENTARY TREATMENTS

Several emerging therapies may be used in combination with traditional mental health services to expand the choices available to clients participating in the development of their own treatment plans. In addition to the sense of empowerment that stems from having choices and assuming greater control in dealing with one's illness, complementary treatments may offer other means of generating psychological, emotional, and spiritual support. They also may offer relief from pain associated with neuropathy linked to antiretroviral therapies. Service programs may seek partnerships with a diverse range of clinicians who have expertise in these treatments and a clinical understanding of HIV and mental health issues, as well as an openness to collaborative and integrated care.

Herbal therapies. There is a growing interest in herbal therapies for the treatment of psychiatric symptoms such as depressed mood, anxiety, insomnia, cognitive slowing, and memory loss. Surveys of research literature have shown that St. John's Wort (*hypericum perforatum*) seems helpful in the treatment of mild to moderate depression (Linde et al, 1996). Similarly, Ginkgo Biloba has shown some efficacy and benefit for persons with moderate to severe memory impairment (LeBars et al, 1997). Other herbal therapies have not yet been found to be demonstrably effective for other mental health symptoms.

Acupuncture. A component of traditional Chinese medicine that dates back many centuries, acupuncture seeks to enhance energy flow with the use of

needles or pressure (commonly called acupressure or shiatsu) at certain points along the body's network of meridians that conduct chi (energy) through the body. Recently published findings indicate that acupuncture seems helpful for HIV and other medical conditions (Shlay et al, 1998). Though promising, research involving acupuncture's treatment for psychiatric purposes is not yet definitive.

Exercise. The physical benefits of exercise are well known and also may benefit clients with emotional distress. For example, involvement in some form of exercise seems to promote a decrease in symptoms related to mild to moderate depression. Additionally, for persons with HIV, exercise appears to reduce other emotional distress and enhance immune functioning (Perna et al, 1998). It is important to ascertain whether clients have previously been involved in exercise and their willingness to resume physical activity.

Stress reduction and relaxation techniques. Relaxation techniques seem to show promise in helping persons cope with anxiety and other distress. Guided imagery, progressive relaxation, meditation, visualization, and hypnotherapy have been shown to reduce emotional distress and promote well-being.

Other nontraditional therapies. Approaches such as massage therapy and body work have been found to be beneficial in reducing tension and alleviating some physical manifestations associated with HIV infection. Some believe that these approaches are useful as adjunctive measures in treating some mental disorders.

ENGAGING CLIENTS THROUGH OUTREACH

Many of the 11 Demonstration projects used outreach as a means to engage and retain clients who may not acknowledge a need for mental health care. In addition, many clients served by the Demonstration Program experienced numerous barriers (e.g., lack of transportation or child care, and psychological distress) that prevented them from keeping appointments or continuing to receive services. Service providers can engage individuals in the service delivery process by making repeated telephone calls, finding clients on the street, or making home visits. Outreach contributes to ongoing clinical service delivery by offering supportive telephone counseling and psychotherapy to persons who are unable to travel to the service site. Outreach can be performed by clinicians or paraprofessionals with sensitivity to individuals in alienated subcultures.

Treatment or services offered outside of the treatment facility. Clients in detention facilities, hospitals, shelters, long-term care facilities, and those who require home-based services often lack access to treatment and support services. By meeting clients where they are, clinical staff can successfully reach people with disabilities, those with debilitating medical complications, those who cannot afford transportation, and parents whose child care responsibilities interfere with treatment. Off-site service delivery can be negotiated and reassessed periodically between clients and clinicians so that clients do not become unnecessarily dependent on clinicians or other program staff and can begin to receive or resume services at the agency setting when able or feasible.

...outreach
contributes
to ongoing
clinical
service
delivery...

COORDINATION OF CARE

Conducting joint assessments with primary medical staff. Offering joint assessments may decrease the need for multiple intakes for clients, reduce the administrative burden for clinicians, and lay the foundation for a team approach to treatment. Involving the client's primary medical providers in the assessment and delivery of mental health services enables providers and clinicians across disciplines to have a more comprehensive understanding of the client's primary medical and mental health needs. This step also fosters a treatment approach informed by a biopsychosocial perspective. Facilitating the development of provider teams also may reduce duplication of services and avoid damaging impediments to the therapeutic process, such as "splitting" or triangulation.

Offering interdisciplinary "prescription" team meetings with clients. When a client is receiving many services at the same time, such as medical care, case management, mental health, and substance abuse treatment, coordination of care among providers becomes essential for several reasons. First, duplication or gaps in service can be problematic. Second, clients with personality disorders sometimes pit one provider against another. And third, a client may present a particular display of symptoms to one provider and quite a different diagnostic picture to another.

By periodically bringing all players, including the client, to the treatment planning table, such obstacles can be addressed and clarified. The Alexandria

project makes frequent use of such prescription team meetings throughout the client's treatment. While, at first glance, coordinating and scheduling such a meeting may seem cumbersome and time-consuming, staff have uniformly found these meetings to be helpful in preventing confusion, misunderstandings, and wasted effort during the course of treatment. The sharing of information from different disciplines also enriches the knowledge, skills, and abilities among providers.

Such meetings can be useful at different phases of treatment. Sometimes, one provider through such a meeting can effectively link a reluctant or hesitant client to an historically stigmatized service such as mental health. In working with mothers who are connected to the Child Protective Service system, close coordination usually is essential. During times of crisis, when the client's situation needs to be stabilized or reassessed, or when an intervention needs to be initiated, the prescription team meeting can be a powerful coordination tool.

Expansion of the traditional mental health role. It was the experience of the Demonstration projects that clinicians benefited from being actively involved in case management activities and serving as a consultant to or liaison with the primary medical provider. In addition, clinicians were effective advocates in linking clients to other service providers as they sought access to entitlements and support services, such as legal advice. Once case management needs are identified, clinicians were able to determine the client's capacity to follow through with potential referrals.

Clinical Assessment

Working with persons with HIV infection in the mental health arena requires a comprehensive approach to the clinical assessment and treatment planning process that fully incorporates the biopsychosocial complexity of living with HIV. For many clients triply diagnosed with HIV, a mental disorder, and a substance abuse disorder, the clinical assessment will be a multi-dimensional and dynamic process.

Clinicians will meet with clients over several sessions to gather factual and perceptual information, draw hypotheses about what clients are revealing about themselves and their behaviors, and integrate what is learned into a diagnosis. Clinical assessments can then be used to develop client-specific treatment objectives that incorporate the client's history and current struggles, as well as his/her strengths and resources. This process requires thoroughness and sound clinical thinking, but is a critical step toward ensuring that each client's unique needs are addressed appropriately—and in a timely fashion.

Lessons learned from the Demonstration Program include the kinds of questions to ask, the value of informal and formal assessment, and issues to consider when conducting a clinical assessment.

AREAS TO BE COVERED IN THE CLINICAL ASSESSMENT

It was the experience of the 11 Demonstration sites that clinical assessments need to be tailored to a program's populations, its settings, and the purpose of its interventions. When clinicians have the opportunity to develop a more comprehensive clinical assessment, it is important to consider the complex biological and social needs of people living with or affected by HIV. This can be accomplished by adding HIV-specific questions to an existing clinical assessment that covers the following areas:

- demographics
- presenting problem
- psychiatric history
- mental status exam
- social history
- medical history
- alcohol and other drug use history
- risk level, including sexual risk-taking and intravenous drug use
- social support
- coping skills
- strengths
- financial and other resources
- employment history
- educational background
- religious and spiritual practices

Relating the Clinical Assessment to Program Issues

The following examples demonstrate how the questions asked in a clinical assessment are related to the program's populations, setting, and purpose.

- If a client comes into a community mental health center in a highly agitated state and is suicidal, then the assessment should focus on stabilizing the client and making sure appropriate safeguards are in place. More detailed information can be gathered after the client's crisis has stabilized.
- If a client is assessed for mental health issues as part of his/her medical services, then staff will likely conduct a screening rather than a comprehensive assessment. The outcome of the screening may include recommendations for further assessment, individual or group treatment, follow-up with clients during medical visits, or no treatment at this time. (See Appendix C for a copy of the screening tool used by the Chicago Project.)
- If a client comes into a psychosocial rehabilitation program for the first time, staff and other clients probably will want to begin by welcoming the client and introducing him/her to the program gradually. After building rapport, the following areas can be assessed: daily living activities; reading and education level; independent living skills; and leisure skills.
- If an HIV-positive custodial parent is bedridden and very sick, staff will likely conduct an assessment of the client's most urgent and immediate needs—putting off the assessment of permanency planning issues until the crisis is stabilized.

...a

multidimensional and dynamic process...

Whether the program is an HIV-specific stand alone program (see Appendix D for a copy of the assessment tool used by the Los Angeles project) or one that offers HIV-specific mental health services within a larger mental health organization (see Appendix E for a copies of the assessment tools used by the Alexandria project), a comprehensive clinical assessment needs to incorporate information from all these areas. This will allow an accurate understanding of the issues that are contributing to the client's presenting symptoms and/or complaints, as well as how a client's symptoms and/or complaints contribute to other areas of functioning (e.g., how depression may affect a client's success in getting social support). Examples of how to incorporate HIV-specific issues into a clinical assessment are provided below. For each area, sample questions are included to keep in mind when gathering information during the clinical assessment. The areas are not presented in any specific order, and the sample questions are not intended to be asked in the manner presented.

Social Support. In addition to informing staff about the quality of interpersonal relationships and the client's reliance upon others, social support questions can be used to ascertain to whom the client has disclosed his/her HIV status. Information about a client's social support may be gained using established clinical tools—like genograms, which graphically depict a person's social support network—or by asking direct questions.

Types of Questions That May Be Helpful in Assessing the Client's Social Supports

- Have you disclosed your HIV status to anyone?
- Is there anyone who knows about your status and helps you with day-to-day needs?
- How often do you have contact with that person?
- Is your contact with that person limited, or is it ongoing?
- How is this person similar to you in age, gender, ethnicity, HIV status, and risk factors?

Coping Skills. These questions can help staff get a sense of how the client has historically and recently approached problems in his/her life, as well as how the client is coping with being HIV-positive. Staff will want to better understand the client's strengths (e.g., strong will to live), adaptive skills (e.g., problem-solving, information-gathering, talking to and getting support from others), and maladaptive behaviors (e.g., self-isolation, taking part in potentially self-destructive activities, avoidance, denial, or poor self-care).

Types of Questions That May Be Helpful in Assessing the Client's Coping Skills

- In the past, when you've had to face challenges, how did you respond? How did you cope? What personal strengths did you bring to the situation?
- How did you react when you first found out you were HIV-positive? How do you deal with it differently today than when you first found out?
- What do you do to make yourself feel better?
- What would make things more manageable for you? What has worked in the past? What hasn't worked as well?

Medical Care. There are many reasons for including questions about a client's past and current medical experiences. For example, many people living with HIV have multiple health problems, so gaining a picture of their HIV medical care and a complete medical history of other acute and chronic illnesses is crucial. In addition, adherence to medical treatment and recommendations is so vitally important

that a clinician can benefit from knowing how clients interact with their medical providers. As medical care serves as a vital service to those with HIV infection, it is critical to understand how it affects their psychological well-being. The following sample questions are provided as a guideline to get a better understanding of the client's perspective and can be woven into the clinical assessment.

Types of Questions that May Be Helpful in Assessing the Client's Medical Care

- When you feel sick, do you go to the emergency room, call your medical provider, or call someone else?
- Have you recently received medical care? What was that experience like?
- Are you currently receiving HIV-specific medical care? What has that been like?
- Has treatment helped, or has it not proved helpful?
- How comfortable do you feel talking to your medical providers?
- How well do your medical providers explain your treatment options?
- Do you think your medical providers are sensitive to your pain (e.g., mental, emotional, physical, and spiritual pain)?
- What is your CD4 count? Has this changed in the past 3 months? What is your current viral load? Has this changed in the past 3 months?
- Do you have any other chronic medical conditions, such as diabetes, asthma, high blood pressure, liver problems, or kidney problems?

- Are you taking any medications for these conditions? What are you taking? How much are you supposed to take? Do you take these medications as prescribed? What are the circumstances when you do not take them as prescribed?
- Are there any side effects with these medications? How do you cope with these side effects?
- How often do you see your medical provider for your other medical conditions? How often do you keep these appointments?

Current Service Utilization. To gain a better understanding of a client's service needs and to help a client maneuver through the service system effectively, it may be important for clinicians to inquire about all the other systems (e.g., community-based agencies that offer HIV support services, AIDS service organizations, and community-based agencies that offer relevant services) to which he/she is already connected.

Types of Questions that May Be Helpful in Assessing the Client's Current Use of Services

- Can you tell me about other services you use?
- What has it been like to use these services, now and in the past?
- How have these services benefited you?
- Do you have a case manager? How has he/she helped you?

Quality of Life. Given that HIV has become a chronic illness for many individuals, quality of life issues have become more salient for assessment and treatment. In addition to conducting a clinical

assessment of specific symptoms and diagnoses, quality of life issues should be assessed because many clients respond more quickly to treatment when these issues are more readily understood and dealt with. One of the benefits of asking quality of life questions is that the clinician is less likely to impose his/her version of quality of life onto the client, and the client's idea of quality of life is better understood.

Types of Questions that May Be Helpful in Assessing the Client's Quality of Life

- When did you find out that you are HIV-positive?
- How did you spend your time before you became HIV-positive? What was your typical day like back then? Who did you spend time with?
- Back then, how satisfied were you with your life?
- How do you spend your time now? What is your typical day like? Who do you spend time with?
- How satisfied are you with your life?
- How do you see yourself spending time in the future? What do you want a typical day to be like? Who do you want to spend time with? Are there people you would like to get to know better?
- How would you like to live your life differently in the following areas: job/career, education/training, social/recreation, spiritual, and volunteer work/advocacy? Would these things give you a greater sense of purpose in life? Would they bring you pleasure?
- If you were able to accomplish those goals, how satisfied would you be with your life?

CONDUCTING THE CLINICAL ASSESSMENT

After program planners and clinicians at each of the 11 Demonstration sites selected areas to assess, it was then necessary to attend to the administration of the clinical assessment. This section describes the three key elements of a clinical assessment: preparing staff to conduct the assessment; preparing clients to participate in the assessment; and conducting the assessment.

Preparing staff to conduct the assessment. Given the complexity of physical and mental health circumstances for persons seeking HIV-specific mental health services, clinicians should prepare themselves for the following:

- Potentially uncomfortable and sensitive issues that may arise during the initial assessment meetings. These issues include death and dying issues; sexuality and sexual practices; different life experiences (e.g., substance abuse, class differences, sexual orientation); and explicit descriptions of physical symptoms. Through supervision and training, clinicians may learn to be sensitive to and comfortable with these and other issues before they actually conduct assessments with clients.
- Alternative terms and slang. Clients may use alternative terms and/or slang to describe their experiences. To enhance a clinician's ability to connect with clients, it is important to familiarize themselves with alternative terms and slang by asking clients or other people who are familiar with the culture to explain unfamiliar words.
- Local jurisdictional laws and regulations regarding confidentiality and safety. When working with HIV-infected clients, clini-

cians need to be aware of state and local liability and disclosure laws—and appropriate ways to respond. This relates to knowing about duty to warn, the emergent risks related to suicidality and homicidality, and the potential risk to children or vulnerable adults. State and local departments of mental health can provide some guidance in these matters.

Preparing clients to participate in the assessment. Many HIV-infected individuals have had negative experiences with human service systems. With that in mind, it is important to make the clinical assessment process as favorable as possible. The collective experience of the 11 Demonstration sites has shown that the following practices can increase the likelihood of a successful assessment experience:

- Explain the purpose of the assessment. A client needs to know why clinicians need to understand their story and how this process will benefit them in the long run.
- Explain the assessment procedures. A client should be told up front what to expect and how long the assessment may take.
- Establish trust. Take time to allow the client to become familiar with the assessment procedure.
- Describe the limits of confidentiality. It may also be helpful to discuss the difference between confidentiality and keeping secrets.
- Recognize that the process for seeking mental health services may be intimidating.
- Recognize that the client or someone in his/her support network may have told the client that he/she is "crazy" for seeking mental health services.

- Acknowledge that a client may be too sick to participate in an assessment and that information may need to be sought from other caregivers or staff who have had previous contact with the client.
- Acknowledge potential discomfort. It is difficult for many clients to discuss their sexual practices, their illness, and other information of a private and intimate nature.
- Inform the client that his/her disclosure of information is completely voluntary.

During the clinical assessment, it is essential to maintain the level of respect and trust initiated with clients prior to conducting the assessment. To demonstrate empathy with the client's situation, some client perspectives to keep in mind when conducting the clinical assessment are:

- Respect a client's endurance. Allow water, coffee, and bathroom breaks.
- Be sensitive to the client's circumstances. Do not begin the clinical assessment by asking the client how he/she contracted the virus.
- Stay client-centered (e.g., Are you doing okay? Are you getting a chance to tell me what would be helpful for you? Is there something you'd like to tell me that I haven't asked?).
- Pay attention to the pace of the assessment. Clients might not be ready to give you all the information all at once.
- Remember that denial and avoidance are adaptive strategies—not necessarily signs of resistance—and that these strategies give client's control in divulging sensitive material.
- Recognize the client's strengths and resources. For many triply diagnosed clients, HIV is an additional burden to a long list of burdens with which they have managed to live.

CONNECTING THE CLINICAL ASSESSMENT WITH THE TREATMENT PLAN

A comprehensive clinical assessment leads naturally to an effective treatment plan. An accurate and client-focused clinical assessment can ensure that treatment goals reflect client goals and priorities, that the client feels a strong sense of “ownership” over his/her treatment plan, and that clients are motivated to engage and remain in treatment.

With those objectives in mind, it might be helpful for clinicians to ask clients the following questions: What are some of the issues you would like to work on in your life? What would you like to improve? And how would you like your life to be different after treatment has successfully been completed?

To ensure that the client has ownership of the treatment goals, the following actions also may be helpful:

- Emphasize client-driven goals in the treatment plan.
- Negotiate treatment goals within the framework of which services and interventions are offered by the program and what the client wants.
- Give clients an opportunity to consent to treatment, to review and revise their service and treatment goals, and to sign the plan when it is finalized.

ADDITIONAL CLINICAL ASSESSMENT TOOLS

Standardized Measures. Many of the Demonstration sites used standardized assessment instruments as an adjunct to their clinical assessment. Standardized measures were used for different reasons. Some sites used standardized measures as a means of describing their populations, while other sites used standardized measures to obtain clinical information in a more uniform manner. It is important for program planners and clinicians to agree on the use of standardized measures before introducing them into the clinical assessment. Some standardized measures used by Demonstration sites are listed in Figure 7. As shown in Figure 8, there are advantages and disadvantages to using standardized measures as an adjunct to the clinical assessment.

Psychological and Neuropsychological Testing. Gathering information on thoughts, feelings, motivations, behavior patterns, personality type, relational style, and cognitive capacities fall within the domain of psychological testing. Assessing the presence of specific cognitive impairments, or HIV-associated dementia, and the status of general cognitive functioning is the domain of neuropsychological testing. Performed by clinical psychologists or neuropsychologists, such testing or screening relies on various tests and instruments to assess intellectual functioning; reading and math skills; speed of mental processing or problem-solving; and status of memory and recall.

Figure 7

Standardized Clinical Assessment Tools Used By Demonstration Sites

Domain	Standardized Measure	Site
Alcohol and Drug Abuse	ASI (alcohol & drug sections)	All sites
	Addiction Problem Survey CAGE	Richmond Atlanta, Alexandria
Anxiety	Beck Anxiety Inventory	San Juan
	State Trait Anxiety Inventory	Atlanta
Demoralization	PERI Demoralization Scale	New York, Elizabeth
Depression	CES-D	New York, Elizabeth
	Hamilton Depression Rating Scale	Atlanta
	Beck Depression Inventory	Elizabeth, San Juan, San Francisco, Alexandria
Neuropsychological Disfunction	Trail Making Test (Parts A & B)	Richmond
	Dementia Rating Scale	Richmond
	Bender Gestalt	Richmond, San Juan
Psychiatric Distress	Brief Symptom Inventory	Atlanta

Figure 8
Pros and Cons of Using Standardized Measures

PROS

- May give clinicians information that they cannot get any other way
- All clinicians use the same procedures to obtain information about specific areas
- There is a greater probability that the data can be quantified and analyzed
- The program will have the capacity to compare types of clients served with other programs that are using the same assessment tools
- May give clinicians another perspective on the client
- Have established validity
- May have greater generalizability
- May provide greater confidence in the findings

CONS

- The norms may not be pertinent to the program's target population
- Can take longer to administer and score than administering non-standardized tools
- Can require formal training of the interviewers
- The information may not be meaningful or clinically relevant
- Getting the information in a timely fashion may not be possible
- Can be an obstacle for treatment, especially when a program's "unspoken rule" prioritizes assessment requirements over helping clients with presenting problems
- Can be an "unfriendly" approach to getting information from clients
- Can be expensive to purchase, administer, and score standardized measures

Because HIV can affect the brain in numerous ways, it is highly desirable for clinicians to use neuropsychological testing as an adjunct to their clinical assessments. While many programs will not have these services available on-site, it is strongly recommended that program planners and clinicians access neuropsychological testing services from other sources because testing can provide a valuable and clinically rich contribution to the assessment and treatment planning process.

Neuropsychological testing can give clinicians a better understanding of the impact of HIV on the brain itself, including functioning associated with tasks related to memory, attention, concentration, planning, and prioritizing. Problems in these areas of functioning may be directly affected by HIV infection—even during its early stages. Clients who complain of forgetfulness, who become lost while traveling, or who have difficulty adhering to scheduled appointments and/or medication dosing may be displaying some signs of the cognitive impairment commonly associated with HIV. Since these symptoms may not be readily identified by the medical provider, it is important to acknowledge, inquire about, and assess these troubling instances when they occur.

Such impairment may not only be related to HIV but may result from other mental or substance abuse disorders, such as depression or substance-induced dementia, as well as from medical diseases, such

as poorly controlled diabetes and/or liver disease. Frequently, there are clients who are triply diagnosed, whose symptoms and disorders related to HIV, mental health, and substance use disorders further complicate and contribute to a decline in cognitive functioning.

Once interpreted, both psychological and neuropsychological test findings can prove valuable in determining a diagnosis—even when the clinical symptomatology may be complex. They also may provide an accurate assessment of previous and current capabilities related to memory, attention, problem-solving, and concentration, and identify specifically how a client's ability to plan, organize, and prioritize life concerns may be impaired. Due to the progressive nature of HIV and its biomedical and psychiatric impact, it is important to monitor cognitive capabilities over time, either informally through observation of a client's behavior and comments or more formally through repeated psychological or neuropsychological screening or testing. For clients, testing results can help demystify troubling and intrusive symptoms, as well as assist with differential diagnosis; support treatment planning; help educate clients about the implications of cognitive impairment in daily living; lead to strategies clients can use to compensate for cognitive changes; support a client's disability claims; inform providers about client strengths; and provide information about client support networks.

Psychiatric & Neurologic Conditions

There are several neuropsychiatric complications associated with HIV infection. These complications have numerous etiologies. Awareness of them will assist clinicians in appropriate client assessment, referral, and treatment. In almost all cases, access to a clinician with skills in neuropsychiatric assessment and treatment is essential.

Neuropsychiatric conditions are rarely isolated occurrences. Instead, they generally occur in conjunction with other medical, mental health, and substance abuse problems. These complications, particularly when left untreated, are associated with increased morbidity and mortality, impaired quality of life, and numerous psychosocial challenges, such as nonadherence with the treatment regimen. The complexity of these conditions should encourage all mental health clinicians to incorporate multidisciplinary approaches to client-centered care.

For the purposes of this Practical Guide, neuropsychiatric complications are categorized as follows:

- Disorders attributed to HIV in the brain
- Disorders due to medical complications of HIV infection
- Psychiatric disorders
- Serious mental illness

For each of these conditions, comprehensive management strategies require skilled interventions that utilize psychotropic medication management, medical treatment, behavioral management, and psychosocial care.

Estimated Prevalence (Past 12 Months) of Selected Psychiatric and Substance Use Disorders Among 1,837 Clients Served in the Demonstration Program

<u>MOOD AND ANXIETY DISORDERS (%)</u>					<u>SUBSTANCE USE DISORDERS (%)</u>	
<u>Major Depression</u>	<u>Dysthymia</u>	<u>GAD</u>	<u>Agoraphobia</u>	<u>Panic Attack</u>	<u>Alcohol Dependence</u>	<u>Drug Dependence</u>
58.8	22.4	25.5	14.3	24.7	22.1	47.6

DISORDERS ATTRIBUTED TO HIV IN THE BRAIN

HIV-Associated Dementia (HAD). Clients who develop HAD generally will experience abnormalities in their cognitive and motor abilities that significantly impair their ability to function effectively. HAD signals progression to AIDS for those HIV-positive persons not yet meeting AIDS-defining criteria. Generally, HAD occurs in later stages of HIV infection, and debilitating symptoms may progress over time. Pharmacological treatments include anti-retroviral therapies and psychotropic medications. This condition cannot be diagnosed when a client is simultaneously experiencing delirium (see below). Screening instruments that may be helpful in diagnosing HAD include the Mini-Mental State Examination (Folstein et al, 1975) and the HIV Dementia Scale (Power et al, 1995).

Minor Motor-Cognitive Disorder (MMCD). Clients who develop MMCD will experience mild and sometimes subtle decrements in their motor or cognitive functioning. Examples include clients who have slight difficulty coordinating finger or hand movements, but not to the extent that use of their fingers or hands is severely limited. Similarly, clients may develop mild impairments in memory, but not to the extent that their impairment is noticeable by others. MMCD does not necessarily progress to HAD.

Delirium. This neuropsychiatric disorder is characterized by a disturbance of consciousness (i.e., reduced clarity or awareness of one's environment) with reduced ability to sustain attention. Delirium is accompanied by memory problems and perceptual disturbances, such as illusions (e.g., misinterpreting objects or persons as something else). The condition develops over hours to days and fluctuates throughout the day. Delirium is the most common neuropsychiatric complication in hospitalized persons with HIV who are severely ill. A screening instrument helpful in diagnosing delirium is the Mini-Mental State Examination (Folstein et al, 1975).

Treatment. Primary treatment for these conditions attributed to HIV in the brain consists of medical management (e.g., psychotropic and antiretroviral agents) in combination with psychotherapeutic and support services.

DISORDERS DUE TO MEDICAL COMPLICATIONS OF HIV INFECTION

The course of HIV infection may include medical complications that create changes in one's mental status that mimic more common psychiatric conditions, such as depression, mania, anxiety, and psychosis. The most critical feature of treatment is accurate diagnosis and treatment of the medical causes. Although psychotropic medications often are warranted for symptom relief, at least temporarily, overall management should focus on treating the underlying medical complication(s). When these conditions occur, coordinated care with medical providers is absolutely essential.

These complications highlight the need for clinicians to be aware of and knowledgeable about clients' medications and substance use patterns and to be suspicious of major changes in mental status, particularly among clients with more advanced illness or those on many medications.

Treatment. Primary treatment for these conditions due to complications of HIV infection relies on treatment of the underlying medical etiology.

Possible Underlying Causes of Common Medical Complications Associated with HIV

Opportunistic brain infections

- Toxoplasmosis
- Cryptococcal meningitis
- Cytomegalovirus infection
- Tuberculosis
- Progressive multifocal leukoencephalopathy

Opportunistic cancers

- Lymphoma
- Kaposi's sarcoma

Metabolic complications

- Fever,
- Anemia
- Blood infections
- Hypoxia

Drug-to-drug toxic interactions

- Corticosteroids
- Alpha-interferon
- Protease inhibitors

Psychoactive substance use complications

Recreational

- Cocaine
- Alcohol
- Methamphetamine
- Hallucinogens
- Nitrate inhalant
- Opiates

Prescribed

- Sedative hypnotics
- Opiates
- Psychostimulants

**Medical
Complication**
**Possible
Causes**

PSYCHIATRIC DISORDERS

Numerous psychiatric disorders have been identified among people with HIV infection. Some of these disorders may have existed prior to the HIV diagnosis, while others may have developed during the course of living with HIV. Some of the more common conditions are listed below.

Psychiatric Conditions	Examples of Symptoms
Mood Disorders	
▪ Depression	Pervasive sadness, apathy, fatigue, suicidal ideation, hopelessness, appetite and sleep changes
▪ Mania (Bipolar Disorder)	Increased energy, decreased need for sleep, racing thoughts, grandiosity
Psychotic Disorders	
▪ Schizophrenia	Auditory hallucinations, delusions, thought disorders
Anxiety Disorders	
▪ Generalized anxiety disorder, panic disorder, obsessive-compulsive disorder, post-traumatic stress disorder	Nervousness, heightened arousal, panic attacks, intrusive anxiety-provoking thoughts, obsessions/rituals, flash backs
Adjustment disorders	Depression and/or anxiety of less severity and directly related to an identifiable stressor
Personality disorders	Persistent, maladaptive life behaviors that interfere with interpersonal relationships
Sleep disorders	Difficulty initiating and/or maintaining sleep
Sexual functioning disorders	Diminished libido, difficulty having an orgasm, difficulty obtaining or maintaining an erection
Constitutional problems	
▪ Chronic fatigue	Chronic lack of energy
▪ Wasting syndrome	Chronic muscle wasting
▪ Pain	Chronic pain from such conditions as neuropathy

Psychotropic Medications

Psychotropic medications, such as those agents used to treat depression, anxiety, psychosis, and other conditions, are well tolerated and clearly efficacious for persons living with HIV infection. Psychiatric disorders should be treated aggressively with these medications when warranted, especially since untreated disorders can impair one's quality of life and may be linked to increases in HIV transmission risk behaviors (e.g., unsafe sex and drug use practices). Psychotropic agents should be used judiciously in persons on antiretroviral and other HIV-related medications. In most cases, psychiatrists should manage these medical regimens. The combined use of psychotropic agents and protease inhibitors requires careful attention to routes of metabolism of each of these medications. Because the medications can alter the metabolism of each other, they are best prescribed and monitored by clinicians with an understanding of potential drug-to-drug interactions, side effects, and routes of metabolism. These medications can be used safely and effectively when combined. However, informed treatment and close monitoring is essential.

Treatment. Mental health treatment of psychiatric disorders should be client-centered, individualized, and comprehensive to encompass the full spectrum of biopsychosocial needs. In most cases, due to the complexity of these conditions, no single modality of treatment will suffice. Clinicians should consider a full range of treatments, including psychopharmacology; cognitive-behavioral, interpersonal, psychodynamic, and other psychothera-

...client-centered,
individualized, and
comprehensive...

pies aimed at individuals, groups, families, and couples; intensive case management; psychosocial rehabilitation; partial hospitalization; day treatment programs; substance abuse counseling; and others.

For persons with serious mental illness, treatment may need to be uniquely tailored to strengthen diminishing social support systems. To promote stability and treatment adherence, consideration must be given to supportive housing, living arrangements, vocational rehabilitation, outreach, and strong linkages with other community resources. Persons with serious mental illness who are not engaged in mental health care are less likely to be engaged in HIV primary medical care (Cournos & McKinnon, 1997). Moreover, they are at higher risk of being lost in the system due to homelessness, incarceration, rehospitalization, and substance abuse relapse. For all of these reasons, diagnosis or identification of mental illness, including HIV-related neuropsychiatric complications, requires aggressive treatment and is a critical component to the overall health care of HIV positive clients.

Caroline's Story

Caroline was an attractive woman in her mid-30s with a pleasant disposition and a ready smile. Diagnosed with schizophrenia and HIV-associated dementia, Caroline's situation was further complicated by volatile and poorly controlled diabetes. While her schizophrenia was stabilized through regular intramuscular injections of Haldol Decanoate, her short-term memory was impaired by HIV-associated dementia, ruling out the possibility that she could adequately adhere to the range of medical treatments she required on her own.

Neuropsychiatric testing revealed that, in addition to short-term memory loss, Caroline had difficulty concentrating, planning, or solving problems. These cognitive deficits prevented her from being able to check her glucose levels (which had soared to as high as 410), determine if she needed insulin, and inject the proper amount. Although her HIV infection was not yet advanced, adherence to needed HIV medications also was problematic.

Her psychological counselor quickly realized that a series of external supports were needed to ensure Caroline's survival. The counselor enrolled her in a psychosocial support day program and arranged for a Medicaid waiver that provided for a nurse to go into the home twice a day to administer Caroline's insulin. She was then placed in a group home in which overnight staff could ensure that she didn't eat middle-of-the-night snacks that would elevate her blood sugar levels or light up cigarettes she might forget to put out. The counselor involved Caroline's family in treatment planning and educated them about her medical condition and her cognitive limitations. Close coordination with the public health nurses, the residential counselor, and Caroline's family members has resulted in a safe and supportive environment where Caroline retains some freedom and self-direction, but where her biopsychosocial needs are met.

SERIOUS MENTAL ILLNESS

Serious mental illnesses (SMI), particularly those illnesses which cause persons to experience severely distorted thinking or cognitive impairment, pose unique challenges in HIV treatment. Serious mental illnesses may be conditions that are directly attributed to HIV infection, such as the neurocognitive disorders previously described (e.g., HAD), or conditions that existed before a person becomes HIV-positive, such as schizophrenia, bipolar disorder, and severe personality disorders. These conditions create numerous challenges for clients and providers alike, including increased likelihood of the client engaging in high-risk behaviors and other maladaptive health behaviors, such as substance abuse and treatment nonadherence.

Persons with SMI often experience high rates of unemployment, poverty, and homelessness. For these reasons, persons with SMI typically lack access to health care, substance abuse treatment, HIV primary medical care, and new antiretroviral therapies. As a result, persons with SMI are likely to have shortened HIV-related survival, severely impaired quality of life, and more complications from HIV and other medical problems that disproportionately affect persons who are marginalized in health care systems.

Case Management

Case management, as an accepted mental health treatment modality, developed largely in response to deinstitutionalization—the release of large numbers of persons with serious mental disorders from state hospitals in the 1980s. Community mental health centers were charged with developing methods for effectively treating and maintaining those who were released back to the community. In order to prevent frequent re-hospitalizations, it was often necessary to put in place a wide range of services to support the client in meeting basic human needs. While the resources—such as food, shelter, medical care, financial assistance—were often already in place in the community, staff with an understanding of serious mental illness and local resources were needed to link clients to services and to monitor treatment adherence and general functioning.

...a service plan based on needs...

Due to the many concrete service needs of those living with HIV infection, case management has long been a cornerstone of HIV care. The Ryan White CARE Act has recognized the importance of case management and allocates a significant amount of its funding for case management. Today, as HIV increasingly moves into communities of poverty, a disproportionate number of persons who are homeless, have mental and addictive disorders, lack experience in accessing services, and/or who are in jails and prisons are affected. Given these trends, the need for case management becomes even more profound.

As the HIV/AIDS Mental Health Services Demonstration Program progressed, many of the 11 projects found themselves allocating more and more resources for case management, underscoring the growing need and demand for this function in assisting people living with HIV who also have mental and/or addictive disorders. This chapter describes the Demonstration sites' experiences in providing case management services to people living with HIV.

CASE MANAGEMENT ACTIVITIES

Assessing the client's needs. With input from the client, the case manager assesses the client's comprehensive biopsychosocial needs. The case manager's assessment will complement the clinical assessment referred to in Chapter 5, which needs to be comprehensive and thorough and take the needs of the whole person into account. In cases where the needs are immediate or urgent, the case manager must possess the judgment and skills necessary to make an emergency referral for food, shelter, psychiatric hospitalization, detoxification, or emergency room care.

Developing a service plan. Together, the client and the case manager develop a service plan based on the needs identified in the case manager's assessment. Encouraging the client to prioritize his/her own needs helps to establish trust between the client and the case manager. It also reinforces the client's sense of self-determination. The case manager needs to honor what the client sees as the priority. For example, the case manager may believe getting medical care for HIV infection is first on the list, while the client may be more worried about paying next month's rent. A written service plan—jointly agreed to and signed by the client and the case manager—is a useful instrument in establishing trust and setting service priorities. The agreement can serve as a valuable reference tool for reflecting back upon what has been accomplished and planning for goals not yet met.

Linking the client to services. Clients with HIV often need a broad range of services. These may include primary medical care, mental health and substance abuse treatment, financial assistance, housing, food, financial entitlements, clothing, transportation, child care, dental care, and legal services. Many clients need help in obtaining resources and/or connecting with services. The process of coordinating a broad range of health care and support services requires a case manager with creativity, negotiation skills, political savvy, and a knowledge of community resources.

In cases where the client is capable of accessing services, simply giving him/her a phone number may be sufficient help. If, on the other hand, the client has a serious mental illness, HIV-associated dementia, poor communication skills, or is unfamiliar with the service delivery system, the case manager may need to schedule appointments and accompany the client to the appointment. The case manager often serves as a “go-between” with the service provider when long and difficult forms must be filled out or when the client becomes tired or frustrated and unable to go through the cumbersome steps required to obtain the needed service. Case managers can make productive use of this time spent transporting or waiting with the client to build a positive therapeutic relationship and to engage him/her in mental health treatment. At the same time, the opportunity can be seized to nurture working relationships with other service providers to facilitate future referrals and collaboration.

Monitoring the client’s progress. Since the client’s biopsychosocial needs are dynamic and ever-changing, it is important for the case manager to regularly monitor the client’s level of functioning and his/her progress. This monitoring includes assessing medication adherence and relapse prevention, reviewing the client’s service needs, and refining the treatment plan. Since many clients’ lives are dominated by chaos related to substance abuse, poverty, and the progression of HIV infection, the case manager’s aggressive follow-up, outreach, and re-engagement efforts can be key to the client’s length and quality of life.

...coordinating
a broad range of
health care and
support
services...

Advocating on behalf of the client.

Persons with HIV face a broad range of stigmatizing attitudes and actions, stemming from society's response to the person's mental illness, substance use, HIV status, race, sexual practices, socioeconomic status, cognitive deficits, homelessness, and/or criminal record. When a door is shut, an opportunity is denied, or a right is violated, feelings of helplessness, hopelessness, and rage can take over. While the goal is to empower the client to advocate for himself/herself, the case manager has a responsibility to intervene when the client is unable to do so.

Examples of discrimination in emergency rooms, housing opportunities, and employment situations abound—as do examples of effective advocacy. While advocacy on an individual level is the immediate task, the dedicated case manager also keeps in mind his/her responsibility to advocate for change on a systems level so that institutionalized prejudice and discrimination against persons with HIV, mental illness, substance abuse, or members of a minority race, minority sexual orientation, or minority religion can be addressed. Effective advocacy on an individual and systemic level can positively affect the whole climate of future service delivery.

CASE MANAGEMENT TREATMENT PHASES

Case managers at the Alexandria project identified five phases of treatment in working with persons who are homeless and dually diagnosed with mental and substance abuse disorders (Alexandria Community Services Board, 1994).

- **The acute stabilization phase** may require detoxification or hospitalization to stabilize acute medical or psychiatric symptoms.
- **The engagement phase** is the time during which the helping relationship is developed and basic services, such as food and shelter, may be provided.
- **The persuasion phase** occurs when the case manager encourages the “engaged” client to recognize and accept the need for treatment.
- **The active treatment phase** is the stage during which the client develops the attitudes, behaviors, skills, and determination to accept treatment and does so.
- **The relapse prevention or rehabilitation phase** is when the client develops a greater sense of mastery over his/her disorder(s) and exhibits greater competence in functional and social capabilities.

Elijah's Story

In recovery from a crack cocaine habit for almost three years and climbing steadily up from a major depression, Elijah faced eviction from the small apartment where he lived with his teenage son. Savings from occasional jobs had supplemented his meager veteran's disability pension, but now a rent increase forced him to look for subsidized housing. His mental health worker had identified an apartment in a well-kept building in a safe neighborhood where another of her clients lived. She had dealt with the landlady before and set up an appointment to look at the apartment.

The moment the white landlady laid eyes on the dark-complected Elijah, she began to make excuses. "Someone in the building has just asked if he could move to a two-bedroom, so I have promised it to him. I'm sorry, but the apartment is no longer available." Elijah immediately became agitated. A sensitivity born of countless encounters with subtle—and not-so-subtle—race discrimination left no doubt in his mind about the motivation of the woman standing before him. "I'll never get this apartment," Elijah mumbled to his worker. "Let's get out of here." Herself Hispanic and a woman of color, the worker also picked up the vibes. Returning to the office in anger, she spoke with her supervisor and colleagues, relating the experience and its impact on Elijah.

The HIV team immediately took action. A team member called to inquire about the apartment's availability and was told she could come to see it in the morning, providing sufficient evidence to call the Housing Authority to register a discrimination complaint. "We'll investigate right away." The mental health worker, realizing she might need to deal with the landlady in the future, called her and diplomatically expressed her puzzlement and dismay at Elijah's being turned down and hinting at discrimination. The landlady vehemently denied she had been discriminating, but lo and behold, the upstairs neighbor had changed his mind about moving into a two-bedroom apartment. Elijah and his son got their clean, new apartment.

In this true case of discrimination, successful advocacy had a beneficial impact on both the individual and the system.

CASE MANAGEMENT PROVIDERS AND SETTINGS

Because the need to link persons with HIV to a spectrum of resources and services is readily apparent, a range of disciplines and persons with varying levels of education and skill have felt called upon to provide case management when necessary—from psychiatrists and psychologists to social workers, counselors, case aides, and peer providers. With the need for case management increasingly being recognized by many health fields, specialized forms of case management have developed in mental health, public health nursing, social services, and substance abuse.

The level of training, education, and skill required to be an effective case manager often is underestimated. To work effectively with clients who are triply diagnosed with HIV, mental illness, and a substance use disorder, a master's degree in a human services field is highly desirable. An effective case manager brings a broad range and high level of skills and/or natural ability to his/her work, including an ability to establish rapport, to understand the client's biopsychosocial needs, and to know the resources that are available in the community. He/she must possess determination, persistence, advocacy skills, empathy, and tact. In the field of behavioral sciences, increased recognition and credit is being given to case managers and the important work they do.

With many case managers working in mental health centers, medical clinics, substance abuse programs, and AIDS service organizations, service duplication and gaps can become problematic. Coordination of services among providers through establishing clear, individual responsibilities is necessary to make the most efficient use of limited resources. Designating a “primary case manager” and holding periodic “prescription team” meetings in which all providers and the client are present is useful in providing quality care. (See Chapter 4 on Mental Health Services.)

Case management can be provided with varying degrees of intensity. Working with persons who are triply diagnosed and also homeless or recently incarcerated requires a high level of assistance or intensity—and a correspondingly smaller caseload. A high-functioning client may need assistance in accessing HIV or mental health resources from time to time but is generally capable of navigating the system on his/her own with little outside help.

...targeted, strategic approaches...

BUILDING A STRONG HELPING RELATIONSHIP

At the heart of effective case management is a strong, trusting, and collaborative helping relationship. Working with an HIV-affected population that is increasingly disenfranchised, stigmatized, and alienated from society requires special skills and a special attitude on the part of the case manager. Efforts to engage and retain the client in service often require targeted, strategic approaches. Meeting the client on his/her own turf and hiring culturally sensitive and street-wise outreach workers who establish contact and serve as a bridge between the client and the provider can significantly improve engagement and retention rates. Many clients feel degraded by their present circumstances and have felt rejection from their family, their church, and their peers. Experiences in dealing with “the system,” including the criminal justice system and recovery programs often have been negative and disempowering. At times suspicious of others, disorganized in their thoughts, and/or in denial about their HIV status or substance abuse, many view the case manager reaching out to help with profound distrust.

In developing rapport and trust with the client, the Demonstration sites found the following approaches effective:

- Focus efforts on the person’s skills, strengths, and potential, as well as his/her capacity to change or improve his/her quality of life.
- Solicit and encourage client self-determination in setting priorities for obtaining services.
- Remain consistent, flexible, nonjudgmental, positive, and helpful.
- Accept the person for who he/she is.
- Be patient in all interactions with the client. Be readily accessible when needed by the client. Avoid demanding too much too soon.
- Respect the person’s need and right to decide when and how he/she will accept help.

BARRIERS TO EFFECTIVE CASE MANAGEMENT

Barriers to obtaining needed services, treatment, and interventions exist for both the client and the provider. The effective case manager is presented with the challenge of using ingenuity, creativity, and people and problem-solving skills to overcome these barriers with and on behalf of the client. In the course of their work, the 11 Demonstration projects encountered, identified, and overcame many such barriers at both individual and systemic levels. Possible ways to address and minimize these barriers are discussed throughout this Guide.

Barriers Faced By The Case Manager

- Personality or value conflicts among service providers
- Ethical issues related to disclosure and “duty-to-warn”
- Difficulty maintaining professional boundaries with clients
- Lack of adequate resources to meet client needs
- Restrictions on the number of days allowed for hospitalization or treatment
- Bureaucratic red tape preventing quick responses
- Discrimination against client population
- Client expectations and demands that are unrealistic or cannot be met

Barriers Faced By The Client

- Distance from needed services and providers
- Unduly cumbersome application and referral processes
- Lack of transportation to and from appointments
- Lack of child care while keeping appointments
- Distrust of the service system
- Fear of confidentiality violations
- Social stigma and discrimination
- Cultural insensitivity and language barriers

Psychotherapy & Counseling

Therapists make decisions about psychotherapy and counseling approaches based on their education, training, supervision, and personal experience. The 11 sites in the Demonstration Program found that client need was the most important factor in selecting the approach. Traditional approaches required modification to meet new and complicated problems associated with living with HIV.

Psychotherapeutic and counseling approaches used by the Demonstration projects included:

- Cognitive/behavioral therapy
- Supportive psychotherapy
- Pastoral counseling
- Crisis intervention/therapy
- Brief psychotherapy
- Educational counseling
- Psychoanalytic psychotherapy
- Existential psychotherapy

PROFESSIONAL INTERVENTIONS

Psychotherapy and many types of counseling are primarily provided by trained professionals who are prepared to facilitate behavioral and cognitive change. A mental health professional must consider how the intervention can be shaped to incorporate the many psychosocial complications of HIV infection.

It is helpful for service providers to be mindful that "traditional" service patterns often have to be reconsidered in order to provide adequate services. The 11 Demonstration projects found the concept of "bending the frame" to be a helpful way of doing this (Winiarski, 1991). For example, through the process of dealing with HIV infection, many service providers have found themselves visiting clients at their homes or at hospitals—something that is not usually considered a common procedure of more traditional mental health service approaches.

Additionally, the crisis of HIV infection brings many individuals into mental health treatment who have no previous experience or familiarity with the process. For example, some traditional psychotherapists elect not to call their clients if they miss a psychotherapy appointment. However, the 11 Demonstration projects found themselves spending a great deal of time focusing on retention efforts, such as calling clients to remind them of appointments and making follow-up calls. Such calls seemed to help Demonstration Program clients understand that the therapeutic process was taken seriously by the

program staff. In time, many clients began to take ownership and responsibility for their own treatment, which may have never occurred without the retention efforts put forth early on in the process. Other examples of "bending the frame" included harm reduction approaches to substance abuse treatment, in-home services, telephone sessions, and intensive case management coupled with psychotherapy.

Another important facet of the process was to develop and/or maintain a "community" in which Demonstration Program clients felt comfortable seeking help. This was accomplished in a variety of ways—from peer interaction to group interventions to a structured community in a psychosocial rehabilitation program.

Individual interventions. For persons with HIV who seek mental health services, individual counseling or psychotherapy sessions are generally a first step in the treatment process. Client concerns about confidentiality, substance use, sexual orientation, and sexual practices may initially make one-to-one interventions the most comfortable modality. Counseling generally refers to explorations and problem-solving interventions relating to current concerns and issues, such as adjusting to the HIV diagnosis, managing relationships, and job and workplace issues. Psychotherapy explores feelings, motivations, behavioral patterns, interpersonal relationships, and patterns of thinking over time.

In the experience of the 11 Demonstration projects, a significant number of clients with HIV had histories of early sexual abuse and boundary violations. For those clients, working through aspects of the childhood trauma can be both a liberating and necessary step in moving toward a commitment to self-care and a reduction of risk-taking behaviors. Psychotherapy can help clients develop greater self-awareness, stronger coping skills, and greater motivation to engage in meaningful and productive activities. Through counseling or psychotherapy, clients in recovery from substance abuse often discover and begin to heal underlying psychological wounds they attempted to mask through substance use.

Length of treatment varies by case. For some Demonstration projects, treatment lasted as long as clients kept returning for their appointments. Since most Demonstration Program clients had complex psychosocial needs, treatment was oftentimes long-term, with mental health professionals constantly re-evaluating their treatment plans to ensure they were realistic and client-centered.

Group interventions. All of the Demonstration projects used group interventions to some degree. Some used group therapy on an occasional basis, while other Demonstration projects were exclusively focused on group interventions. Group interventions can be a very powerful way of facilitating change or managing mental health issues associated with HIV infection. Group interven-

tions can often be modified to better address the specific needs of the group and its members.

Groups can be led by either professionals, peers, or a combination of both. Mental health professionals may be better suited to serve as facilitators in groups designed to deal with mental health issues, such as psychotherapy groups. Peers, on the other hand, may be better suited to lead support groups and group discussions relevant to the experience of living with and adapting to HIV. However, both professionals and peers, depending on their personal experience and training, may be qualified to address either of these concerns.

The 11 Demonstration projects found the following issues important when creating a “safe” group:

- Consider issues relating to inclusion/exclusion criteria.
- Have individual selection interviews in which group processes and rules are reviewed and agreed upon.
- Create a “confidentiality agreement” that all clients read, agree to, and sign before ever coming to the group.
- Establish clear rules for the group process, including rules on how to address others, accepted behavior in the group, maintaining a safe environment, outside visitors to the group, schedule and meeting place, and interactions outside the group.

GROUP INTERVENTIONS

Support groups are organized meetings in which participants exchange information on life situations to develop new ways to manage, adapt, or change the situation. Support groups have been the mainstay of psychosocial support within HIV-affected communities since the beginning of the epidemic. Particularly for people living with HIV, support groups offer a venue for sharing information and experiences. For example, disclosure of status with family and friends, reaction to medications and their side effects, disappointments regarding medical setbacks, and issues around re-entering the job market are common themes one may encounter in an HIV support group. A major goal of support groups is to increase the social support networks of its members. One of the benefits is the creation of friendships among participants that may last beyond the group process. Outside interaction is sometimes promoted.

Derrick's Story

Derrick had been released after serving several years in prison. He had stayed sober while incarcerated and continued to do so in the new community in which he had settled with his family. His HIV course had improved, but he felt lonely and isolated. He became involved in a community support group where he developed several friendships. This proved necessary as he learned that, in addition to his HIV infection, he also had diabetes and advanced liver disease. Months later, a friend from the group was hospitalized with the same diagnoses and died soon after. Derrick became consumed with the idea of his own death and physical status. He focused his energy on weight loss and appetite. He had linked progressive wasting with death. The support group helped Derrick confront this irrational belief and refocus his energies toward self-care.

Psychoeducational groups are directed at obtaining and processing new information. They usually have a limited scope and duration. Many use "invited" speakers in addition to the group facilitator. "Teaching" by the facilitator or invited guests can be part of the group process but other interactional processes also can serve as a powerful way of "learning" (Freire, 1993). Examples of psychoeducational group topics from the 11 Demonstration projects included recognizing depression, managing cognitive impairment, HIV medication adherence, understanding psychotropic medications, disclosure of status, and returning to work.

Couple and family interventions provide the opportunity for the client's significant other and/or loved ones to join the treatment process. The diagnosis of HIV not only affects the infected person but his/her entire "family." For example, disclosure of status, safer sex negotiations with a partner, permanency planning, sero-discordant couples, and unresolved fear and anger are issues that may be encountered by treating a family or couple. Additionally, HIV may bring additional stresses to families already made vulnerable by substance abuse or poverty.

Andy and Phillip's Story

Andy had been living with HIV for 10 years when he met Phillip, a younger, HIV-negative gay man. Though initially they expressed comfort with their sero-discordant status, several years into their relationship Phillip seemed less interested in a sexual interaction with Andy and both seemed to struggle with communicating with each other. Couples' counseling sessions over several weeks brought them to a point of trust that they were able to discuss their fears—Phillip's concerns about HIV infection and his worry about the impact of HIV on Andy's health.

Psychosocial Programming Groups involve creative expression, skill-building, insight development, and socialization. These groups are very interactive, often involving doing a task rather than verbal discussion alone. (See Chapter 13 on Psychosocial Rehabilitation.)

PEER COUNSELING

Peer counseling involves the provision of services by individuals who are members of the treatment population. At some of the Demonstration sites, peer counselors shared a number of characteristics, usually including HIV status and/or ethnic and cultural membership. Peer counseling, like professional psychotherapy, can be done in several modalities (individual, couples, families, and groups). While traditional professional psychotherapy may focus on psychological change, peer counseling typically focuses its intervention on support and education.

Peer counseling may be a less stigmatizing experience than traditional mental health treatment, increase a sense of trust and empathy between the counselor and the client, allow for a more open discussion of treatment adherence and negotiating the service system, and promote the development of “community” among clients. It also may be a cost-effective way to serve clients.

Training is a crucial component of peer counseling. Peer counselors need specific guidance on when to refer clients to professionals and may need training to improve their listening and assessment skills. Supervision by a professional mental health clinician is critical to safeguard the quality of services and to help ensure that clients who need professional psychotherapeutic help are getting it. There are also ethical considerations to be addressed to ensure that appropriate counselor/client boundaries are observed. Again, supervision is critical.

How One Program Used Peer Counselors

“Our peer counselors have done outreach in medical clinics, provided individual and group support, led educational forums, and directed peer-based substance abuse groups. Those clients whose needs were greater or expressed interest or readiness for professional psychotherapeutic treatment were referred to the mental health team. Many clients have come to mental health treatment through the normalization of the counseling experience by peers. This program is supervised by a licensed mental health clinician in order to ensure appropriate triage.”

– Phil Meyer, LCSW
Los Angeles Project

CHAPTER 9:

Counseling Themes & Clinical Considerations

“**W**ill I lose my dignity / Will someone care /
Will I wake tomorrow / From this nightmare?”

These lines from *RENT*, the Pulitzer prize winning musical by Jonathan Larson, evoke the emotional turbulence often accompanying a diagnosis of HIV disease.

Counseling and psychotherapy sessions may include poignant, harrowing stories filled with anger, sadness, shame, and rejection. During these same sessions, however, people living with HIV can find hope, survival, acceptance, and redemption. When working with HIV-infected persons, it is essential to be present with such pain and hope, whether it is verbalized or not.

It was the experience of the 11 Demonstration projects that certain counseling themes and clinical considerations emerged among all sites. While not an exhaustive list, this chapter highlights the common themes and considerations encountered in the Demonstration projects.

Louis' Story

Louis was in his early forties when he learned of his HIV infection. He had survived a traumatic childhood and adolescence in which he was a victim of family incest that was tolerated since the perpetrator brought money into the family. Multiple oppressions had strangled his self-esteem. He is African American, and he questioned whether his darker complexion was the reason that his mother and grandmother did not love and protect him. Aware of his same-sex sexual attractions, he was confused and troubled following the sexual assaults by his uncle and chose a path of pansexuality and prostitution during which he felt hypervigilant, empty, and vacant. Impoverished, he recalls holidays and birthdays without gifts while watching other children play. Such victimization and lack of nurturance thwarted his ability to trust. Nearing his 45th birthday, he stopped using alcohol and drugs, an addiction since his teens, and began intensive outpatient substance abuse treatment accompanied by psychotherapy—resulting in full-time employment, securing his own apartment, and several years of sobriety.

What arises as the important core issues for clients will vary, depending on their specific life circumstances. For example, clients living with families who are fearful and uninformed about HIV transmission may describe how family members demand that they use only disposable plates and utensils—to “protect” others. Lacking knowledge, the family contributes to a conclusion for the person with HIV that he/she is unclean, thereby promoting isolation and stigma.

The 11 Demonstration projects identified the following counseling themes and clinical considerations common in the provision of mental health services to people living with or affected by HIV: sense of self and self esteem; parenting; fear; disclosure; sexual orientation; loss of loved ones; adherence; Lazarus Syndrome; and spirituality.

SENSE OF SELF AND SELF-ESTEEM

Clients whose sense of self and self-esteem are not strong or fully developed may be especially vulnerable to stigma by family members and friends. For all clients, the sense of stigma and shame related to infection may foster feelings of guilt, anxiety, and self-loathing. They also may contribute to symptoms of depression. For women, there are particularly subversive effects. They may perceive that HIV will mark them as sexually undesirable, cause their partners to leave them, or result in abuse. For those who have survived sexual abuse and assault, infection with HIV further complicates the healing of one's shattered self.

PARENTING

Specifically for parents, complex personal struggles will naturally involve guilt over having become infected, having shortened time with their children, and/or leaving orphaned children—all of which may generate a permissive parenting style that impedes setting limits and discipline. As a result, parents may too readily gratify their children's wants in an effort to assuage their guilt. When HIV-infected parents become ill, it may be more difficult for them to actively

parent—to discipline and provide care-taking. In such a situation, children may develop parentified behaviors and assume a caregiver role toward both the parent and younger siblings. When a parent recovers or ultimately dies, a child may find it difficult to relinquish such a role and return to a developmental stage suited to his/her age.

Maria's Story

Maria, a 22-year-old Latina, lost custody of her daughter, due to neglect relating to Maria's addiction to crack cocaine. Maria did not appear to understand the responsibilities of being a parent, but she was intent upon regaining custody of her daughter—even though her worker from Child Protective Services (CPS) thought this highly unlikely. Over the course of three years, Maria, with the help of her therapist, worked diligently on parenting skills, communication with her family, her relationship with CPS, and her substance abuse problem—in both individual and family therapy sessions. Several months ago, Maria was given custody of her daughter, and her CPS case was closed. Maria remains in treatment and currently is working on setting clear and consistent limits with her daughter, as well as issues around returning to school to get her GED.

FEAR

Fear is a reasonable and expected reaction to HIV. Clients may fear the infection and its progression. They also may fear rejection from friends, family, or co-workers when they disclose their status. As a result, they may choose not to disclose their infection, preferring to keep this a secret. This becomes especially complex for families and their children as noted above. A parent may choose to keep his/her children and the family removed from interacting with others in the extended family or in the community to protect this secret and to delay or avoid disclosing his/her status. Parents also may decide to disclose HIV-related information selectively—but only after determining criteria about who will be told.

Families that fear repercussions related to stigma may develop a boundary around the family and limit contact with extended family or the community. Such insularity may deplete the parent as he/she serves as the sole emotional link for the children and limits other potentially supportive contacts for the children. Older children may sense that a secret exists and may become suspicious regarding the nature and reason for the secret—a suspicion that the parent is unwell and has HIV.

...a reasonable
and
expected
reaction...

DISCLOSURE

Disclosure can present its own turbulent struggle. Disclosing one's HIV status may contribute to strong feelings of rejection and isolation, or it may facilitate finding support and lessening one's burden. The risk and complexity of disclosing one's status is especially weighty for those in intimate relationships or those attempting to establish such a connection.

For many, disclosure becomes a complicated dilemma that may best be handled through discussion in counseling sessions. Therapists can encourage clients to discuss their own emotional responses to HIV and their beliefs about reactions from others. This will assist clients in determining if disclosure needs to occur at all. For clients whose boundaries in relationships frequently blur and may become enmeshed with others, there may be benefits if clients can learn to protect their privacy and limit disclosure to prevent emotional upset.

SEXUAL ORIENTATION

Gay, lesbian, or bisexual clients may feel guilt or shame as a result of society's negative and distorted beliefs about homosexuality. Some may even believe that their infection is a "punishment" for being gay. Many people remember when HIV was initially identified as gay-related immunodeficiency disease (GRID), and for some, disclosure of one's HIV-positive status is complicated by whether others will automatically assume they are gay. Many heterosexual individuals do not want to risk what they view as a societal stigma, and many gay individuals are not prepared to publicly acknowledge their sexual orientation. Such reactions may damage the client's sense of self and lead to low self-esteem and isolation. Therapeutic work with issues of sexual orientation requires specific knowledge, sensitivity, an appreciation of the effects of homophobia, and an affirming attitude.

LOSS OF LOVED ONES

In communities where there have been a great number of deaths associated with AIDS, such as in the gay community and now more commonly in impoverished communities of color, there is a toll from the trauma of multiple deaths that complicates grieving. Multiple losses is a common theme for many people living with or affected by HIV. For clients not infected with HIV who belong to communities hard hit by HIV's impact, such as older gay men and long-standing injection drug users, there may be survivor guilt merely from still being alive while close friends and associates have died from AIDS. Work in this area involves an acknowledgment of a client's loss. For HIV-infected persons, the reactions to multiple deaths may be naturally compounded by fear of HIV's progression for themselves.

Alan's Story

Alan had cared for his partner, Jerome, for a year after symptoms of HIV-associated dementia appeared and created drastic changes in Jerome's personality. Alan speaks of how he tenderly cared for Jerome until his death. When faced only a month later with his father's death, he describes how he felt numb and disconnected. Further complicating his grieving was the earlier death of a family member and several deaths of friends. Alan's therapist helped him reflect on his relationship with Jerome and strive for reconciliation. His coping capacity was enhanced after grief work was incorporated into several counseling sessions.

adherence and health are critically linked

ADHERENCE

The interplay between adherence to medication and treatment regimes, clients' psychological and emotional state, and their health is critically linked. The greater use of protease inhibitor treatment, for example, has contributed to renewed health for some with advanced HIV infection and a longer period without disease progression for those with asymptomatic HIV infection. Managing the doses and administration of these drugs requires a significant level of commitment from providers and clients as there are risks when medications are not taken properly. Realistic fears about adverse effects, reluctance to acknowledge one's need for medications, and avoidance of HIV itself may affect one's emotional reaction to initiating protease inhibitor treatment. For many to cope, HIV itself needs to be put out of their minds as they continue to live from day-to-day. However, beginning protease inhibitor therapy becomes a frequent reminder of their HIV infection.

LAZARUS SYNDROME

A central psychological theme that accompanies protease inhibitor therapy is the emergence of the "Lazarus Syndrome," in which persons with advanced HIV infection notice a significant improvement in the medical indicators of immune system function and HIV viral load. With improved health, they may experience varying degrees of increased energy and fewer immobilizing symptoms. For many, this is a relief and becomes a welcome opportunity to reconstruct their lives. For others, there may be a sense of existential angst and the development of symptoms of depression, such as lethargy, isolation, and sadness, because they already had prepared to die.

Edward's Story

Edward had begun treatment with protease inhibitors in May of the previous year. His response to the medications was excellent, as his viral load became undetectable and his T-cells increased. Edward had survived the deaths of practically everyone else he knew who had been infected with HIV. When he considered his survival, he was consumed with the question, "Why me?" Diagnosed with an AIDS-defining illness in the 1980s, Edward expected a trend of deterioration and death. However, protease inhibitor treatment revised that assumption. Edward was called upon to confront the task of life reconstruction complicated by survivor guilt and the developmental dysynchrony that comes from not progressing to the next stage he was expecting. Edward seemed ashamed that he was not happier and more pleased by his improved health. Treatment, consisting of both an increase in an anti-depressant medication and insight-oriented psychotherapy with a focus on loss, helped Edward to re-invest himself in life and make a true return to work.

SPIRITUALITY

Attending to the spiritual aspect of clients' coping may prove helpful in stimulating resources for living, as well as assisting clients to extract and integrate

meaning into their experiences of living with HIV. Provider insensitivity to the client's spiritual background and belief system can erect an insurmountable barrier to treatment.

Mental health providers may need to increase their own comfort with religious traditions and spiritual practices as clients may not wish to meet with a separate pastoral counselor. Counselors and therapists may consider integrating spiritual issues into their counseling work by exploring the meaning of faith, as it relates to the client, and the purpose it serves in the client's life. Linked to this is the need for providers to remain open to clients' belief systems—especially when clients' beliefs are not reflective of their own religious traditions (specifically for individuals among recent immigrant groups and communities of color) and utilize the client as a resource.

By incorporating concepts of faith, strength, and redemption (as determined and described by the client) into the therapeutic process, mental health providers may find that this approach offers comfort and solace to clients, especially those experiencing increasing health complications or those facing death. By being willing to explore the topic of spirituality or faith, mental health providers can begin to discuss ways to help clients integrate their spirituality and HIV status into their lives more effectively.

Substance Abuse Treatment

There has been a long-standing relationship between HIV infection and substance use disorders. The correlation between injection drug use and HIV infection is well known and documented. There also exists a relationship between non-injection drug use and HIV infection. Individuals are at greater risk for HIV transmission while under the influence of alcohol or other drugs due to impaired decision-making processes. Continued alcohol or other drug use can further suppress the immune system. It also has potentially damaging psychological effects that may interfere with well being and functioning.

The experience of the 11 Demonstration projects confirms the high correlation of HIV infection and substance abuse. Demonstration data show that approximately 25 percent of clients served in the 11 sites had a diagnosis of alcohol dependence, while approximately 50 percent of clients met criteria for drug dependence.

A diagnosis of HIV can be overwhelming, and a common response of the newly diagnosed is to self-medicate with alcohol or other drugs. HIV-specific substance abuse treatment must incorporate treatment approaches that are sensitive and responsive to the presence of multiple diagnoses. In addition, service providers need to be better informed of the broad range of substance use disorders and better equipped to make accurate substance use diagnoses.

To make sound and clinically responsible choices about the proper approach to substance abuse treatment and the selection of the appropriate treatment modality, service providers can look to the assessment process as the best place to start the treatment regimen. This is especially true when a client meets criteria for substance abuse and/or dependence. (See Chapter 5 on Clinical Assessment.)

TREATMENT APPROACHES

Increasingly, persons infected with HIV are from indigent, marginalized populations. It is essential that they be linked with some type of substance abuse treatment programming if they are dependent on alcohol or other drugs.

Abstinence. The historical approach to substance abuse treatment has been to promote abstinence from non-prescribed substances. This approach has been, and continues to be, supported by involvement in 12-step programs (Alcoholics Anonymous, Narcotics Anonymous, and Cocaine Anonymous). Abstinence-based programs are generally appropriate

for individuals who are diagnosed as substance dependent, self-identified as addicted, or who want to abstain regardless of diagnosis. Some professionals working within the 12-step framework believe that the prescribed use of psychotropic and/or pain medications is not appropriate. However, adherence to this belief has declined significantly in recent years.

Harm reduction. The harm reduction model has become increasingly popular, partially in response to the HIV pandemic. It recognizes that some people will not or do not need to abstain from all substance use. In light of this recognition, the harm reduction model focuses on the need to decrease the potentially damaging effects of alcohol or substance use and on reducing the risk of HIV transmission. Persons with HIV who use alcohol and illicit drugs are vulnerable to engaging in high-risk behavior. Furthermore, these individuals may have failed abstinence-based substance abuse treatment programs in the past. They may, however, benefit from approaches that emphasize health and well being, rather than total abstinence from substances. Harm reduction is applicable to a range of self-destructive behaviors, including high-risk sexual activities. Types of harm reduction programming include methadone maintenance, needle exchange, and programs that teach persons to use alcohol and other drugs in ways that are less harmful. Frequently, individuals are referred to abstinence-based programs from harm reduction programs.

TREATMENT MODALITIES

A number of substance abuse treatment modalities were used by Demonstration projects in working with people with HIV who also had a substance use disorder. In sites where substance abuse treatment services were not provided, existing community resources were critical. These modalities are described below.

Medical detoxification may be required for the individual with a long history of substance use/dependence—particularly those using alcohol or heroin. Medical detoxification includes a brief period of hospitalization (approximately 3 to 7 days) and the administration of medication to alleviate withdrawal symptoms. Medical detoxification also may be considered when beginning substance abuse treatment for those with chronic medical diseases to control the impact of withdrawal on the client's medical condition. Mental health services offered in conjunction with detoxification services may be effective in encouraging participants to access more structured care following the detoxification experience.

Social detoxification occurs in either a hospital or non-hospital setting and usually does not include medication to treat withdrawal symptoms. The length of stay varies from 7 to 21 days, depending on the client and his/her available financial resources. Social detoxification provides the individual with an opportunity to quit using substances without medication while under constant supervision.

Inpatient treatment programs provide a 24-hour-a-day structure for clients in substance

abuse treatment. These programs are located within hospitals, psychiatric institutions, or as separate, stand-alone facilities. The length of inpatient treatment varies, depending on program rules, ability to pay for services, and other concerns. Clients may receive more personal attention than in other substance abuse treatment settings, as well as a higher number of service contacts in a shorter period of time. This approach does not work for some clients—largely because they are placed in a setting that is dramatically different and more structured than their usual environment. In addition, they are not exposed to situations that may jeopardize their recovery. One cautionary note is that this may create a false sense of success. Also, inpatient treatment programs often are short-term interventions that may not provide ongoing support services. Fewer insurance companies reimburse for inpatient treatment than in the past, and many others have decreased the number of days that they will cover for such services.

Residential treatment can occur in a setting that provides constant structure and substantial client supervision. Residential treatment programs vary both in the length and the intensity level of treatment. Some programs are as short as 30 days, while others may provide residential treatment for more than a year. These programs may include treatment groups, individual sessions, vocational rehabilitation services, and other support to clients. While some residential treatment programs may provide housing and require the client to attend 12-step group meetings, other residential treatment programs provide little additional support, structure, or supervision.

Partial hospitalization programs (PHPs), also known as day treatment programs, often are affiliated with inpatient treatment and are part of the continuum of care offered by such entities. PHPs offer group and individual sessions during daytime hours to clients who require some supportive structure in their lives but do not require 24-hour monitoring. The comprehensiveness of such programs depends on the needs of the client and varies from one agency to another. Some clients participating in a PHP attend a few hours a day, while others attend one or two days a week, depending on whatever is deemed appropriate and necessary for the client. This option is particularly necessary for addicted single parents with children who are unable to move into a residential treatment program without losing their dependents.

Methadone maintenance is useful for some persons with a long history of heroin use. Methadone is used in place of heroin and is itself addictive. Methadone maintenance requires medical supervision. Clients usually are required to submit urinalysis or blood toxicology screens to determine if they have used other substances while on methadone. If these screens are positive, there may be appropriate repercussions related to their treatment eligibility. Some treatment difficulties may include individuals selling methadone on the street or exchanging it for heroin. Since methadone is addictive and is a replacement drug, some programs implement tapering procedures. Tapering is a process to lower the dose in small

... a continuum of care

amounts over a period of time, leading to eventual abstinence from this substance. The use of methadone in combination with antiretroviral drugs, such as protease inhibitors, requires close monitoring of drug interactions.

Outpatient treatment allows clients to maintain their daily routine while receiving substance abuse treatment. These programs may provide services during evening hours, daytime hours, or on weekends so participants do not have to take time away from work to attend appointments. Clients receive services and support through group or individual sessions, or both if indicated. This approach allows the client to apply what he/she is learning in treatment to real life situations outside of the substance abuse treatment setting. A major downfall of this approach is that clients may have difficulty stabilizing since they remain in their daily routines and encounter their earlier temptations. A significant adjunct to traditional outpatient substance abuse treatment is participation in 12-step programs. There are HIV-specific 12-step programs in many cities across the U.S.

RELAPSE PREVENTION

Relapse prevention acknowledges that addiction is a chronically relapsing condition, but that relapse can be avoided. Relapse prevention is essential for HIV-infected populations, because relapse with alcohol and other drugs is frequently associated with other high-risk behaviors. Successful relapse prevention treatment often focuses on both behavior modification and restructuring internal processes. Relapse prevention planning services are provided at two levels:

- Relapse prevention counseling focuses on identifying high-risk situations and developing plans to decrease any potential for resuming alcohol and other drug use. This is achieved through either individual or group sessions for a specific period of time—usually eight to twelve sessions.
- Relapse prevention therapy helps the client identify core psychological and emotional issues that may lead the client to placing himself/herself in high-risk situations. Individuals work with professionals to identify those changes necessary to prevent them from putting themselves at risk. This often involves a thorough examination of the individual's system of core values and beliefs. This process occurs once a client has stabilized, has maintained abstinence for an appropriate period of time, and has demonstrated the necessary behavioral changes. The length of the process varies with the client's history and level of commitment to change.

The Realities of Relapse

Relapse is often a normal part of the recovery process and should not be considered a treatment failure. Substance abuse is an underlying behavioral symptom of dysfunctional coping skills. Relapse to substance abuse generally begins with internal dysfunction that is either psychological, emotional, or mental in nature. Resuming substance use often is the last in a series of steps that lead to alcohol and other drug use.

CLINICAL CONCERNS

Comorbidity. Individuals diagnosed with a substance use disorder, a mental disorder, and HIV infection are commonly referred to as triply-diagnosed. These clients require a broad range of comprehensive and individually tailored services. Such services may be offered within one agency or through the collaboration of several agencies. In the latter case, meeting the client's needs requires a great deal of coordination by a case manager or another service provider. Often, responsibility for helping the client to access available services falls on the service provider. Failure to assist clients in obtaining services for such needs can negatively affect treatment adherence and may lead to treatment failure.

Self-medication. Many individuals with pre-existing psychological problems begin alcohol or other drug use to medicate themselves in order to cope with such problems. To promote and support successful outcomes, clients need to be assessed for any mental disorder and provided services as needed. This may include the need for psychotropic medications to treat any identified mental disorder.

Prescription medications. Clients living with HIV infection eventually will be prescribed medications to help manage the progression of the illness. The client may be required to take multiple pills at numerous points during the day. Taking the many medications necessary to manage HIV infection can cause drug interactions, and any one of these medications may cause severe side effects. The service provider can be an important resource for the client by providing information and support that helps the client adhere to his/her medication regimen. If clients are reluctant to take certain prescribed medications, the service provider can discuss various treatment options with the client and help him/her make a clinically appropriate and informed decision. In particular, clients who have a history of drug use—especially those currently in recovery—may be reluctant to take certain psychotropic or pain medications. Conversely, clients accustomed to abusing alcohol and other drugs may manipulate service providers to secure more medication than is necessary.

Medicinal marijuana. Currently, the federal government does not deem the use of medicinal marijuana appropriate or legal. However, some jurisdictions have passed legislation legalizing the use of marijuana for medical purposes. People living with HIV may use marijuana to deal with the side effects of certain medications or to increase their appetite. For example, some clients with persistent nausea or a poor appetite may try tetrahydrocannabinol, an active metabolite of marijuana, in pill form (e.g., Marinol, by prescription). However, delineating use and abuse of marijuana in the setting of HIV infection is important. Program staff must be fully informed of state and local laws related to the medicinal use of marijuana.

Adherence. Successful substance abuse treatment can play a major role in helping clients adhere to recommended services and prescribed medications. Individuals can become more willing and able to take HIV-related and psychotropic medications as prescribed, thus impeding the progression of HIV infection and improving the client's mental and emotional well being. There is a strong correlation between HIV medication adherence and longevity, and it is common for many individuals actively using drugs and/or alcohol to not adhere to their HIV medications.

Risk reduction. Risk reduction refers to the impact substance abuse treatment may have on decreasing HIV-related risk behaviors. Due to decreased inhibitions while under the influence of drugs and/or alcohol, clients may participate in unsafe sexual activity or use injection drugs. Individuals participating in substance abuse treatment should be encouraged to reduce or eliminate behaviors that put them or others at risk for HIV transmission. Risk reduction efforts can be further strengthened by relapse prevention planning, mental health services, abstinence, or harm-reduction approaches. (See Chapter 11 on Risk Reduction.)

PROGRAMMATIC CHALLENGES

Outreach. Since a large number of clients may not access mental health and substance abuse treatment through traditional avenues, it is important for programs to include outreach as a key programmatic activity. Outreach helps agencies reach a greater number of potential clients and establish and maintain important relationships. It also can increase public awareness of the service program and its efforts.

Here are examples of activities that make for successful outreach:

- **Going to the places where clients use alcohol and other drugs.** This means traveling into the neighborhoods where drug use is prevalent and meeting clients in a diverse range of areas, such as where the sex trade is prevalent, shooting galleries, crack houses, neighborhood bars, street corners, and parks. Safety training is important for workers going into dangerous areas.
- **Providing tangible items to potential clients.** These may include “safer sex kits” that include condoms and lubricants or “safer drug use kits” that offer clean needles and/or bleach.
- **Using peers.** Outreach efforts can be enhanced and more effective when peers or clients are part of the outreach effort. These individuals may be able to relate to potential clients more effectively because they know the drug “lingo;” understand the subcultures of drug use, the sex trade, and formerly incarcerated individuals; and are better equipped (because of their personal experience with the program) to establish trust with potential clients. Such individuals may be able to educate clinical staff in such issues.
- **Persistence.** Outreach activities should go beyond an initial contact. Additional outreach efforts and multiple contacts with clients may be necessary to engage and retain them in the service delivery process.

Engagement. This concept involves being able to identify and encourage individuals to accept and receive treatment and support services. Genuine engagement is an ongoing process that only starts by getting a client involved in service delivery.

The following elements are key components of a sound approach to engagement:

- **Ability to provide immediate services.** Clients may request substance abuse treatment when in crisis. It is essential that services be available at that time.
- **Provide clinically and socially appropriate services that are based on a thorough assessment.** Assessing the client's substance use history—including past involvement in treatment, types of treatment attempted, previous periods of recovery, and relapse history—will generate a treatment plan that matches the client's current needs. Agencies frequently offer limited substance abuse treatment options, such as outpatient group therapy or short-term inpatient treatment. These limited approaches may not be sufficient for some clients.
- **Cultural competence.** This concept encompasses taking a multicultural approach to client engagement. As clients are engaged, service providers and other staff must be sensitive to the client's race/ethnicity, sexual orientation, personal and professional experience, and other factors. Although staffing patterns do not have to specifically match the client base, program managers should take whatever steps are necessary (e.g., sensitivity or cross-cultural training for staff) to ensure that staff are prepared to take a multicultural approach to client outreach and engagement.

The Demonstration projects tried a variety of creative approaches to engaging substance abusing clients:

- Holding raffles and offering prizes to people at sessions
- Offering gift certificates
- Holding holiday parties for clients and their families
- Giving away fast food coupons
- Providing child care, transportation, refreshments, and other benefits that make it easy and desirable to visit the program

it is essential that treatment remain accessible

BARRIERS

The Demonstration projects found that numerous barriers to substance abuse treatment can arise. For example:

- Potential clients may view substance abuse treatment programs as part of the legal system and therefore want to avoid it. This perception may be based on an individual's previous, court-ordered experience in treatment programs.
- There is high potential for relapse—especially among clients who have not stabilized or made a solid connection with the treatment program. Extra efforts may be needed to pursue these clients.
- Language itself can be a barrier to substance abuse treatment. Clients may use street or drug culture language, and this “lingo” may differ from one geographical location to another. Service providers must be able to work through this barrier by learning the language or at least asking clients to explain terms that are not immediately clear to the provider.
- Lack of support is another barrier that may prohibit individuals from accessing substance abuse treatment. Potential clients may not have the encouragement from family, friends, or service providers to enter or re-enter substance abuse treatment.
- Finally, substance abuse treatment should be offered to anyone requesting such services, including those individuals who remain under the influence of alcohol and/or drugs. It is essential that treatment remain accessible to HIV-infected populations even if they have not previously benefited from a treatment episode.

These are just a few of the barriers that may occur. Programs need to be aware of these and other barriers to ensure that services are available and accessible to the target population, and appropriate for their needs.

CHAPTER 11:

Risk Reduction

Risk reduction activities cover a range of educational, cognitive-behavioral, and skills-building interventions. The Demonstration Program considered risk reduction as an intervention designed to diminish maladaptive behaviors and promote a healthy lifestyle. Risk reduction activities can be delivered via both individual and group modalities at any time during the intervention process. Risk reduction interventions may be implemented in locations where persons with HIV are served.

FACTORS AND BEHAVIORS

The 11 Demonstration projects identified several factors and behaviors that may negatively affect the health and well being of people living with HIV. For example:

- **Engaging in unprotected sex.** Re-infection often results in the introduction of new strains of HIV. Persons are especially vulnerable to other sexually transmitted diseases and hepatitis.
- **Use of alcohol and other drugs.** The use of alcohol and drugs reduces inhibitions and increases the likelihood of engaging in unsafe sexual activities. Their use can further impair the immune system and can adversely interact with HIV medications. Sharing of hypodermic needles can re-infect and spread HIV as well.
- **Lack of medication adherence.** HIV medications must be taken as prescribed to have maximum benefit. The lack of strict adherence to antiretroviral medications can lead to ineffective treatment and the potential to produce drug-resistant strains of HIV. Although medication regimens often are difficult to follow, clients need to understand the importance of observing a strict dietary routine and medication schedule—largely because treatment adherence is strongly associated with survival. Other medications, including psychotropic drugs, often are essential in helping persons adhere to HIV medication regimens.
- **Poor nutrition.** It is important that persons with HIV pay close attention to nutritional guidelines. Optimum absorption of HIV medications depends upon following these guidelines. Proper nutrition is necessary to avoid HIV-related wasting syndrome and to enhance one's ability to cope with a compromised immune system.
- **Untreated medical conditions.** Persons with HIV frequently have co-occurring medical conditions. Chronic illnesses, such as diabetes, liver and renal disease, and cancers must be treated aggressively, and adherence with medical regimens must be monitored.
- **Untreated emotional distress.** A range of psychological or emotional disorders frequently interfere with an individual's ability to actively manage HIV. It can interfere with medication adherence, the client's ability to keep appointments, the client's judgement, and one's ability to assume responsibility for his/her behavior.
- **Homelessness.** Without stable housing, all other therapies and treatment interventions can be seriously compromised. Lack of housing can exacerbate co-occurring disorders or other problems with mental health, substance abuse, and HIV infection.
- **Lack of a strong sense of self worth.** Poor self-image can be one of the greatest barriers to the cultivation of healthier habits.

promoting healthier behaviors

IMPLEMENTING RISK REDUCTION ACTIVITIES

Clinicians can employ a range of techniques to teach persons with HIV risk reduction practices. The process of immunizing clients against high-risk behaviors can be woven into the treatment process by providing information, teaching skill-building techniques, and offering self-esteem enhancing activities.

First and foremost, persons with HIV must be made aware of high-risk activities and how certain behaviors can jeopardize one's health. This can be accomplished through didactic seminars, written materials, and individual and group therapy sessions. It is essential that a curriculum be developed that covers behaviors associated with increasing or decreasing risk.

Information by itself, however, is not sufficient. Clients may not have the motivation or self-esteem to engage in preventive activities. Skill enhancement concerning assertive behaviors can be taught effectively. Insisting on condom use, negotiating other safe sex practices, and saying no to drugs and alcohol under peer pressure can all be taught in skill-building or assertiveness training workshops.

Methods of promoting healthier behaviors and improving physical, emotional, and spiritual health include:

- Involvement in support groups focused on HIV-related medical conditions
- Close monitoring of people with advanced HIV infection
- Access to prenatal care
- Tools to enhance medication adherence
- Taking a more active role in one's health care
- Linkage with medical treatment advocates

OTHER CONSIDERATIONS

Many service providers may need education and training to increase their knowledge and understanding of risk reduction activities and the potential benefits for the clients they serve. In addition, an awareness of cultural practices is necessary to help negotiate risk reduction behaviors. For example, women of different cultures and socioeconomic groups have varying degrees of power in heterosexual relationships, which may affect their ability to insist upon safer sexual practices. It also helps to know how different cultural groups manage and interpret different social contexts. For example, poor, gay Latino immigrants sometimes use class markers (e.g., how well someone is dressed, what kind of job someone has) as part of their decision-making around sexual risk-taking (Ayala & Diaz, 1997).

Knowledge of the specific dynamics of relationships among various cultural groups and the kinds of attributions individuals may make regarding class, race, and power can assist clinicians in their efforts to assist clients in adopting healthier behaviors.

Permanency Planning

One of the 11 sites participating in the HIV/AIDS Mental Health Services Demonstration Program devoted its treatment approach to permanency planning. This chapter reflects the lessons learned from the Kinship Connection Program in Elizabeth, New Jersey—as well as the collective experience of the other 10 projects.

Permanency planning is the process by which custodial parents living with HIV develop a viable plan for the future care of their minor children in the event of their own death. For the purposes of this chapter, the term “caregiver” refers to the person selected by the parent to take responsibility for the future care of the children. Permanency planning can be done by any individual who has legal custody of minor children—whether he/she is the biological parent, an adoptive parent, a grandparent, an aunt, an uncle, or another individual.

Planning for the future care of the child is a very emotional and difficult task for the parent. Acknowledgement of the need for permanency planning does not necessarily mean that the custodial parent is ready to take the necessary steps to start working on permanency plan. Engaging the client, building trust, and assessing the client's readiness is crucial to completing the permanency planning process. Likewise, it is in the best interests of the parents and the children to face the decision about who will be the future caregiver of the children after the parent dies. It is very important that this decision be made while the parent is still capable of making an informed and competent decision.

Unquestionably, permanency planning is difficult. It involves thinking about the illness and one's potential death. Many parents facing death intend to leave their children with relatives in some kind of informal adoption, not realizing the importance of planning, discussing it, and making a "legal plan" ahead of time. Parents can make the most appropriate decision for their children if they are well-informed of all available legal options. Many parents with HIV fear the many legal mazes that they must go through to secure a safe and viable family for their children. They also may fear Child Protective Services, the possibility of losing their parental rights, or having their children removed from their home before it is necessary.

Facts About HIV, Women, and Their Children

Women—especially those in their child-bearing or child-rearing years—continue to become the fastest growing segment of the population to be infected with HIV or diagnosed with AIDS. Consequently, there is a corresponding increase in the number of children who are directly affected by HIV. For example, it is estimated that, by 2000, between 72,000 and 125,000 children and teenagers in the U.S. will have lost their mothers to HIV. An additional 60,000 young adults (18 and older) also will have lost their mothers (Levine & Stein, 1994).

Permanency planning also is difficult because some clients may feel that completing a permanency plan and "taking care of business" equals giving up—not knowing that developing a permanency plan may also bring peace of mind.

Charlotte's Story

Charlotte was referred to treatment after she was diagnosed with advanced HIV infection. Charlotte had three children—two boys ages 6 and 12, and a girl age 14. Charlotte lived alone with her children. She also had a history of drug use.

After becoming engaged in the permanency planning process, Charlotte identified her mother, as the potential guardian for her children. But she soon changed her mind and identified her sister Karen as the preferred future caregiver, with her other sister as a back-up potential guardian.

Steps to complete the permanency planning process were taken. Case workers met with both of Charlotte's sisters to determine if each sister would be able to carry out the plan. Regular meetings between both of Charlotte's sisters and her children were held. An attorney made the plan legal.

Then Charlotte's health rapidly began to deteriorate. Because of HIV-associated dementia, Charlotte was unable to care for her children. At one point, Charlotte called her lawyer and ordered that her will and custody plan be changed so that a hospital employee would get custody of her children. Charlotte's sisters went to court, and the court gave custody of Charlotte's children to Karen, based on Charlotte's previous permanency plan. Charlotte went into hospice care. She died soon after.

Karen had a difficult time with her niece and nephews. They were not accustomed to having rules. They exhibited behavioral problems—both at home and at school—and they consistently received D's and F's in school. Program staff, however, continued to provide mental health and case management services, including bereavement counseling and a range of other services.

Today, Charlotte's children are earning A's and B's in school. Their behavior has improved, and they have adjusted to their new home.

The 12 Steps of Permanency Planning

1. Assist the parent in feeling comfortable with the idea.
2. Determine whether or not the parent has discussed his/her illness with the potential caregiver.
3. Talk to potential future caregiver(s).
4. Identify and address potential legal and non-legal barriers to the custody plan.
5. Find out who lives with the future caregiver or who visits frequently so that the child's physical, emotional, and sexual safety is protected.
6. Assess the future caregiver's readiness and availability to care for the children (e.g., health status, financial status, and housing situation).
7. Get the children involved at the appropriate time.
8. Try to keep siblings together. If this is not possible, help future caregivers understand and plan the need for frequent contact between siblings in the future.
9. Assist in planning and easing transitions into new schools, when necessary.
10. Determine when it is an appropriate time for the child and the future caregiver to start spending more time together.
11. Obtain legal approval of the custody plan.
12. Provide ongoing counseling and case management, as needed.

WHY PERMANENCY PLANNING IS IMPORTANT

Permanency planning is important for many reasons:

- If there is no custody plan, individuals other than the custodial parent will have to make several important decisions when the parent becomes too ill or after the parent's death. These decisions will be necessary at a time when the children and the possible caregiver will be grieving.
- The informal caregiver, even if he/she is a close relative, has no legal authority to make decisions on the child's behalf, such as enrolling the child in school, obtaining health insurance coverage or affordable health care, or securing other services the child may need.
- Child Protective Services may be required to intervene by placing children in foster homes, which may result in separating siblings.
- Final decisions may be made by the court, without hearing the parent's wishes, and the court's decision may not be what the parent wanted.

parents, children, future caregivers, attorneys, case managers, family therapists, other family members

THE PARTIES INVOLVED IN PERMANENCY PLANNING

Depending on the situation, permanency planning can involve several individuals who share an interest in carrying out the parent's wishes and protecting the children and their future. For example:

- The parent explains his/her wishes and makes decisions about the future care of the children.
- The children identify their preferences and dislikes, provide reactions to different options, and prepare to adjust to new living arrangements.
- The future caregiver expresses his/her availability, willingness, and readiness to assume new responsibilities for the children. At the same time, program staff can assess the caregiver's ability to care for the children and make arrangements for additional services and support systems.
- The attorney advises the client on his/her legal options, remaining sensitive and responsive to the client's unique legal needs.
- The case manager coordinates the full range of services that are needed to support the parent, the children, and the caregiver; ensures continuity of care; and advocates on behalf of the client and the reconfigured family.
- The family therapist assists the client, the child, and the future caregiver in dealing with the parent's illness—including issues associated with denial, stigma, isolation, disclosure to the caregiver and/or child, and coping with HIV and its effect on the family. The therapist also facilitates the permanency planning process from beginning to end by maintaining contact with the child and the future caregiver after the parent's death to ensure continuity of therapy and permanency of the plan.
- Other family members and friends can be active participants in developing and implementing the permanency plan and in supporting the identified caregiver.

BENEFITS OF INVOLVING FAMILIES

The benefits of involving families in the permanency planning process include the following:

- It is empowering and can help the custodial parents retain a sense of control.
- Permanency planning minimizes disruptions in the child's life. For example, the child will not be bounced from one family member to another and will have an opportunity to gradually spend time with the potential caregiver as a way to ease transition into the caregiver's family. The ultimate goal is to meet the child's need for continuity, familiarity, and stability.
- It can ease the transition for the parent, the child, and the caregiver by addressing needs, fears, and concerns prior to and during the transition into the caregiver's family.
- Decisions can be made that may help keep all siblings together. If that is not possible, arrangements can be made for siblings to get together during special occasions, such as birthdays, anniversaries, holidays, etc.
- Parent, child, and caregiver family needs can be identified so that all needed support services are put in place to ensure the viability of the plan.
- The parent, the children, and the caregiver are afforded an opportunity to discuss concerns and/or potential problems with the potential permanency plan.
- Involving the concerned parties in this process helps to minimize the potential for future legal custody battles once the permanency plan is implemented.
- When an infected parent is using alcohol or other drugs and refuses to discuss permanency planning, program staff may be able to work with the individual who supervises the client's children, a family member, or someone else close to the client who is interested in protecting the children in the future.

Whenever possible, children should be active participants

WHEN TO GET FAMILIES INVOLVED

The sooner custodial parents begin to confront permanency planning the better. Many parents agree to work on permanency planning issues, but they may not be ready to do it when it is brought up for the first time. Permanency plans take time to develop and the amount of legal paperwork may be daunting, especially in cases where there is the potential for custody battles. In spite of these challenges, clients should be encouraged to begin permanency planning as soon as they are willing and able to make these decisions.

While there is no easy time to bring up the need for permanency planning, some times may be better than others. For example, if a parent is hospitalized and has not yet developed a permanency plan, he/she may be more prepared to discuss the possibility when hospitalized. Clinicians can use this opportunity to discuss the options and resources available to the client.

HIV-affected children also require a careful approach to engagement. Program staff can encourage parents to allow their

children to be engaged at an appropriate point in the permanency planning process. Whenever possible, children should be active participants in permanency planning so they can begin to identify preferences. In fact, if a custody plan is reviewed by the court, many judges will ask older children to indicate their preferences for a potential caregiver.

Future caregivers also play an important role in permanency planning. Identifying the future caregiver early in the process ensures that he/she is aware of and in agreement with the plan itself. This provides an opportunity to assess the caregiver's ability to carry out the permanency plan and to determine what services may be necessary to help him/her care for the children, such as support systems, appropriate housing, financial resources, insurance coverage, and other potential services. This also provides an opportunity for the future caregiver to spend time with the children (e.g., staying overnight), which can help ease the transition for all parties involved.

LEGAL OPTIONS AVAILABLE TO PARENTS

It is important to educate and empower parents regarding the different permanency planning and guardianship options available. The following brief descriptions of current legal options available to families are provided for educational purposes only. Before any actions are taken, one should consult an attorney in the state of residence.

A **will** is a legal document used to record a person's wishes upon his/her death. It may include a nomination of a caregiver who will serve as the child's future guardian. Drafting a will is relatively simple and allows a parent to retain full legal custody of the children until death. However, a will does not guarantee placement with the parent's chosen guardian. Following the death of the parent, the chosen guardian must petition the court. The court then determines what it believes to be in the best interest of the child. If there is a surviving biological parent, he/she will have to consent to the chosen guardian. A biological parent will most likely be successful in gaining full custody if he/she wishes to seek custody after the parent's death. A will is only a method to indicate a "preference" and is not binding as a final determination.

Adoption is the most permanent form of placement. In an adoption, the parental rights are "terminated" and transferred to the adoptive parent(s). To initiate adoption, an application or petition must be filed with the court. The petition requires a signed document from both parents giving up their rights over the child. A hearing is then scheduled and the judge makes a final determination. The process may take a year or more. Because of its time and permanency, adoption is impractical and not emotionally feasible for some parents with advanced HIV infection.

Guardianship is a less permanent placement than adoption and usually is a more plausible choice for parents. Guardianship involves a process in which a parent's rights are suspended, allowing the designated guardian to serve as the primary caregiver. A petition must be filed in court, and a judge makes a final ruling after a hearing several weeks later. In the interim, a court-appointed social worker will visit and assess the prospective guardian's home. If there is a surviving biological parent, he/she must consent to the placement, legally abandon the child, or waive his/her rights for placement to proceed. Surviving parents who challenge the appointment may succeed, unless demonstrated to be unfit parents. Once guardianship papers are signed, all parental rights are suspended. The new guardian has legal authority and will not have to take any steps following the parent's death. Although this fairly simple process allows the parent to complete the

process of finding a home for the child before his/her death or disability, the parent must give up his/her parental rights and decision-making authority over the child. In some cases, the parent may be required to give up physical custody of the child as well.

Stand-by Guardianship allows a parent to complete a process to designate a secondary individual as a stand-by guardian to be empowered to assume the parental role immediately on the death or adjudication of incapacity of the last surviving natural parent or adoptive parent of the child. Typically, the statute requires the triggering event to be either the parent's physical debilitation, mental incapacity, or death. Stand-by Guardianship allows parents to care for their children and retain parental rights. However, upon parental death or declared incapacity, the legal authority automatically goes to the stand-by guardian. Under Stand-by Guardianship, a parent can make legal arrangements while still in good health, be involved with these arrangements throughout the court process to insure his/her wishes will be carried out, and retain parental rights until death or incapacity. Stand-by Guardianship is not an appropriate option for every parent. When there are two natural parents, both parents have an equal right to custody of a child. Stand-by Guardianship cannot be established if the other parent desires custody and is able to care for the child. Even when the other parent has been absent from the child's

life or has abandoned the child, the custodial parent must always attempt to notify the non-custodial parent of the intent to name a stand-by guardian. The custodial parent must show that the other parent has no intent or desire to seek custody or that the other parent did not respond to the notification. Some states also will allow the custodial parent to show evidence that the non-custodial parent is not a suitable custodian for the child.

Joint Guardianship is a permanency planning option available in only a few states. The primary purpose of Joint Guardianship is to allow a parent to complete the guardianship process while still healthy, without relinquishing or suspending all parental rights. This option allows the parent to choose the legal guardian and allows the child to become familiar with the guardian. However, since Joint Guardianship requires a parent to give up some control of the children by sharing decision making responsibility with the chosen guardian, this may not be a perfect solution for some parents. In those cases, Stand-by Guardianship may be more suitable.

permanency planning
offers
numerous
therapeutic
opportunities

Foster care/adoption becomes the option of last resort when parents living with HIV do not have family members or friends to take care of their children or when permanency plans are not in place. Once families are involved in the foster care system, options are limited. In most states, regulations give parents 18 months to correct or make needed changes in their life to regain custody of their children. If the children do not return to their biological parents, the next step is to put them up for adoption. Given that most foster care systems already are overburdened, this process may lead children to a series of placements and risk the possibility that siblings may be separated prior to and/or after adoption.

Because of the psychological implications associated with the permanency planning process, there are numerous therapeutic opportunities. The roles of the worker and mental health clinician are important. (See Chapter 4 on Mental Health Services, Chapter 8 on Psychotherapy and Counseling, and Chapter 9 on Counseling Themes and Clinical Considerations.)

Psychosocial Rehabilitation

One of the 11 Demonstration projects—the Community Living Room in Philadelphia—used the psychosocial rehabilitation (PSR) model exclusively in serving an inner-city population living with HIV. PSR has a long history in providing services to persons with mental illness. Its adaptation to clients who have mental health issues and who are HIV-positive has particularly proven effective with a population that is difficult to engage, traditionally does not seek services, and has often been marginalized to the outer fringes of society. Numerous PSR models exist, but most PSR models share specific characteristics that are integral to engaging and meeting the needs of the individual who has both HIV and a mental disorder.

PSYCHOSOCIAL REHABILITATION PRINCIPLES

By highlighting what PSR emphasizes in comparison to what it does not emphasize, some key principles of PSR can be illustrated in the following list:

Emphasizes	De-emphasizes
Strengths	Deficits
Wellness	Illness
Hope	Pity
How-to	Why
Goal planning	Treatment planning
Working with the client	Providing services to the client
Small steps	Leaps
“Here and now” orientation	Past
Clients as active decision-makers	Clients as passive recipients

PSR
has a
long
history...

STAFF/CLIENT THERAPEUTIC RELATIONSHIP GOALS

PSR program staff must be firm believers in, and supporters of, PSR values and principles, which places total emphasis on engaging and involving the client as an equal partner in the therapeutic relationship. Relationships between staff and clients are non-hierarchical and must be environmentally generalized (e.g., occur in several different everyday milieus). Clients are treated in a PSR program not as “unfortunate people with a deadly virus.” Instead, they are viewed as functioning human beings with dreams, capabilities, skills, creativity, and aspirations—as people in possession of a life to still be lived.

...proven effective

with a population that is difficult to engage, traditionally does not seek services, and has often been marginalized to the outer fringes of society

PROGRAM OBJECTIVES

Philadelphia's Community Living Room Program centered its objectives around three change agents that functioned as the foundation upon which program services and activities were built.

- **Meaningful social and support networks.** The primary goal of the PSR clubhouse model is that enjoyable and supportive relationships in the program setting are the catalysts for the formation of a working therapeutic community. The therapeutic community then serves as a mold of behaviors, a marketplace for ideas, and an incubator for growth.
- **Achievement.** Helping clients to achieve success has long been the central catalytic change agent of expectancy model psychosocial programming. This approach is driven by the belief that achievement—no matter how small—is a stepping stone toward greater achievement (“successive successes”). Confidence in exerting more control on the present and exploring the possibilities of the future results from the intrinsic and extrinsic rewards that come with achievement.
- **Client empowerment.** PSR programs provide a nourishing milieu for client empowerment. Becoming empowered can be a compelling change agent in anyone's life. To aid clients in empowering themselves, this specifically means that the program must provide education on mental health and HIV, teach and build skills so that clients are able to access that knowledge, and help motivate clients to use their skills and knowledge in day-to-day living.

In PSR programs, clients are considered “members” and are instrumental in formulating rules, facilitating community meetings, helping to determine services offered, giving support to one another, and in performing many of the tasks needed for the daily operation of the program. They also are integral to the process of outreach and engaging new members, as well as providing support and direction to other members as they navigate their own life transitions. The cohesive partnership between members and staff ensures that the therapeutic community becomes a viable village in which everyone has a vital role to perform in helping all inhabitants thrive and be properly sustained. For many clients with HIV and a mental disorder, being a member of a PSR program may present the first opportunity in years where input and contributions are not only valued, but also are expected and deemed necessary. A visitor to a successful PSR program should be struck by activity, enthusiasm, and a profound sense of ownership of the therapeutic community.

doing is
as important
as talking

The program’s services, which emanate from the program objectives, are many and varied. However, the range of services almost always includes groups, workshops, activities, and counseling. At the Community Living Room, groups and workshops are divided into six categories:

- **Mental health and HIV education** concerning issues such as illness management, risk prevention, medications, and nutrition
- **Skill enhancement** in such areas as vocational training, activities of daily living, communication, and leisure time
- **Creativity and self-expression** through such venues as art, music, writing, and drama
- **Insight development** involving areas such as relationships, sexuality, goal-setting, and decision-making
- **Complementary and holistic therapies**, such as yoga, herbalism, and meditation
- **Support groups**, such as Alcoholics Anonymous, Narcotics Anonymous, Triple Trouble, and other groups such as those focusing on male- and female-specific issues

The structure of groups and workshops is varied so that doing is as important as talking. Task, recreation, and interactive exercise groups have equal weight in importance as process groups.

Activities are an integral part of any PSR program. They are planned as enjoyable ventures in which members can interact with other members and staff in normalizing milieus. Excursions to museums or theatres, boat cruises or historic walks, outside lunches or retreats in the country emphasize that programming is a mission that exists beyond its four walls. Internal program activities, such as seasonal celebrations, birthday parties, dances, or talent shows celebrate client and staff milestones and collaborative capabilities. An especially meaningful activity of a PSR program may be lunch time, when staff and members eat together as a family.

Counseling in PSR can also be varied in its modality and style but is primarily directed by members and staff working together to develop achievable, client-centered goals and to support their attainment. Intervening life issues and crises can also be shared and addressed in group settings, as well as in one-on-one counseling.

The program space and environment should be warm, stimulating, aesthetically pleasing, and functional.

Comfortable furniture, plants, and artwork should fill the large spaces and corners of the facility. The physical environment should support the program's groups and activities and not detract from them. For example, a theatre group will need a space where it can spread out, while a support group needs a space where it can be close together. Likewise, an art group will need a space it can mess up, and an education group will need a space where it can easily focus and not be distracted by clutter.

The amenities of programs are varied from site to site but are always present to complement and augment services offered and to further enrich the PSR environment. At the Community Living Room, coffee and tea are provided throughout the day. Showers and laundry facilities are on site for members who do not have suitable living arrangements. Member lockers are available for storage. Purified water and public phones are centrally located. Pamphlets and bulletin boards supply information on mental health and HIV issues and resources, as well as leisure time opportunities. A piano, electronic keyboard, games, and books are readily accessible to members, as are lounges and spaces for quiet conversation. A computer room is open for members to learn and perfect skills, as well as play interactive games, write résumés, or surf the Internet.

POTENTIAL BARRIERS

Though an HIV-specific PSR program may seem on the surface rather easy to develop, there are actually many obstacles that must be overcome.

- The first major hurdle is finding a flexible funding source which recognizes that many of the nontraditional psychiatric aspects of a PSR program are indeed therapeutic.
- Hiring staff who can thrive in an egalitarian, client-centered environment and remain firmly committed to the PSR model is a challenging endeavor. In many cases, a person may have to adapt previous professional experience or education that did not include PSR principles. Since the therapeutic community is a living organism, staff need to be flexible to constant change in their roles and responsibilities.
- A PSR program must often operate in a larger system in which most workers may not understand its principles and operations. It is often thought of as an adjunctive therapy or kind of “play time” rather than a complete treatment modality. Therefore, to be a vital cog in a wider system, a PSR program must strive to communicate with other components of the organization and to interact with other interventions that may be vastly different in style and not appreciative of the uniqueness of the PSR approach.

A PSR model program is only one of several possibilities for providing ongoing services to the client living with HIV and a mental disorder. The Community Living Room has proven especially effective with the client who does not easily participate in the traditional programs of group and individual psychotherapy or cannot effectively deal with hierarchical systems.

**EVALUATING SERVICES
& PROGRAMS**

Program Evaluation

Program evaluation was a requirement of the HIV/AIDS Mental Health Services Demonstration Program and a critical component of developing and providing services at each of the 11 Demonstration sites. This chapter describes some of the issues to consider when developing and implementing a program evaluation of HIV-specific mental health services.

DEFINITION OF PROGRAM EVALUATION

Program evaluation means different things to different people. A utilization-focused approach to evaluation was found by some members of the Demonstration Program to be a comprehensive and practical way to conceptualize and evaluate HIV-specific mental health programs. According to Patton (1989), program evaluation is:

"the systematic collection of information about the activities, characteristics, and outcomes of programs for use by specific people to reduce uncertainties, improve effectiveness, and make decisions with regard to what those programs are doing and affecting (p. 14)."

Using this definition, program evaluation is focused on gathering data with the purpose of improving programs and decision-making. For the purposes of this Practical Guide, the remainder of this chapter, incorporating the lessons learned from the 11 Demonstration projects, follows Patton's utilization-focused approach to evaluation.

REASONS TO EVALUATE THE PROGRAM

Because evaluation can be a time- and effort-consuming process, it is important for program administrators and directors to ask themselves: “Why should we evaluate our program?” There are a variety of answers to that question, including:

- **To get a better idea of what the program is doing.** Conducting an evaluation can provide information about the program’s activities and the extent to which the program is being implemented as intended.
- **To assess the effects on clients.** An evaluation can provide information on how well a program is accomplishing its goals and objectives. It also can help administrators and the public better understand how a program is helping clients.
- **To improve the program’s services.** Evaluation findings can be used to make informed decisions about the program, including where to make improvements, where to cut back on or add resources, and how to bolster weaknesses or enhance successes.
- **To obtain future funding.** Given current federal and state funding priorities and strong emphasis on measuring outcomes, evaluation findings can assist an organization in obtaining funding for the program. For example, sharing evaluation findings with local or state HIV policymakers can lead to increased funding for a program.
- **To disseminate information.** Evaluation findings can be disseminated to service providers, program developers and evaluators, funders, and researchers so that others can benefit from past experiences and avoid making similar mistakes.
- **To meet requirements.** More and more HIV-specific programs are required to evaluate their services and outcomes as part of receiving federal, state, and local dollars. The most forward-looking programs see this requirement as an opportunity rather than a burden.

IDENTIFYING THE PRIMARY USERS OF THE EVALUATION

The Demonstration projects found that, prior to conducting a program evaluation, it was important to identify their stakeholders. Program planners can identify key stakeholders by determining who will benefit most from knowing about the evaluation findings. Stakeholders may include an organization's CEO, clinical

director, clinicians, case managers, clients, peers, HIV medical providers, Ryan White planning council members, community leaders, or members of a collaborative network. Stakeholders usually have a lot of influence over the program, the overall organization, and the system of care for people living with HIV. Examples of different stakeholders in the Demonstration Program and the kinds of questions they asked are presented in Figure 9.

Potential Stakeholders What Do They Want to Know?

Figure 9

Clients

- How will mental health services help me?
- Are services consistent with my cultural beliefs and expectations?

Community-Based Organizations (CBOs) and AIDS Service Organizations (ASOs)

- Will mental health services help our clients?
- Will services improve treatment adherence?

Staff

- Does the work I do really help people?
- What can we do better?

Federal, state, and local funding entities

- Are our funds being well-spent?
- Are future requests for funding justified?

The public

- Will this program benefit our community?
- How does this program help people?

There may be a multitude of stakeholders who have a multitude of questions about the program. Often, it is a good idea to start with a small list of stakeholders who have the most investment in the program. These primary stakeholders should be committed to the evaluation process from its initiation through implementation. At any point in the evaluation process, additional stakeholders can be added when:

- There is decreased anxiety around conducting the evaluation
- The scope of questions to be addressed expands to include other people who are invested in the answers
- There is increased confidence regarding the group decision-making process

DOING AN EVALUABILITY ASSESSMENT OF THE PROGRAM

An important "first step" for the program and its key stakeholders is to figure out if the program is ready to be evaluated and who should lead these efforts. One way to accomplish this is to convene stakeholders for a series of meetings to discuss critical areas of the program's functioning. Prior to these meetings, one of the stakeholders should be elected to lead the discussions, to be responsible for providing written feedback to the group, and to develop a written description of the group's responses at the end of the meetings. In the Demonstration Program, it was useful to address questions in each of the following areas:

- **The program's target population.** Who does the program serve? Be specific and exhaustive in the description. If, for example, the target population is "families affected by HIV," how are they affected? Does an adult family member have to be infected? Does the target population include children who are HIV-negative who have lost a caregiver to HIV? What are the demographics, characteristics, and trends (e.g., many more women are presenting with depression at intake) of the target population?
- **The program's mission and philosophy.** What is the program's mission and philosophy? Does it adequately describe the problem that the program is trying to solve? Does it need to be updated to better reflect the services provided? Is the program's mission and philosophy responsive to the needs of the target population? How is the larger organization's mission and philosophy connected to the program's mission and philosophy?
- **The program's goals.** What are the major goals related to achieving the program's mission? What changes are necessary among the target population? What must the program accomplish in terms of its role in the larger community in such areas as community relations, advocacy, education, etc.? Do all of the program's goals have end results, rather than processes or steps leading to results?

- **The program's objectives.** What are the program's objectives? Are they measurable? Are they achievable? Is there a time-frame for accomplishing each objective? Are program objectives really activities, or are they stated with end results? Do the objectives naturally lead to accomplishing program goals?
- **The program's interventions.** For each program objective, what are the services and activities provided by the program that will lead to the accomplishment of the objective? How much of a service or what type of activity is needed? What are the resources needed (e.g., staff, funding, and equipment) to achieve the objectives?

If the stakeholders adequately address each of these areas and develop a written document that describes the group's combined response to each area, the program has made the first step in preparing to be evaluated.

FINDING A PROGRAM EVALUATOR

At this juncture, stakeholders need to determine if the evaluation will require the services of an outside, professionally trained evaluator or if an individual from within the program or group of stakeholders can serve in this capacity. In the Demonstration Program, all 11 sites hired professionally trained evaluators or researchers. Because evaluation is such a critical component of most HIV programs, it is highly recommended that program administrators and directors seek and utilize the professional services of trained evaluators.

Finding an evaluator who is a “good fit” with a program and its stakeholders can be a fairly involved process. This section is devoted to addressing issues that may arise in achieving this goal. Project Directors in the Demonstration Program found evaluators by:

- Asking colleagues if they knew of any evaluation support in the area
- Contacting Departments of Public Health, Social Work, Epidemiology, Sociology, Psychology, and Health Administration at local universities or community colleges
- Asking local ASOs and CBOs about evaluation support in the area
- Contacting the American Evaluation Association (AEA) for a list of evaluators located in the area
- Referring to the literature on HIV and mental health and identifying researchers whose work they respected and admired

When a list of potential evaluators is obtained, the next step involves contacting individuals to find out about their experience, availability, and interests. Don't be intimidated by this process. There are many evaluators who would welcome the opportunity to expand their experience in the field of HIV. Figure 10 describes some tips on how to choose an evaluator.

Figure 10

Choose the Evaluator Wisely

From the collective experience of the 11 Demonstration projects, the programs with the most compatible program director/evaluator relationships fared much better in terms of developing and implementing an evaluation that was satisfactory for all parties involved. Some tips on how to choose an evaluator include:

- Know communication preferences in advance (in person, in writing, on the phone, via e-mail or faxes, on a regular basis, or on an as needed basis) and how program staff and stakeholders like to learn (through reading, lecture, back-and-forth discussions, or combination of approaches).
- Interview multiple individuals. Don't "settle" for the first one that comes along.
- Make sure he/she is committed to helping stakeholders frame and answer the evaluation questions rather than promoting his/her pet theories or methodologies.
- Ask about the evaluator's methodological preferences (e.g., quantitative vs. qualitative). This issue is discussed in more detail later in this chapter.
- If the candidate is not experienced and knowledgeable about the focus of the program or the target population, make sure he/she is interested in becoming more experienced and knowledgeable.
- Check references. Ask about the candidate's communication style and listening skills. Find out if he/she is a naturally collaborative and flexible person.
- Don't be overly impressed by the candidate's curriculum vitae or résumé. Talk about the candidate's beliefs and values about clients, his/her approach to the work, and experiences with other programs.
- Ask if the candidate has helped other programs write evaluation sections of grants and whether that has been done "pro bono" or for a fee.
- Ask if the candidate has experience disseminating knowledge and information. Find out if he/she is familiar with publishing articles in peer-reviewed journals.
- Ask about the candidate's availability to participate with the program. Also, find out if the candidate uses less-experienced staff to take over their responsibilities once program evaluations are up and running.

Before launching the search for an evaluator, it is important for program administrators to allocate a portion of their program's budget to evaluation. This will help in the negotiation process when the subject of fees arises. While most human service programs are tight for extra dollars, there are creative measures that program administrators can take to pay an evaluator.

The end of the fiscal year may be an ideal time to locate resources for this purpose. If none are available, stakeholders can be asked to contribute to the cost of hiring an evaluator. Stakeholders may be more willing to do so if they are a part of the interview process. It may be possible to convince program leaders, administrators, or the Board of Directors that a program evaluation can help the organization generate more revenue to expand programs that serve clients well. Figure 11 describes some incentives that may be useful in obtaining the services of an evaluator.

Once the services of an evaluator are secured, it is recommended that an informal contract be developed that outlines his/her roles and responsibilities in designing and implementing the program evaluation (see Appendix F for an example). When an agreement is reached, it is time to bring together the evaluator and stakeholders with the goal of further defining and describing the program's target population, mission and philosophy, goals and objectives, and interventions. The evaluator needs to be a key figure in guiding this process, ensuring that there is consensus in each area and that this consensus is clearly written down and communicated to key stakeholders. The next step of designing the program evaluation involves focusing on the questions it will seek to answer.

Figure 11

Other Incentives to Obtain the Services of an Evaluator

- Offer access to client and program data that may be used for publishable research.
- Offer access to client and program data for dissertation or master's thesis research.
- Ensure that program staff will assist the evaluator with data collection, relieving him/her from the burden of having to assign extra staff to collect data.
- Discuss ways to collaborate on future projects.
- Discuss ways to collaborate on future grant proposals.
- Offer the potential evaluator an opportunity to analyze results of a randomized experiment that might be done at the program.
- Sell this as an opportunity to expand the potential evaluator's HIV expertise.

IDENTIFYING AND FRAMING EVALUATION QUESTIONS

The worst thing that could possibly happen when a program evaluation is completed is for stakeholders to express the following sentiment:

"The evaluation did not tell us what we really wanted to know."

To keep this from happening, it is imperative that the “right” questions are chosen to be evaluated and that the “right” people are part of the process in choosing these questions. Important questions to ask when identifying and framing evaluation questions are:

- What is the purpose of the evaluation?
- How will the information be used?
- What will be understood after the evaluation is completed that is not known now?

While the answers to these questions may seem straightforward, connecting them to the evaluation questions frequently involves disagreement among the stakeholders as to which evaluation questions need to be asked to satisfy all parties involved. One way to work through this kind of disagreement is to utilize a logic model.

Using a Logic Model. To help stakeholders frame relevant evaluation questions, several evaluators in the Demonstration Program used logic models (See Appendix G for the Chicago Project's logic model). This approach gives stakeholders a way of tying program results or achievements to program inputs or resources. It stresses the importance of making sure a logical relationship exists between a program's goals and what it wants to accomplish. (See Resources for more information on logic models).

Developing a logic model for a program evaluation takes time and effort on the part of both the evaluator and stakeholders. The following guidelines are recommended when undertaking such an endeavor:

- Educate stakeholders about logic models before one is developed for the program.
- Provide examples of other logic models.
- Have the evaluator develop a first draft of the program's logic model based on his/her perceptions during the initial meetings. This step will make it easier for the stakeholders to respond to an incorrect logic model versus a blank logic model.
- Encourage input and questions about a program's logic model from stakeholders.

Selecting the type of evaluation to conduct. Using the logic model, the next step is to select the type of evaluation that should be conducted. The choice will depend on the purpose of the evaluation and the type and extent of programmatic and client information desired. Two types of evaluation are:

• **Process Evaluation.** If the stakeholders are interested in the extent to which the program is being implemented as planned, then a process evaluation would be conducted. Process evaluation requires that the evaluator work closely with the stakeholders to determine how they view program implementation versus how program implementation is described in a grant or other program document. Examples of process evaluation questions are:

- How many intakes were conducted with newly diagnosed HIV-seropositive clients during the first quarter?
- How well did the mental health clinicians coordinate their treatment planning efforts with primary care providers?
- How many HIV-infected and -affected clients attended at least 80 percent of the treatment adherence groups?

• **Outcome Evaluation.** If the stakeholders are interested in knowing how well the program is doing in meeting its goals, then an outcome evaluation would be conducted. Examples of outcome evaluation questions are:

- Before your HIV-specific mental health program began, how many HIV-seropositive clients kept at least 75 percent of their medical appointments? After your HIV-specific mental health program began, how many HIV-seropositive clients kept at least 75 percent of their medical appointments?
- How do high service utilizers differ in their quality of life compared to low service utilizers?
- In comparison to other clinics where mental health and substance abuse treatment services are provided, what percentage of HIV-infected clients remain drug-free?

Once the evaluator and stakeholders select the type of evaluation to conduct, it is time to refocus on identifying and framing the evaluation questions. Which program processes should be evaluated? Which outcome would be the most interesting to measure? Needless to say, much confusion may arise at this juncture because of the seemingly endless choices of questions to ask and evaluate. It is the evaluator's responsibility to remind stakeholders to think clearly about the intended uses of the evaluation and to choose only those questions that fit those criteria. (See box for Atlanta's site experience).

After the evaluator and stakeholders have selected the specific process and/or outcome questions to address, it is time to select the evaluation methodology.

Deciding on the methodology. When making evaluation methodology decisions, the goal is to get the best possible data, given available resources and time, to adequately answer stakeholders' questions. The essence of utilization-focused evaluation is to decide on the measures, samples, and comparisons that are most appropriate and credible to address the program's evaluation questions.

It is important for stakeholders to have some information about quantitative and qualitative methodologies because evaluators tend to lean toward one or the other. The dominant paradigm espouses the use of quantitative methods (i.e., using statistical methods under experimental conditions, "hard data"). Most of their proponents believe that this scientific method is superior to the use of qualitative methods (i.e., systematically describing differences in a phenomenon by considering the context and its development, "soft data"). Both methods reflect particular world views.

In actuality, there are strengths and weaknesses in relying solely on either quantitative or qualitative methodologies in an evaluation. What is required is flexibility in attitude and thinking, and creativity in using the most appropriate approaches for the questions at-hand. In addition, the evaluator should be honest about his/her methodological prejudices. More than

"At our site, all of the coalition members were given an opportunity to provide input into the evaluation plan. A preliminary plan was developed by Steve McDaniel, the Project Director; Peter Campos, the Project Coordinator; and me; but this was significantly revised as a function of input from other members. In addition, the other members suggested consumer focus groups, which we conducted, that were used to help develop the intervention itself. All forms were also reviewed by the group, and the evaluation team reported on our progress at monthly coalition meetings."

– James Emshoff, Ph.D.

Chief Evaluator

Atlanta Project

likely, the program's methodology will be a combination of quantitative and qualitative methods because this strategy often produces the most worthwhile findings.

To further ensure that a program is getting the most use of evaluation findings, the evaluator and stakeholders also should consider the following issues when selecting the evaluation methodology:

- **What will the findings look like?** Imagine what the evaluation findings will look like and how to interpret them. Design a mock-up report or visual representation of the findings, and guide stakeholders through an exercise on how they might actually use the findings.

“We had to streamline our originally planned local evaluation to meet the needs of our population, who needed to receive services as soon as possible rather than participate in lengthy evaluations. So the lesson for us was that, unlike other dually diagnosed groups, HIV-positive patients seeking substance abuse and mental health services require abbreviated evaluations and rapid entry into treatment for physical and psychological reasons.”

– Karen Ingersoll, Ph.D.
Chief Evaluator
Richmond Project

- **Is it okay to start with a simple evaluation?** Yes, especially if evaluation is a new experience. Start with process evaluation questions. That will give stakeholders an idea of the state of the program's recordkeeping system (see the next bullet). Be successful first with a small endeavor, then expand the scope with additional successes.
- **How good is the program's recordkeeping?** Evaluation relies on the program's recordkeeping system. It is important to know when, how well, and by whom records are kept. The four basic types of records that a program's process evaluation may access are resource expenditures; administrative activities; client intake/assessment information; and service delivery activities.
- **How good is the program's management information system (MIS)?** Another concern is whether any or all of these records are entered into, stored, and easily accessed through a computerized MIS. If so, are there staff who can help the evaluator access and transfer this information? Numerous questions regarding a program's MIS capacity will need to be addressed as it affects the evaluation methodology in terms of costs, effort, and time.
- **Will program administrators thwart the evaluation?** Because the burden of conducting a program evaluation often falls upon the program administrator, he/she must be the one to commit to the evaluation. If program administrators are unwilling to do so, it is unlikely that a good evaluation will take place, even though he/she may pay “lip service” to it.
- **Will program staff thwart the evaluation?** Because many evaluations rely on staff to administer evaluation tools and/or document services in new ways, their fears

and discomfort must be acknowledged and attended to in a firm, respectful manner. There will be less resistance if the evaluation questions are clinically relevant, if staff feel that the evaluator respects and values their work, and if staff perceive the findings as being beneficial to themselves and their clients. Resistance from staff also may be addressed by including them in the group of stakeholders so their points of view are considered.

- **How will the program's intervention affect the methodology?** If the program's intervention is too difficult to define, then it will be very difficult to measure. If treatment changes with each client, then the evaluation will need to be flexible to measure these differences. If there is not enough of an intervention (dosage), then it may not be worth measuring—but it may be worth describing.
- **How will the program's target population affect the methodology?** Developing the evaluation methodology depends directly on the program's target population. Will the measures require clients to read? If so, at what level? Are the measures culturally and linguistically sensitive? When is it ideal to administer pre- and post-test instruments? How intrusive will certain measures be to the engagement process? Will clients need to be paid to participate? Again, having a member of your target population or an HIV-positive peer participate in your group of stakeholders may be one way of understanding and managing these issues.

Deciding what information and how much data to gather in an evaluation involves difficult decisions and trade-offs. For example, stakeholders may decide to conduct qualitative interviews only with clients who successfully complete treatment. The trade-off is not

knowing how and why the program failed to work with clients who dropped out of treatment. In general, collecting more data costs more and takes more effort and time, but getting less data may reduce confidence in your findings. Issues of reliability and validity need to be addressed by the evaluator and stakeholders, as well as threats to using the evaluation findings.

Unfortunately, there is no evaluation template that will help stakeholders make these methodology decisions, and there are no magical strategies to offer other than revisiting the question: "Is the methodology focused on providing intended users with information they can use?" There are steps, however, that the evaluator can take to help stakeholders better understand the program in order to make informed suggestions related to the evaluation methodology decisions:

- Assess the points in the program's intervention where evaluation would be the least intrusive and where conducting the evaluation would be most clinically relevant.
- Assess the feasibility of using existing staff as data collectors.
- Identify alternative data collectors (e.g., receptionists, research assistants).
- Assess the feasibility of using existing administrative and clinical records as data sources.
- Develop and/or locate alternative data sources (e.g., standardized instruments).

Having a better sense of the program's flexibility and its readiness to be evaluated will lead to a clearer picture of what needs to be incorporated into the evaluation methodology.

IMPLEMENTING THE EVALUATION

When it is time to implement the evaluation, various stakeholders may have different ideas about how to proceed. The evaluator may be excited and anxious to start collecting data. Program administrators may be distracted by new mandates or the every day crises that arise in doing HIV-related work. Staff may be nervous and unsure about what evaluation will mean to their day-to-day work life and their treatment approach with clients. Other stakeholders may be tired from the process and/or exhibit a combination of these feelings. Before the group embarks on this next stage of the evaluation, it is important to recognize all the hard work that has gone into the evaluation process so far. It is truly a milestone. After that is acknowledged, it is time to implement the evaluation. What follows are action steps taken by many of the evaluators and program administrators within the 11 Demonstration projects that helped make implementation more successful.

At the end of the pilot period, convene a meeting with program administrators, staff, and data collectors to discuss problems and solutions related to implementation. The evaluator must be ready to listen with an open mind and a non-defensive approach because there will be issues to work through. It helps to reframe these "problem-solving" meetings as "relationship building" meetings because it promotes continued enthusiasm and support for all members of the evaluation and clinical teams. If decisions have been made about the changes to the evaluation procedures and processes, incorporate them into both written and visual materials.

The evaluator and stakeholders need to be flexible, creative, and understanding of the many issues that may arise during the implementation phase. These include changes in the organization and program, changes in the epidemic, and tension between clinical and evaluation needs. Part of the evaluation may involve tracking these changes, noting occurrences of tension, and integrating observations with changes in client and program outcomes. Part of the evaluation may also involve giving stakeholders feedback on a regular basis about the effect of these changes and issues on client and program outcomes.

Evaluation, Implementation, Action Steps

- Conduct a series of staff trainings related to implementing the evaluation. Encourage participants to raise potential obstacles and solutions. Acknowledge fears and discomfort around changing the staff's routine. Reassure staff that, for most of them, it will become natural to blend evaluation into their clinical work over time.
- Conceptualize the evaluation for clinicians in such a way that it can provide valuable feedback for the treatment of their clients.
- Develop confidentiality procedures. Create the consent form for clients to sign before participating in the evaluation. Develop procedures for storing and accessing data on-site and off-site. Develop and/or utilize existing client identification system.
- Devise written procedures for staff around administering instruments, entering or storing data, and sending data to the evaluator (see Appendix H for an example of written procedures for the Chicago Project's service encounter record). While this task may take a long time to accomplish, staff appreciate having a written reference.
- Pilot the evaluation over a four-to-six week period—or longer if the evaluation is more involved. During this period, give program administrators and staff permission to make mistakes. Reinforce that there is a learning curve involved in implementing new processes and procedures. Encourage staff to document any problems, solutions tried, and results as they occur in order to present it accurately in future problem-solving sessions.
- Establish expectations. Give administrators and staff expectations of how the evaluator is going to maintain communication. Ask staff for best ways and times to communicate. Provide staff with information about who to contact (and their back-up contacts) should problems arise.
- Establish timetables that clarify when staff will be interviewed, when record abstractions will be conducted, and when written and verbal feedback will be provided.

Important Steps to Take With Stakeholders During the Analysis Phase

- The evaluator is responsible for analyzing the data first, explaining how this was accomplished, and sharing the findings with stakeholders. Findings should be presented in multiple ways (e.g., written, orally, and visually) so that each stakeholder has an opportunity to understand them and respond.
- Stakeholders should have the first stab at interpreting the evaluation results. The evaluator should facilitate a discussion with stakeholders and insert his/her own interpretations and recommendations as the discussion progresses.
- Stay focused on the findings that will be the most useful for intended users. It may be tempting to discuss all the findings at the same intensity, but stakeholders will lose interest if too much information is presented and discussed.
- Recommendations need to be carefully developed and clearly connected to the evaluation findings. Too many programs fail to do this because stakeholders want to present the “news” or a grant proposal or program report would benefit from have the evaluation findings included. Work through the recommendations until they are mutually satisfying.

ANALYZING AND INTERPRETING THE DATA

The data analysis and interpretation phase occurs when the evaluator and stakeholders convene to look at the data and determine what it means. There is a difference between analyzing and interpreting data. Data analysis involves organizing the data in a systematic way (i.e., constructing statistical tables if quantitative data is being collected) and arranging the data in an orderly and easily understood format. Interpretation involves deciding what the data mean, providing reasons for the findings, and assigning importance to the findings.

The procedures that the program uses to analyze data will be defined mostly by the evaluation questions and design. A description of the different ways to analyze quantitative and qualitative data is beyond the scope of this chapter. There are several issues that may influence the analysis of the data, including:

- **Competing projects for the evaluator.** The evaluator likely will be involved in other projects. The evaluator should be encouraged to be up front about his/her situation so that negotiations can be made to possibly make the analysis a higher priority.
- **Qualitative versus quantitative analysis.** It takes much longer—and usually costs more—to perform a qualitative analysis than a quantitative analysis because it takes more effort to develop and utilize a systematic framework for organizing and extracting qualitative data into meaningful units of analysis; qualitative data is frequently converted (i.e., transcribed from audiotaped interviews or archival records) before it is analyzed; and there are many statistical packages that allow for quicker quantitative analysis.
- **Accuracy of the data.** In circumstances where the completion of forms or instruments has gone unchecked for any period of time, there may be problems with the accuracy of the data. Examples include periods of time during which client services were not tracked because of staff turnover; a failure to train new staff on how to complete instruments as intended; and a natural tendency for trained staff to forget how to complete instruments. When situations such as these arise after the fact, it may stall data analysis if the evaluator and stakeholders decide to somehow retrieve and enter the data.

Stay focused on
the findings
that will be
most useful

DISSEMINATING THE EVALUATION FINDINGS

As experienced in the Demonstration Program, the dissemination of evaluation findings varied greatly from site to site. Some sites disseminated findings internally to program staff, while other sites disseminated findings to professional audiences. The nature of dissemination is a matter for negotiation between the evaluator and stakeholders. Not everybody is going to be as excited as the evaluator and stakeholders are about the findings and recommendations. The reality is that most evaluation reports end up on a funder's shelf or under a pile of other unread reports. It is the joint responsibility of the evaluator and stakeholders to ensure that this does not happen. Some ways to accomplish this are:

- **Know the audience.** Different audiences will be interested in different types of information. For example, a presentation of the findings at a local coalition meeting probably will be less formal, require some handouts, and involve questions from the audience that are more specific to sharing of similar experiences or "gut instincts" from the audience. On the other hand, a presentation of the findings to the local Ryan White council may be more formal, require more visual rather than written materials, and involve questions from the audience that may be more specific to the target population's response to the evaluation.
- **Take on a marketing stance.** In order to disseminate the findings, the evaluator and stakeholders may need to reframe their thinking and roles. They have to think like marketing agents and get the message out. The character of the mes-

sage is critical. Evaluation findings will need to be translated into whatever languages are spoken by the target audiences. If this stance seems beyond the evaluator's and/or stakeholders' skills and abilities, a marketing consultant can be hired to do the job.

- **Use multiple strategies to reach multiple audiences.** Multiple strategies (e.g., written vs. verbal, executive summary vs. complete description, slides vs. handouts) will need to be devised to present the findings and recommendations for multiple audiences. It also is important to have different combinations of the evaluator and stakeholder group (e.g., clinician and evaluator; client, funder, and evaluator) present the findings.
- **Have these discussions during the development of the evaluation.** Although it may seem odd to have a discussion about how, to whom, and where to present the evaluation findings and recommendations during the development of the evaluation, these discussions will help the evaluator and stakeholders focus their methodology and questions on how the information will be gathered and how it will be used.

People who participate in successful program evaluations from its development through implementation and dissemination usually look forward to the next opportunity to do so again. Because it is so critical to conserve time, dollars, and effort in finding ways to help people with HIV live better lives, program evaluations need to be done completely and effectively so that the most useful information can be shared with stakeholders and others who share the program's mission and vision.

References & Suggested Reading

INTRODUCTION

Centers for Disease Control and Prevention, *Update: Trends in AIDS incidence, deaths, and prevalence—United States, 1996*. Morbidity and Mortality Weekly Report, 46:861-867, 1997.

CDC Update, *CDC releases 1997 data on the HIV epidemic: Data from 25 states suggest that HIV infection has increasing impact among women and minorities*. Centers for Disease Control and Prevention, Atlanta, GA. April 23, 1998 news release.

Webster's New Riverside University Dictionary, 2nd Edition, Riverside Publishing Company, 1988.

CREATING PROGRAMS

Establishing Services

Collins BE & Reed GM, *Ten principles proposed as policy guidelines for mental health intervention research and mental health services among persons living with HIV/AIDS*. Psychosocial Rehabilitation Journal, 17(1):83-95. 1993.

Feingold A & Slammon WR, *A model integrating mental health and primary care services for families with HIV*. General Hospital Psychiatry, 15(5):290-300. 1993.

Harris K & Williams LD, *Communities of caring: Integrating mental health and medical care for HIV-infected women*. Focus: A Guide to AIDS Research and Counseling, 10(12):1-4. 1995.

Linn JG et al, *Stage of illness, level of HIV symptoms, sense of coherence and psychological functioning in clients of community-based AIDS counseling centers*. Journal of the Association of Nurses in AIDS Care, 4(2):24-32. 1993.

Sarwer DB & Crawford I, *Therapeutic considerations for work with persons with HIV disease*. Psychotherapy, 31:262-269. 1994.

Voelker R, *Rural communities struggle with AIDS*. Journal of the American Medical Association, 279(1):5-6. 1998.

Collaborative Networks

Ridgely MS et al, *Interagency collaboration in services for people with co-occurring mental illness and substance use disorder*. *Psychiatric Services*, 49(2):236-238. 1998.

Rosenes R et al, *Providing for the mental health needs of staff in AIDS service organizations: Collaborating with the private sector*. International Conference on AIDS. 1996. Vancouver.

Staffing

Bennett L & Kelaher M, *Longitudinal predictors of burnout in HIV/AIDS health professionals*. *Australian Journal of Public Health*, September; 18(3):334-336.

Elia N, *Grief and loss in HIV/AIDS work*, in *HIV mental health for the 21st century*, Winiarski MG, Editor. 1997, New York: New York University Press. 67-81.

Knox MD et al, *Training HIV specialists for community mental health*. *Community Mental Health Journal*, 30(4):405-413. 1994.

Macks JA & Abrams DI, *Burnout among HIV/AIDS health care providers in AIDS Clinical Review*. Feldman DA & Johnson TM, eds. New York: Praeger. 283-299. 1992.

McDaniel JS et al, *Caregivers working with AIDS: Avoiding burnout*, in *American Psychiatric Press Textbook of Homosexuality and Mental Health*, Cabaj RP & Stein TS, Editors. 1996, Washington, DC: American Psychiatric Press, Inc. 839-858.

Rudd RE, et al, *HIV-related training programs for health care professionals: Findings from a collaborative assessment*. *AIDS Education and Prevention*, 6(4):283-295. 1994.

Silverman DC, *Psychosocial impact of HIV-related caregiving on health providers: A review and recommendations for the role of psychiatry*. *American Journal of Psychiatry*, 150:705-712. 1993.

DELIVERING SERVICES

Mental Health Services

Braithwaite RL et al, *Prisons and AIDS: A public health challenge*. 1996, San Francisco: Jossey-Bass Publishers, Inc.

Conforti P, *Spirituality*, in *HIV mental health for the 21st century*, Winiarski MG, editor. 1997, New York: New York University Press. 52-66.

Ernst E et al, *Complementary therapies for depression*. *Archives of General Psychiatry*, 55:1026-1032. 1998.

Kalichman S & Sikkema K. *Psychological sequelae of HIV infection: Review of empirical findings*. *Clinical Psychology Review*, 1994.

Kalichman SC, *Understanding AIDS: A guide for mental health professionals*. 1995, Washington, DC: American Psychological Association.

LeBars, P.L., Katz, M.M., Berman, N., Itil, T.M., Freedman, A.M., and Schatzberg, A.F. (1997) *A placebo-controlled, double-blind, randomized trial of an extract of Ginkgo biloba for dementia*. North American EGb Study Group. *Journal of the American Medical Association*. October 22-29; 278 (16): 1327-32.

Linde, K., Ramirez, G., Mulrow, C.D., Pauls, A., Weidenhammer, W. and Melchart, D. (1996) *St. John's wort for depression - an overview and meta-analysis of randomised clinical trials*. *British Medical Journal*, 313, 253-258.

MacIntyre RC & Holzemer WL, *Complementary and alternative medicine and HIV/AIDS. Part II: Selected literature review*. *Journal of the Association of Nurses in AIDS Care*, March-April; 8(2):25-38. 1997.

Martin JL & Dean L, *Bereavement following death from AIDS: Unique problems, reactions, and special needs*, in *Handbook of bereavement: Theory, research, and intervention*, Stroebe MS, Stroebe W & Hansson RO, Editors. 1996, New York: Cambridge University Press.

O'Conner ME, ed., *Treating the psychological consequences of HIV*. *The Jossey-Bass library of current clinical technique*, ed. I.D. Yalom. 1997, San Francisco: Jossey-Bass Publishers.

Odets W & Shernoff M., eds., *The second decade of AIDS: A mental health practice handbook*. 1995, New York: Hatherleigh Press.

Pace JC & Stables JL, *Correlates of spiritual well-being in terminally ill persons with AIDS and terminally ill persons with cancer*. Journal of the Association of Nurses in AIDS Care, 8(6):31-42. 1997.

Perna FM et al, *Cognitive-behavioral intervention effects on mood and cortisol during exercise training*. Annals of Behavioral Medicine, Spring; 20(2):92-98, 1998.

Shelby RD, *People with HIV and those who help them*. 1995, New York: Haworth Press, Inc.

Shlay et al, *Acupuncture and amitriptyline for pain due to HIV-related neuropathy: A randomized controlled trial*. Terry Bein Community Programs for Clinical Research in AIDS. Journal of the American Medical Association, 11;280(18):1590-1595. 1998.

Stoff DM, *HIV infection in people with severe mental illnesses*. NAMI Advocate. 20(2):25-26. October/November 1998.

Wheatley, D. (1998) *Hypericum Extract: Potential in the treatment of depression*. CNS Drugs, June: 9 (6): 432-440.

Winiarski MG, ed. *HIV mental health for the 21st century*. 1997, New York: New York University Press.

Wong A et al. *Herbal remedies in psychiatric practice*. Archives of General Psychiatry, 55:1033-1044. 1998.

Clinical Assessment

Abidin RR, *Parenting Stress Index Manual*. Second Edition. Charlottesville, VA: Pediatric Psychology Press. 1986.

Batki SL, *Drug abuse, psychiatric disorders, and AIDS. Dual and triple diagnosis*. Western Journal of Medicine, 152(5):547-552. 1990.

Baumann SL, *Mental health assessment of persons with HIV*. Journal of the Association of Nurses in AIDS Care, 4(4):36-44. 1993.

Butters N et al, *Assessment of AIDS-related cognitive changes: Recommendations of the NIMH Workshop on Neuropsychological Assessment Approaches*. Journal of Clinical and Experimental Neuropsychology, 12(6):963-978. 1990.

DeJong P & Miller SD, *How to interview for client strengths*. *Social Work*, 40(6):729-736. 1985.

McLellan AT et al, *An improved diagnostic evaluation instrument for substance abusing patients: The Addiction Severity Index*. *Journal of Nervous and Mental Disease*, 168:26-33. 1980.

Radloff LS, *The CES-D Scale: A self-report depression scale for research in the general population*. *Applied Psychological Measurement*, 1:385-401. 1977.

Scofield EC, *A model of preventive psychosocial care for people with HIV disease*. *Health and Social Work*, 20(2):102-109. 1995.

Psychiatric and Neurologic Conditions

Atkinson JH et al, *Prevalence of psychiatric disorders among men infected with human immunodeficiency virus*. *Archives of General Psychiatry*, 45:859-864. 1988.

Berger JR, Levy RM, eds. *AIDS and the nervous system*. 2nd ed. 1997, Philadelphia: Lippincott-Raven Publishers.

Carey MP et al, *Risk for human immunodeficiency virus (HIV) infection among persons with severe mental illness*. *Clinical Psychology Review*, 17:271-291. 1997.

Carmen E & Brady SM, *AIDS risk and prevention for the chronic mentally ill*. *Hospital and Community Psychiatry*, 41(6):652-657. 1990.

Cournos F & Nicholas B, eds, *AIDS and people with severe mental illness*. 1996, New Haven: Yale University Press.

Cournos F & McKinnon K, *Substance use and HIV risk among people with severe mental illness*. *Research Monograph Series*. Rockville, MD: National Institute on Drug Abuse. 172:110-129. 1997.

Deeks SG et al, *HIV-1 protease inhibitors: A review for clinicians*. *Journal of the American Medical Association*, 277:145-153. 1997.

Folstein MF et al, *Mini-mental state: A practical method for grading the cognitive state of patients for the clinician*. *Journal of Psychiatric Research*, 12:189-198, 1975.

- Goodkin K et al, *HIV-related neuropsychiatry complications and treatments*. AIDS and HIV Disease - A Mental Health Perspective: APA Training Curriculum. 1996, Washington D.C.: American Psychiatric Association.
- Grant I & Martina A, eds. *Neuropsychology of HIV infection*. 1994, New York: Oxford University Press.
- Kalichman SC et al, *Human immunodeficiency virus risk among the seriously mentally ill*. Clinical Psychology: Science and Practice. 1996.
- Maj M et al, *World Health Organization Neuropsychiatric AIDS study, cross-sectional Phase I: Study design and psychiatric findings*. Archives of General Psychiatry, 51:51-61. 1994a.
- Maj M et al, *World Health Organization Neuropsychiatric AIDS study, cross-sectional phase II: Neuropsychological and neurological findings*. Archives of General Psychiatry, 51:39-49. 1994b.
- McArthur JC, *Neurological and neuropathological manifestations of HIV infection*, in *Neuropsychology of HIV infection*, Grant I & Martin A, Editors. 1994, New York: Oxford University Press. 56-107.
- McArthur JC et al, *Dementia in AIDS patients: Incidence and risk factors*. Neurology, 23:S34-37. 1993.
- McDaniel JS et al, *An assessment of rates of psychiatric morbidity and functioning in HIV disease*. General Hospital Psychiatry, 17:346-352. 1995.
- McDaniel JS & Purcell DW, *Neuropsychiatric disorders in HIV and AIDS*, in *Medicine for the practicing physician*. Hurst JW, editor. 1996, Norwalk, Connecticut: Appleton and Lange. 60-63.
- McDaniel JS et al, *Severe mental illness and HIV-related medical and neuropsychiatric sequelae*. Clinical Psychology Review, 17(3):311-325. 1997.
- Perry SW, *Organic mental disorders caused by HIV: Update on early diagnosis and treatment*. American Journal of Psychiatry, 147:696-710. 1990.
- Peterson J et al, *Stress, coping, HIV status, psychosocial resources, and depressive mood in African American gay, bisexual, and heterosexual men*. American Journal of Community Psychology, 24:461-486. 1996.

Power C et al, *The HIV Dementia Scale: A rapid screening test*. Journal of AIDS, 68:261-264, 1995.

Preston SL & Stein DS, *Drug interactions and adverse drug reactions with protease inhibitors*. Primary Psychiatry, (July):64-69. 1996.

Rabkin JG et al, *Treatment of depression in HIV+ men: Literature review and report of an ongoing study of testosterone replacement therapy*. Annals of Behavioral Medicine, 18:24-29. 1996.

Satz P, et al, *Depression, substance use, and sexual orientation as cofactors in HIV-1 infected men: Cross-cultural comparisons*. Treatment of Drug-Dependent Individuals with Comorbid Mental Disorders: National Institute on Drug Abuse Research Monograph Series, 172:130-155. 1997.

Sewell DD et al, *HIV-associated psychosis: A study of 20 cases*. American Journal of Psychiatry, 151:237-242. 1994.

Stober DR et al, *Depression and HIV disease: Prevalence, correlates and treatment*. Psychiatric Annals, 27(5):372-377. 1997.

Case Management

Albrecht GL & Peters KE, *Peer intervention in case management practice*. Journal of Case Management, 6(2):43-50. 1997.

Alexandria Community Services Board, *Breaking the cycle: An intensive case management model to engage homeless people with co-occurring mental illness and substance abuse disorders*. 1994.

Indyk D et al, *A community-based approach to HIV case management: Systematizing the unmanageable*. Social Work, 38(4):380-387. 1993.

Riley TA, *HIV-infected client care: Case management and the HIV team*. Clinical Nurse Specialist, 6(3):136-141. 1992.

Schwartz B et al, *Case management of substance abusers with HIV disease*. Journal of Case Management, 3(4):173-178. 1994.

Snyder CM et al, *An interdisciplinary, interagency, primary care approach to case management of the dually diagnosed patient with HIV disease*. Journal of the Association of Nurses in AIDS Care, 7(5):72-82. 1996.

Sowell RL, *Community-based HIV case management: Challenges and opportunities*. Journal of the Association of Nurses in AIDS Care, 6(2):33-40. 1995.

Sowell RL & Meadows TM, *An integrated case management model: Developing standards, evaluation, and outcome criteria*. Nursing Administration Quarterly, 18(2):53-64. 1994.

Ulmer C et al, *Categorical funding to seamless systems of care: The challenge for community-based primary care providers*. Journal of Case Management, 6(3):96-103. 1997.

Psychotherapy and Counseling

Barouch G, *Support groups: The human face of the HIV/AIDS epidemic*. Long Island Association for AIDS Care, Inc., 1992.

Caldwell SA et al, eds. *Therapists on the frontline: Psychotherapy in with gay men in the age of AIDS*. Washington DC: American Psychiatric Press, Inc., 1994.

Dworkin SH & Pincu L, *Counseling in the era of AIDS*. Journal of Counseling and Development, 71:275-281. 1996.

Farber EW, *Psychotherapy with HIV and AIDS patients: The phenomenon of helplessness in therapists*. Psychotherapy, 31:715-724. 1994.

Farber EW & Schwartz JAJ, *Changing conceptions of self and world through the spectrum of HIV disease: Implications for psychotherapy*. Journal of Psychotherapy Practice and Research, 6:36-44. 1997.

Freire P, *Pedagogy of the oppressed* (Translation by Myra Bergman Ramos). New York: Continuum Publishing Company, 1993.

Getzel GS, *Survival modes for people with AIDS in groups*. Social Work, 36(1):7-11. 1991.

Kelly J & Sykes P, *Helping the helpers: A support group for family members of persons with AIDS*. Social Work, 34(5):239-242. 1989.

Kennedy E & Charles S, *A Basic Guide for Nonprofessional Counselors*. 1996, New York: Crossroad Press.

Markowitz JC et al, *Individual psychotherapies for depressed HIV-positive patients*. American Journal of Psychiatry, 152:1504-1509. 1995.

Posey EC, *Confidentiality in an AIDS support group*. *Journal of Counseling and Development*, 66(5):226-227. 1988.

Rabkin JG et al, *Maintenance of hope in HIV-spectrum homosexual men*. *American Journal of Psychiatry*, 147:1322-1326. 1990.

Rounds KA et al, *Linking people with AIDS in rural communities: The telephone group*. *Social Work*, 36(1):13-18. 1991.

Somlai AM et al, *An empirical investigation of the relationship between spirituality, coping, and emotional distress in people living with HIV infection and AIDS*. *Journal of Pastoral Counseling*, 50:171-179. 1996.

Thomason G et al, *Cognitive behavioral interventions with persons affected by HIV/AIDS*. *Cognitive and Behavioral Practice*, 3:417-442. 1996.

Vincent E et al, *Peer counseling skills, ethics and perspectives*. 1996, Palo Alto: Science & Behavior Books.

Vinogradov S & Yalom ID, *Concise guide to group psychotherapy*. Washington, DC: Concise Guides/American Psychiatric Press. 1989.

Walker G. *In the Midst of Winter: Systemic therapy with families, couples, and individuals with AIDS infection*. 1991, New York: W. W. Norton & Co.

Winiarski MG, *AIDS-related psychotherapy*. 1991, New York: Pergamon Press, Inc. (Now distributed by Allyn & Bacon.)

Winiarski MG, *HIV mental health for the 21st Century*. New York: New York University Press. 1997.

Counseling Themes and Clinical Considerations

Benevedes JM, *The protease inhibitors and the therapist*. *Focus: A Guide to AIDS Research and Counseling*, 12(16):5-6. 1997.

Besch, CL, *Compliance in clinical trials*. *AIDS*, 9(1):1-10. 1995.

Crespo-Fierro M, *Compliance/adherence and care management in HIV disease*. *Journal of the Association of Nurses in AIDS Care*, 8(4):43-54. 1997.

Ferrando SJ et al, *Psychiatric morbidity, illicit drug use and adherence to zidovudine among injection drug users with HIV disease*. American Journal of Drug and Alcohol Abuse, 22(4):475-487. 1996.

Frank E, *Enhancing patient outcomes: Treatment adherence*. Journal of Clinical Psychiatry, 58(suppl 1):11-14. 1997.

Herek GM & Glunt EK, *An epidemic of stigma: Public reactions to AIDS*. American Psychologist, 43:886-891. 1988.

Hogg RS et al, *Improved survival among HIV-infected individuals following initiation of antiretroviral therapy*. Journal of the American Medical Association, 279(6):450-454. 1998.

Kissinger P et al, *Compliance with public sector HIV medical care*. Journal of the National Medical Association, 87(1):19-24. 1995.

Singh N et al, *Determinants of compliance with antiretroviral therapy in patients with human immunodeficiency virus: Prospective assessment with implications for enhancing compliance*. AIDS Care, 8:261-269. 1996.

Stall R et al, *Decisions to get tested and to accept antiretroviral therapies among gay/bisexual men: Implications for secondary prevention efforts*. Journal of Acquired Immunity and Human Retrovirology, 11:151-160. 1996.

Stokes JP & Peterson JL, *Homophobia, self-esteem, and risk for HIV among African American men who have sex with men*. AIDS Education and Prevention, In Press.

Substance Abuse Treatment

Barth RP et al, eds., *Families living with drugs and HIV: Intervention and treatment strategies*. 1993, New York: The Guilford Press

Broner RK et al, *Antisocial personality disorder and HIV infection among intravenous drug abusers*. American Journal of Psychiatry, 150:53-58. 1993.

Freeman RC et al, *Compliance with AZT treatment regimen of HIV-seropositive injection drug users: A neglected issue*. AIDS Education and Prevention, 8(1):58-71. 1996.

McCarty D et al, *Substance abuse treatment and HIV services: Massachusetts' policies and programs*. Journal of Substance Abuse Treatment, 13(5):429-438. 1996.

Merzger DS et al, *HIV conversion among in and out-of-treatment intravenous drug users in Philadelphia*. *Journal of AIDS*, 6(9):1049-1056. 1993.

O'Conner PG et al, *Medical care for injection-drug users with Human Immunodeficiency Virus infection*. *New England Journal of Medicine*, 331(7):450-459. 1994.

Shernoff M, ed., *Counseling chemically dependent people with HIV illness*. 1991, New York: Haworth Press.

Sobell MB & Sobell LC, *Problem drinkers: Guided self-change treatment*. New York: Guilford Press. 1993.

Wells EA et al, *Retention in methadone maintenance is associated with reductions in different HIV risk behaviors for men and women*. *American Journal of Drug and Alcohol Abuse*, 22(4):509-521. 1996.

Risk Reduction

Ayala G & Diaz R, *Racism, poverty, and other truths about sex: Race, class, and HIV risk among Latino gay men*. Workshop presentation at the 10th Annual National AIDS Update Conference, San Francisco, CA.

Brook DW et al, *Psychosocial risk factors for HIV transmission in female drug abusers*. *American Journal of Addiction*, 6(2):124-134. 1997.

Cochran SD, *Applying social psychological models to predicting HIV-related sexual risk behaviors among African Americans*. *Journal of Black Psychology*, 19(2):142-154. 1993.

Cournos F et al, *AIDS prevention for people with severe mental illness*. *Journal of Practical Psychiatry and Behavioral Health* (September):285-292. 1997.

DiClemente RJ & Peterson JL, eds. *Preventing AIDS: Theories and methods of behavioral interventions*. 1994, New York: Plenum Press.

Doll LS et al, *Bisexuality and HIV risk: The Canadian and U.S. experience*. *Annual Review of Sex Research*. In Press.

Jemmott LS et al, *African American women and HIV-risk reduction issues*, in *Women at risk: Issues in the primary prevention of AIDS*. *AIDS prevention and mental health*, O'Leary A & Jemmott LS, editors. 1995, New York: Plenum Press, 131-157.

Kalichman S et al, *Fatalism, future outlook, current life satisfaction, and risk for human immunodeficiency virus infection among gay and bisexual men*. *Journal of Consulting and Clinical Psychology*, 65:542-546. 1997.

Kalichman S et al, *Prevention of human immunodeficiency virus infection among chronic mentally ill adults: Effects of a brief behavioral skills intervention*. *Psychiatric Services*, 46. 1995.

Kelly JA, *Changing HIV risk behavior: Practical strategies*. 1995, New York: Guilford Press.

Kelly JA et al, *Psychological interventions are urgently needed to prevent HIV infection: New priorities for behavioral research in the second decade of AIDS*. *American Psychologist*, 48:1023-1034. 1993.

Marin G, *AIDS prevention among Hispanics: Needs, risk behaviors, and cultural values*. *Public Health Reports*, 104(5):411-415. 1989.

Meyer IH & Dean L, *Patterns of sexual behavior and risk taking among young New York City gay men*. *AIDS Education and Prevention*, 7(Suppl 5):13-23. 1995.

Peterson J & Carballo-Dieguez A, *HIV prevention among minority men who have sex with men*, in DiClemente RJ, Peterson JL, editor. In Press, New York: Plenum Press.

Stephens TT et al, *Perceptions of vulnerability to AIDS among African American men: Considerations for primary preventive counseling for undergraduates*. *Social Behavior and Personality*, 25(1):77-91. 1997.

Thomas S & Quinn S, *The Tuskegee Syphilis Study 1932-1972: Implications for HIV education and AIDS risk reduction programs in the Black community*. *American Journal of Public Health*, 81(11):92-95. 1991.

Thomas S & Quinn S, *The burdens of race and history shaping Black American attitudes toward needle exchange policy to prevent HIV infection*. *Journal of Public Health Policy*, 14(3):320-347. 1996.

Tortu S et al, *Factors associated with needle exchange use in East Harlem*. *Journal of Drug Issues*, 26(4):735-749. 1997.

Strathdee SA et al, *Needle exchange is not enough: Lessons from the Vancouver injecting drug study*. *AIDS*, 11(8):59-65. 1997.

Woody GE et al, *Psychiatric symptoms, risky behavior, and HIV infection in National Institute on Drug Abuse Research Monograph Series: Treatment of Drug-Dependent Individuals with Comorbid Mental Disorders*, Onken LS., et al., eds. Rockville, MD: National Institute on Drug Abuse. 156-169. 1997.

Permanency Planning

Boyd-Frankin N et al, *Children, families, and therapeutic issues*. New York-London: Guilford Press. 1995.

Feyler N et al, *Building bridges: How social service providers can help parents with HIV/AIDS make appropriate custodial decisions about their children*. Philadelphia, PA: MCP & Hammer University Department of Community Health. 1995.

Geballe S et al, *The forgotten children of the AIDS epidemic*. New Haven and London: Yale University Press. 1995.

Grollman E, *Talking about death*. Boston: Beacon Press. 1976.

Heim MD & Digeronimo T, *AIDS: Trading fears for facts: A guide for young people*. Yonkers, N.Y. (3rd Ed): Consumer Reports Books. 1989.

Kubler-Ross E. *On children and death*. New York: Collier Books/Macmillan Publishing Co. 1983.

Levine C & Stein GL, *Orphans of the HIV Epidemic Unmet Needs in Six U.S. Cities*. 1994.

McNaught D, *The gift of good-bye: A workbook for children who love someone with AIDS*. New York: Delta/Dell Publishing Group, Inc. 1993.

Tasker M, *How can I tell you? Secrecy and disclosure with children when a family member has AIDS*. Bethesda: Association for the Care of Children's Health. 1992.

Psychosocial Rehabilitation

Anthony WA & Liberman RP, *The practice of psychiatric rehabilitation: Historical, conceptual, and research base*. *Schizophrenia Bulletin*. 12:542-559. 1986.

- Beard JH, *The Fountain House model of psychiatric rehabilitation*. Psychosocial Rehabilitation Journal. 5(1). 1982.
- Breier A & Strauss JS, *Social relationships in the recovery from psychotic disorders*. American Journal of Psychiatry. 141:949-955. 1984.
- Cnaan RA, *Psychosocial rehabilitation: Toward a definition*. Psychosocial Rehabilitation Journal. 11(4). 1988.
- Cnaan RA, *Expert's assessment of psychosocial rehabilitation principles*. Psychosocial Rehabilitation Journal. 13(3). 1990.
- Hatfield A, *Serving the unserved in community rehabilitation programs*. Psychosocial Rehabilitation Journal. 13(2). 1989.
- Weinberg RB, *Recognizing the social in psychosocial competence: The importance of social network interventions*. Psychosocial Rehabilitation Journal. 6(4). 1983.

EVALUATING SERVICES AND PROGRAMS

Program Evaluation

- Beigel A & Levenson AI, *Program evaluation on a shoestring budget* in *Evaluation of human service programs*. Attkisson CC, Hargreaves WA & Horowitz MJ, eds. New York: Academic Press. 1978.
- Depoy E et al, *Training trainers: Evaluating services provided to children with HIV and their families*. Research on Social Work Practice, 2(1):39-55. 1992.
- Patton MQ, *Utilization-focused evaluation*. Newbury Park CA: Sage. 1989.
- Strauss A & Corbin J, *Basics of qualitative research*. Newbury Park, CA: Sage. 1990.

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Appendices

APPENDIX A

THE 11 HIV/AIDS MENTAL HEALTH SERVICES DEMONSTRATION PROGRAM SITES

Alexandria Mental Health HIV/AIDS Project
 Alexandria Community Services Board
 720 North Saint Asaph Street
 Alexandria, VA 22314

Center for AIDS/HIV Mental Health Services
 Emory University
 Grady Health System Infectious Disease Program
 341 Ponce de Leon Avenue
 Atlanta, GA 30308

Chicago HIV Health and Psychological Support Project
 Cook County HIV Primary Care Center and Chicago Department of Health
 1900 West Polk
 Chicago, IL 60612

Kinship Connection
 Department of Psychiatry/Elizabeth General Medical Center
 655 East Jersey Street
 Elizabeth, NJ 07206

SPECTRUM Community Services and Research
*(Services for HIV Prevention, Education, Care, Treatment,
 and Research for Underserved Minorities)*
 Drew University of Medicine and Science
 1774 East 118th Street, Building K
 Los Angeles, CA 90059

APPENDIX A (Continued)

The Special Needs Clinic
Presbyterian Hospital
622 West 168th Street
New York, NY 10032

Harambee
Charles R. Drew Health Center, Inc.
2915 Grant Street
Omaha, NE 68111

The Community Living Room
COMHAR, Inc., and Philadelphia Office of Mental Health
207 North Broad Street, 5th Floor
Philadelphia, PA 19107

Mini Mental Health Center
Virginia Commonwealth University/Medical College of Virginia
P.O. Box 980109
Richmond, VA 23298

Walden House Planetree Assessment and Treatment Services
Walden House, Inc.
520 Townsend Street
San Francisco, CA 94103

Puerto Rico HIV/AIDS Mental Health Services Demonstration Project
Puerto Rico Department of Health
P.O. Box 70139
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PROCESS RECORDING OUTLINE

Student’s Name: _____ Client’s Name: _____ Interview Date: __/__/__ Session #: _____
 Date Submitted: __/__/__ Date Discussed: __/__/__

1. **PURPOSE OF THE SESSION:** (Statement of the purpose that is concise, clear and specific. Show relatedness between this session and the previous session).
2. **CONTENT:** (Using the recording form below, record one significant exchange in the beginning, in the middle, and at the end of the interview)

INTERVIEW CONTENT (I said, she said)	CLIENT'S FEELINGS/AFFECT	STUDENT'S FEELINGS/AFFECT	SUPERVISORY COMMENTS

Use feeling words to describe your own feelings from the session (see attached).

INTERVIEW CONTENT (I said, she said)	CLIENT'S FEELINGS/AFFECT	STUDENT'S FEELINGS/AFFECT	SUPERVISORY COMMENTS

Use feeling words to describe your own feelings from the session (see attached).

3. IMPRESSIONS/ASSESSMENT: A) How did the client present her/himself – appearance, behavior and affect; B) What did you observe throughout the session – behavior and affect; C) Was the behavior/affect appropriate, explain; and D) How does this behavior/affect fit with what you know about the client’s past behavior affect?

4. IDENTIFY THE MAJOR THEMES/ISSUES THAT EMERGED:

5. INTERVENTIONS: Choose two significant interventions you made: A) Identify/describe; B) What was your impression of your effectiveness; and C) What would you change?

6. PROFESSIONAL USE OF SELF: A) Body language/use of space/voice; B) Worker's own feelings/values – how did they help or hinder the process; and C) How worker dealt or is dealing with own feelings.

7. PLAN: (Brief statement of your plans for the next session, long range goals, short range goals that are relevant for this client.)

8. ISSUES, QUESTIONS OR PROBLEMS: (To explore in supervisory sessions. Areas to explore in your supervisory conference, including issues of diversity, value dilemmas, counter-transference, etc.)

APPENDIX C

APPENDIX C (Continued)

GUIDE TO COMPLETING THE PSYCHOSOCIAL ASSESSMENT

In an attempt to provide greater uniformity in completing our psychosocial assessments. We thought providing some general guidelines on completing the various components would be helpful.

For each section we ask that you indicate in writing at minimum the following domains:

- 1) Appearance: Please comment on: a) age; b) ethnicity; c) gender d) build/height; e) dress; f) hygiene; g) Sexual orientation and risk factor if patient is forthcoming.
- 2) Mental Status: This section aims to provide a brief mental status of the patient at assessment. Please comment on the following areas: a) intelligence; b) judgment; c) memory (STM & LTM); d) thought disorder; e) delusions/hallucinations; and f) mood/emotional state.

For example: pt is oriented x3, displays above average intelligence, memory appears intact, judgment intact, no indication of thought disorder or delusions/hallucinations and mood seems to be sad.

- 3) Suicide/homicide: If patient denies suicidal ideation at present, check denies and move on. If patient reports suicide or homicidal potential, elaborate with focus on ideation vs gestures vs attempts.

For example: “pt reports having suicidal ideation w/o plan”; or “pt. has made suicidal gesture (took larger amount of meds than needed) but denies being suicidal at present”; or “pt. reports being suicidal has plan (slit wrists) and means

- 4) Psychiatric history: In this section, we would like to get an indication current and past psych. Tx. Indicate whether pt. is currently in tx by marking yes or no. If yes, indicate type frequency and duration (e.g. pt. is being seen at ISPT’s output. program on a weekly basis x 2yrs. or “Pt. Has recently been released from Read where he was hospitalized for 2 weeks for Suicide attempt”) If patient is aware of his diagnosis it may be helpful to indicate.
- 5) Substance Use: This section should provide a snapshot of pt. Drug use and indicate whether it is a factor in psychological functioning AT INTAKE. Specifically, indicate pt.’s primary drug of choice and attempt to get as accurate of an assessment of onset, frequency, and attempts to stop. The past use section should cover past substance abuse patterns and previous tx. For substance use. Below are a few examples of varying degrees of specificity:

POOR: Pt. reports using various drugs on an intermittent basis. Past: pt reports have heroin prob. In past.

APPENDIX C (Continued)

BETTER: Pt. drinks alcohol and smokes marijuana occasionally. He does not identify substance use as a concern. Past: blank

BEST: Pt. indicates that he drinks (beer x3day/wk, 1 sixpack per day) Pt. uses cocaine (snorts lgm x 1/month). He reports onset of alcohol use at age 18 and cocaine use at age 27. No other drug use at present. Past: Pt. Has entered 3 detox programs (88, 94 & 95) never successfully completed drug tx. Program

- 6) **Social support:** This section has provided in the past a great deal of variability. It would be best to indicate social support along two domains (practical/financial and emotional). Practical support which would include assistance with daily living activities. Emotional support refers to who the person talks with to receive emotional support around living with HIV. Also, may want to assess level of HIV disclosure (to who and why and reasons not disclosed to others)

For example: “pt reports living w/ family who provide food, and transportation to medical appointments. Family not supported around emotional needs w/ family not telling other family member of pt’s health status. Pt. Reports not talking to anyone about living with HIV”

- 6) **Vocational:** please indicate whether pt works full, pt, unemployed or unable to work at present. Indicate nature of work. (e.g. fast food or administration). For past, indicate primary job or job hx. (e.g. pt. Worked for gas company for 9yrs. or pt. held numerous part time jobs) You may want to comment on whether Pt. has concerns about HIV impacting work situation.

- 7) **Initial Impressions:** This section is the section where the most variability has existed. It may be best to conceptualize this section in the following way: 1) Consider the audience other health and social service staff; 2) “What would be helpful for them to know about the patient’s psychological functioning?” and “what’s your impression of this client’s psychological management of his HIV diagnosis?” I would write very clearly (try to keep psychological jargon to a minimum) and provide concrete examples to substantiate your impressions. Providing an initial diagnosis is optional at present. Below is an example:

“Pt. is a 35 y/o gay AA male dx. HIV+ in 6/95. Pt. Appears to have cognitive impairments particularly in memory superimposed with active substance use, and failing health. Etiology for memory impairment is unclear but may be due to seizures, HIV, underlying psychosis (as evidenced by possible delusions) or a personality disorder. Preliminary diagnosis: Cocaine Abuse, R/O psychotic disorder, NOS. Pt. Does appear to respond well to structure and this should be factored in to tx. Planning.

- 8) **Recommendations:** self explanatory. Use “other” section for a more detailed discussion of tx. Rec.

APPENDIX D

The Mental Health SPECTRUM
Clinical Diagnostic Assessment

Date:

Clinician:

Patient Name:

Patient ID#:

ID (Gender, Race, Ethnicity, Age, D.O.B., HIV Status and Stage, Living Environment)

Source

Presenting Problem

Current Stressors

APPENDIX D (Continued)**Psychiatric Hx**

Hospitalizations, where, reason

Family Hx

Medications

Previous Dx

ETOH/Drug Hx

Current Use (Substance, how much per day, how ingested)

Past Hx

Hospitalizations for SA

Treatment: current and past (counseling, groups, day treatment, 12 step)

Arrests, accidents, financial losses secondary to SA

Medical Hx

Past status

Current status

APPENDIX D (Continued)

Diagnosis

Medications

Surgeries

Social Development/Family Hx

Sexual Behavior & Orientation

Coping skills

Religious and/or Spiritual

Employment and Education

Legal

Financial

APPENDIX D (Continued)**Services Needed**

- Transportation
 - voucher
 - dis bus pass
 - taxi ability card
- Disability
- Social Security
- Food Services

Psychosocial Needs

- 12 Step Program
- Case Management
- Child care
- Group(s)
- Housing
- Psychiatric Evaluation
- Medication Evaluation
- Neuropsych Consult
- Psychological Testing
- Individual Psychotherapy
- Couples Counseling
- Family Counseling
- Detox/Sober Living
- Domestic Violence

Mental Status Exam

Attitude, appearance and motor activity

Mood

- Depressed
- Euphoric
- Labile
- Dysphoric
- Angry/Hostile
- Brief Description:

APPENDIX D (Continued)

Affect

- Flat
 - Broad
 - Bright
 - Blunted
 - Inappropriate
- Brief Description:

Structure of thought and speech

- | | | | |
|---|--|---|--|
| <input type="checkbox"/> rapid speech | <input type="checkbox"/> slurred speech | <input type="checkbox"/> within normal limits | <input type="checkbox"/> incoherent |
| <input type="checkbox"/> perseveration | <input type="checkbox"/> flight of ideas | <input type="checkbox"/> circumstantiability | <input type="checkbox"/> blocking |
| <input type="checkbox"/> neologisms | <input type="checkbox"/> tangentiality | <input type="checkbox"/> loose associations | <input type="checkbox"/> distractibility |
| <input type="checkbox"/> clang/associations/rhyming/punning | | | |
- Brief Explanation:

Content of thought and speech

- | | | |
|---|---|--|
| <input type="checkbox"/> preoccupation/rumination | <input type="checkbox"/> somatic concerns/hypochondriasis | |
| <input type="checkbox"/> derealization/depersonalization | <input type="checkbox"/> compulsions/obsessions | <input type="checkbox"/> grandiosity |
| <input type="checkbox"/> dreams and fantasies | <input type="checkbox"/> ideas of reference/influence | <input type="checkbox"/> excessive religiosity |
| <input type="checkbox"/> delusions: types and content _____ | | |
- Brief Explanation:

Perception: hallucinations (types and content) and illusions

Sensorium and Cognition

Potential for destructiveness

APPENDIX D (Continued)

Suicidal attempts, thoughts and ideation

Insight and motivation

Summary**DSMIV DX**

Axis 1

Axis 2

Axis 3

Axis 4

Axis 5

Problems

1.

2.

3.

Treatment Plan

1.

2.

3.

Signature

Title

Date

APPENDIX E

DEPARTMENT OF MENTAL HEALTH, MENTAL RETARDATION AND SUBSTANCE ABUSE
ADMISSION/CRISIS INTERVENTION RECORD

CLIENT NUMBER:		CLIENT NAME:	
STAFF CODE:		STAFF NAME:	
PROGRAM CODE:		PROGRAM NAME:	
DATE OF REPORT:	SVC:	MINUTES:	LOCATION:

1. Identifying Information:
2. Chief Complaint:
3. Presenting Problems with Precipitating Events:
4. Relevant History of Treatments (include psychiatric, substance abuse, medical, criminal involvement, family relationships): <i>--PSYCHIATRIC TREATMENT OR HISTORY:</i> <i>--SUBSTANCE ABUSE HISTORY:</i> <i>--MEDICAL:</i> <i>--CRIMINAL HISTORY:</i> <i>--FAMILY RELATIONSHIPS:</i>

Service Location: AS= St. Asaph	JA = Jail	MI = Mill Road	CO = Community	HO = Hospital/Training Center
PA = Patrick Street	CL = Client Home	CH = Charles Houston	HE = PIE	CO= Colvin Stree

APPENDIX E (Continued)

CLIENT NAME:

CLIENT NUMBER:

<p>5. Mental Status Examination (include current appearance, behavior, speech, affect, mood, content and process of thought, memory, orientation, abstraction, suicidal/homicidal ideation, potential for acting out, judgment and insight):</p>	
<p>6. Risk Assessment: Describe below and rate the level of risk. (Consider especially a recent history, such as the last two weeks, of plans to commit suicide, violent or assaultive behaviors, threats of violence or fear inducing behaviors such as throwing objects. Be particularly concerned with acute states of psychosis or substance abuse intoxication/withdrawal associated with potentially violent or self-destructive behaviors, and also note the degree of mental disorganization. Mention any remote history of suicide attempts or violent behaviors. Discuss involvement of recent losses, stressors, threatened or identified victims, availability of weapons/lethality of means, support system available, and demonstrated adaptive coping skills. Do not necessarily limit yourself to these factors.)</p>	
<p>RISK LEVEL: Circle one.</p>	
<p>A.</p> <p><u>Elevated Risk:</u> Current and/or recent history of suicidal plans or behaviors, violence, threats or similar acting-out behavior which may be associated WITH a disorganized mental state or substance abuse.</p>	<p>B.</p> <p><u>Concern of Risk:</u> No recent history of the elevated risk factors, yet does have a history of suicide attempts, violence, or threats which may be associated WITH psychosis or substance abuse, and/or moderate risk factors in current presentation.</p>
<p>C.</p> <p><u>Low Risk:</u> No past history of suicide attempts or violence, but clinical presentation contains some factors which raise concern.</p>	<p>D.</p> <p><u>No Concern of Risk:</u> No risk factors present in client's history.</p>
<p>7. Diagnostic Impression:</p>	<p>DIAGNOSIS</p>
	<p>AXIS I:</p>
	<p>AXIS II:</p>
	<p>AXIS III:</p>
	<p>AXIS IV:</p>
	<p>AXIS V (GAF):</p>

APPENDIX E (Continued)

CLIENT NAME:

CLIENT NUMBER:

8. Initial Service Plan: (Include immediate action required and taken, and follow-up plans; purpose; who, what, by when, and indication for hospitalization when appropriate.)

I have participated in the development of this service plan, have read the goals and objectives, and agree to its implementation.

CLIENT SIGNATURE: _____ DATE: _____

SIGNATURE OF QMHP, QMRP, OR QSAP: _____ DATE: _____

APPENDIX E (Continued)

**DEPARTMENT OF MENTAL HEALTH, MENTAL RETARDATION AND SUBSTANCE ABUSE
CONSUMER ASSESSMENT**

CONSUMER NUMBER:**STAFF CODE:****PROGRAM CODE:****DATE OF ASSESSMENT:****PURPOSE OF ASSESSMENT** (check one): Initial ___ Follow-up ___ Crisis Intervention ___ Other (specify): _____**CONSUMER NAME:****STAFF NAME:****PROGRAM NAME:****LOCATION:****1. Identifying Information:****2. Reason for Contact:****3. Presenting Problems with Precipitating Events:****4. Relevant History:**

Institutionalizations (Date/Place):

Hospitalizations (Date/Place):

Past Services (Date/Place):

Medications (Type/Amount):

Educational History:

Employment History:

Substance Abuse History:

Criminal Involvement/History:

Medical Problems:

Service Location: AS= St. Asaph
PA = Patrick StreetJA = Jail
CL = Client HomeMI = Mill Road
CH = Charles HoustonCO = Community
HE = PIEHO = Hospital/Training Center
CO= Colvin Street

APPENDIX E (Continued)

CONSUMER NAME:

CONSUMER NUMBER:

Family History/Support:
5. Mental Status (complete all sections):
Current appearance:
Behavior:
Speech:
Affect:
Mood:
Content process of thought:
Memory:
Orientation:
Abstraction:
Suicidal/homicidal ideation:
Potential for acting out:
Judgment:
Insight:
6. Risk Assessment (Describe below rate the level of risk).
Recent history (such as the last two weeks) plans or attempts to commit suicide, violent or assaultive behaviors, threats of violence or fear-inducing behaviors such as throwing objects:
Acute state of psychosis or substance abuse intoxication/withdrawal associated with potentially violent or self-destructive behaviors, also note the degree of mental disorganization:
Any remote history of suicide attempts or violent behaviors (include dates):

APPENDIX E (Continued)

CONSUMER NAME:

CONSUMER NUMBER:

Describe involvement in recent losses, stressors, threatened or identified victims, availability of weapons/lethality of means, support system available, demonstrated adaptive coping skills (do not necessarily limit yourself to these factors):			
FACTORS INCREASING RISK		(CHECK ALL THAT APPLY)	STRENGTHS REDUCING RISKS
Aggressive Behavior – Past		Denial of Mental Illness	Compliant with Treatment
Aggressive Behavior – Recent		Access to Weapons	Compliant with Medications
Fear Inducing Behaviors		Head Injury/Organic Brain Syndrome	Adaptive Coping Skills
Fear Inducing Behavior Toward Property		Sexual Excitation Through Inappropriate/Aggressive Means	Has/Uses Strategies to Cope with Command Hallucinations
Threats of Aggression		Intellectual Impairment	Social/Peer Support
Aggressive Ideation		Suicide Attempts	No History of Violence
Criminal History/Psychopathy		Suicide Ideation	No Current Substance Abuse
Anger or Repressed Hostility		Suicide Plans	Family (Significant Other) Support
Homicidal Ideation		Suicide Attempts by Family Members	Acceptance of Mental Illness
Impulsiveness by History		Non-Compliant with Medications	Insight into Mental Illness
Paranoid Delusions		Non-Compliant with Treatment Plans	
Sadistic Tendencies		Lack of Social Support	
Command Hallucinations		Current Substance Abuse	
RISK LEVEL: Circle one.			
A. <u>Elevated Risk:</u> Current or recent history of suicidal plans or behaviors, violence, threats, or similar acting out behavior which may be associated with a disorganized mental state or substance abuse.			
B. <u>Concern of Risk:</u> No recent history of elevated risk factors, yet does have a history of suicide attempts, violence, or threats which may be associated with psychosis or substance abuse, or moderate risk factors in current presentation.			
C. <u>Low Risk:</u> No past history of suicide attempts or violence, but clinical presentation contains some factors which raise concern.			

APPENDIX E (Continued)

CONSUMER NAME:

CONSUMER NUMBER:

<p>7. Diagnostic Summary of Assessment:</p>
<p>DIAGNOSIS</p>
<p>AXIS I:</p>
<p>AXIS I:</p>
<p>AXIS II:</p>
<p>AXIS II:</p>
<p>AXIS III:</p>
<p>AXIS IV:</p>
<p>AXIS V (GAF):</p>
<p>8. Initial Service Plan:</p> <p style="margin-left: 40px;">Immediate action required/taken:</p> <p style="margin-left: 40px;">Follow-up plans (include purpose, by whom, by when, indication for hospitalization when appropriate):</p>

I have participated in the development of this service plan, have read the goals and objectives, and agree to its implementation.

CONSUMER SIGNATURE: _____ DATE: _____

SIGNATURE OF QMHP, QMRP, OR QSAP: _____ DATE: _____

APPENDIX E (Continued)

**DEPARTMENT OF MENTAL HEALTH, MENTAL RETARDATION AND SUBSTANCE ABUSE
DIAGNOSTIC STUDY OF THE CLIENT**

CLIENT NUMBER:
STAFF CODE:
PROGRAM CODE:
DATE OF REPORT:

CLIENT NAME:
STAFF NAME:

1. REFERRAL INFORMATION (include source and reason):

2. HISTORY OF PRESENT CONDITION, ILLNESS, AND/OR SUBSTANCE ABUSE:

3. SOCIAL HISTORY:

A. Developmental Background:

B. Family Structure and Relationships:

C. Significant Milestones in Childhood or Adult Development:

D. Critical Incidents in Childhood or Adult Life (include trauma, victimization):

E. Employment/Vocational/Educational History (including current employment and military history, if any):

4. HISTORY OF AGGRESSIVE/CRIMINAL BEHAVIOR AND CURRENT CRIMINAL JUSTICE STATUS: NONE

5. SUBSTANCE ABUSE HISTORY: CLT REPORTS OCCASIONAL CANNABIS USE; TO EXPLORE FURTHER.

Substances Used	Age at Onset of Use	Frequency	Quantity	Method of Administration	Last Time Used
A. CURRENT:					
B. PAST:					

Is use sufficient to warrant further exploration? (Yes or No. If yes, complete C through M. If no, skip to 6).

C. Are/were substances used in either combination or sequentially?

APPENDIX E (Continued)

CLIENT NAME:

CLIENT NUMBER:

Page 2

D. Client's reason for starting substance use:	
E. What purpose(s) does client believe that these substances have served?	
F. Have any family members or significant others complained about the client's alcohol or drug use?	
G. Has client ever done anything while intoxicated that s/he has regretted?	
H. Has substance abuse caused any trouble in the client's life (e.g., keeping family, child care or work responsibilities, financial or social obligations, or problems with physical or psychological well-being)?	
I. Does substance use recur in situations that are physically dangerous?	
J. Has the client ever committed any violent acts towards self or others while intoxicated?	
K. How long has the client attempted to maintain a drug-free lifestyle?	Presently attending AA/NA?
	AA or NA Sponsor?
L. Do characteristic withdrawal symptoms occur if use of the substance is discontinued?	
6. FAMILY HISTORY OF PSYCHIATRIC ILLNESS, SUBSTANCE ABUSE, SEXUAL/PHYSICAL ABUSE (by whom/against whom):	
7. FAMILY HISTORY OF SELF-DESTRUCTIVE, SUICIDAL OR HOMICIDAL BEHAVIOR (by whom, against whom, circumstances):	
8. RESULTS OF INDIVIDUAL PSYCHOLOGICAL, PSYCHIATRIC AND NEUROLOGICAL EXAMINATIONS, IF APPLICABLE:	
9. PREVIOUS MENTAL HEALTH AND/OR ALCOHOL/DRUG TREATMENT (include psychiatric hospitalizations):	
10. MEDICAL HISTORY:	
A. Serious illnesses and chronic conditions of family members:	
B. Recent physical complaints/conditions; changes in or concerns about eating/sleeping patterns:	Date of last physical:
C. Past serious illnesses, infectious diseases, HIV testing, serious injuries, head trauma, hospitalizations:	
D. Physician/Dentist contact information: Physician Name, Address and Phone: Dentist Name, Address and Phone:	
11. MEDICATION USE:	
A. History of prescription and/or non-prescription drug use:	
B. Drug allergies, idiosyncratic and/or adverse drug reactions:	
C. Ineffective medication therapy:	

APPENDIX E (Continued)

CLIENT NAME:

CLIENT NUMBER:

Page 3

12. MENTAL STATUS EXAMINATION (include current appearance, behavior, speech, affect, mood, content and process of thought, memory, orientation, abstraction, suicidal/homicidal ideation, potential for acting out, judgment and insight):

13. RISK ASSESSMENT: Describe below and rate the level of risk. (Consider especially a recent history, such as the last two weeks, of plans or attempts to commit suicide, violent or assaultive behaviors, threats of violence or fear inducing behaviors such as throwing objects. Be particularly concerned with acute states of psychosis or substance abuse intoxication/withdrawal associated with potentially violent or self-destructive behaviors, and also note the degree of mental disorganization. Mention any remote history of suicide attempts or violent behaviors. Discuss involvement of recent losses, stressors, threatened or identified victims, availability of weapons/lethality of means, support system available, and demonstrated adaptive coping skills. Do not necessarily limit yourself to these factors.)

RISK LEVEL: Circle one.

A.

Elevated Risk: Current and/or recent history of suicidal plans or behaviors, violence, threats or similar acting-out behavior which may be associated WITH a disorganized mental state or substance abuse.

B.

Concern of Risk: No recent history of the elevated risk factors, yet does have a history of suicide attempts, violence, or threats which may be associated WITH psychosis or substance abuse, and/or moderate risk factors in current presentation.

C.

Low Risk: No past history of suicide attempts or violence, but clinical presentation contains some factors which raise concern.

D.

No Concern of Risk: No risk factors present in client's history.

14. CLINICAL IMPRESSION: (include diagnosis, maintenance of current psychological and/or substance abuse problem, ego strengths and weaknesses, pathological personality traits, patterns of interpersonal relationships, impulsive and/or aggressive tendencies, responsiveness to previous interventions/medication, motivation for change.)

AXIS I

AXIS II

AXIS III

AXIS IV

AXIS V

APPENDIX E (Continued)

CLIENT NAME:

CLIENT NUMBER:

Page 4

PSYCHOSOCIAL ASSESSMENT	
15. Behavioral/Emotional Symptoms, Strengths, Needs:	Service Need:
	Barriers to Service:
	Plan for Service Linkage:
16. Substance Abuse Needs:	Service Need:
	Barriers to Service:
	Plan for Service Linkage:
17. Health Strengths, Needs:	Service Need:
	Barriers to Service:
	Plan for Service Linkage:
18. Familial/interpersonal Relationships Strengths, Needs:	Service Need:
	Barriers to Service:
	Plan for Service Linkage:
19. Current Living Situation Strengths, Needs:	Service Need:
	Barriers to Service:
	Plan for Service Linkage:
20. Vocational, Educational Strengths, Needs:	Service Need:
	Barriers to Service:
	Plan for Service Linkage:
21. Social, Recreational Strengths, Needs:	Service Need:
	Barriers to Service:
	Plan for Service Linkage:
22. Communication Strengths, Needs:	Service Need:
	Barriers to Service:
	Plan for Service Linkage:
23. Transportation Strengths, Needs:	Service Need:
	Barriers to Service:
	Plan for Service Linkage:
24. Financial Assistance, Needs:	Service Need:
	Barriers to Service:
	Plan for Service Linkage:

APPENDIX E (Continued)

CLIENT NAME:

CLIENT NUMBER:

Page 5

PSYCHOSOCIAL ASSESSMENT	
25. Legal Assistance Needs:	Service Need:
	Barriers to Service:
	Plan for Service Linkage:
26. High Risk Behavior Management Needs (high-risk behaviors which currently pose an elevated risk to client or others, as described in # 13).	Service Need:
	Barriers to Service:
	Plan for Service Linkage:

I have participated in the development of this service plan, have read the goals and objectives, and agree to its implementation.

CLIENT SIGNATURE: _____ DATE: _____

SIGNATURE OF QMHP, QMRP, OR QSAP: _____ DATE: _____

APPENDIX E (Continued)

**DEPARTMENT OF MENTAL HEALTH, MENTAL RETARDATION AND SUBSTANCE ABUSE
MASTER INDIVIDUAL SERVICE PLAN**

CONSUMER NUMBER:
UNIT/SUBUNIT:
CASE MANAGER STAFF CODE:
DATE FORM COMPLETED:

CONSUMER NAME:
PROGRAM NAME:
CASE MANAGER NAME:
Estimated length of consumer's need for service:

Objectives and strategies must include desired outcomes, how (modality), who (responsible person) and frequency of planned service.

CONSUMER PROBLEM/NEED:	TARGET DATE	QUARTER			
		CODE/ DATE	CODE/ DATE	CODE/ DATE	CODE/ ANNUAL DATE
GOAL OF SERVICE:					
OBJECTIVES AND STRATEGIES:					
BARRIERS TO SERVICE:					

CONSUMER PROBLEM/NEED:	TARGET DATES	QUARTER			
		CODE/ DATE	CODE/ DATE	CODE/ DATE	CODE/ ANNUAL DATE
GOAL OF SERVICE:					
OBJECTIVES AND STRATEGIES:					
BARRIERS TO SERVICE:					

I have participated in the development of this treatment plan and agree with it.

Consumer Signature

Date

CODES: C = Continue OM = Objective Met MS = Modify Strategy AR = Annual Review
 D = Discontinue MO = Modify Objective N = New Objective Added

APPENDIX F

Contract Agreement for Services
(Name of Evaluator)

THIS AGREEMENT, made and entered into by and between (Name of Evaluator), hereinafter referred to as “Evaluator,” and (Name of Agency), a not-for-profit corporation duly organized and existing under the laws of the State of (Name of State), with a place of business at (Address of Agency), stipulates:

1. (Name of Agency) and Evaluator agree to enter into a relationship as described in this Contract, and to be bound by the terms of this Contract.
2. This Contract shall commence on (Start date), and shall continue until (End date).
3. Evaluator agrees to conduct a (Scope of work) with (target group). Such a (Scope of work) will include: (list of specific things that will be done).
4. (Name of agency) agrees to assist in these efforts by providing the following: (List of specific things the agency will provide).
5. Evaluator agrees to perform the services described in this Contract for (amount - hourly or payment for entire service). Evaluator will submit invoices and description of activities to (Name of Agency) on a _____ basis before receiving payments.
6. At their discretion, (Name of agency) shall compensate Evaluator for expenses incurred while conducting (scope of work), including: (list of expenses).
7. Evaluator acknowledges that all information received as a result of this agreement shall be deemed confidential, and Evaluator shall not release or reveal such information without the express, prior, written agreement of (Name of Agency). Evaluator understands that only aggregate data is sought, and to that effect, the confidentiality of individual participants in the individual and focus group interviews will be maintained. Evaluator agrees to take extensive notes during interviews, but will use audio or videotape equipment to record responses. If particular themes emerge, Evaluator may use non-identified quotes in the final report to further illustrate such themes. Because of the size of (Name of Agency) and the composition of the focus groups and individual interviews, it may be inferred from the final report whose perceptions are being presented.

APPENDIX F (Continued)

8. Evaluator acknowledges that in receiving, storing or otherwise dealing with any client information that they are bound by the requirements of 42 CFR part 2 and/or the Mental Health and Developmental Disabilities Confidentiality Act. Evaluator agrees to institute appropriate procedures for safeguarding information and to resist in judicial proceedings or other efforts to obtain access to any client information.
9. (Name of Agency) and Evaluator agree that any and all collected data will be the property of the (Identify who will own the data), and that the final report will be the property of (Name of Agency). Evaluator agrees that in any reference to the (Name of Agency) experience, the identity of (Name of Agency), its location, the identity of (Name of Agency) staff and community members, and the identity of any and all interviewees will remain confidential.
10. Evaluator acknowledges and understands that he/she is an independent contractor, and shall not be considered to be an employee of (Name of Agency) for any purpose.
11. (Name of Agency) acknowledges and understands that any services provided by the Evaluator beyond the scope of this CONTRACT will involve different fees for service and requires the development of a separate Contract agreement.
12. (Name of Agency) and Evaluator agree that this Contract agreement may be terminated by either party, with or without cause at any time, on sixty (60) days written notice.

In witness whereof, each party to this agreement has caused it to be executed at (Address of agency), on the date indicated below.

(Name of Agency):

Evaluator:

BY ITS EXECUTIVE DIRECTOR

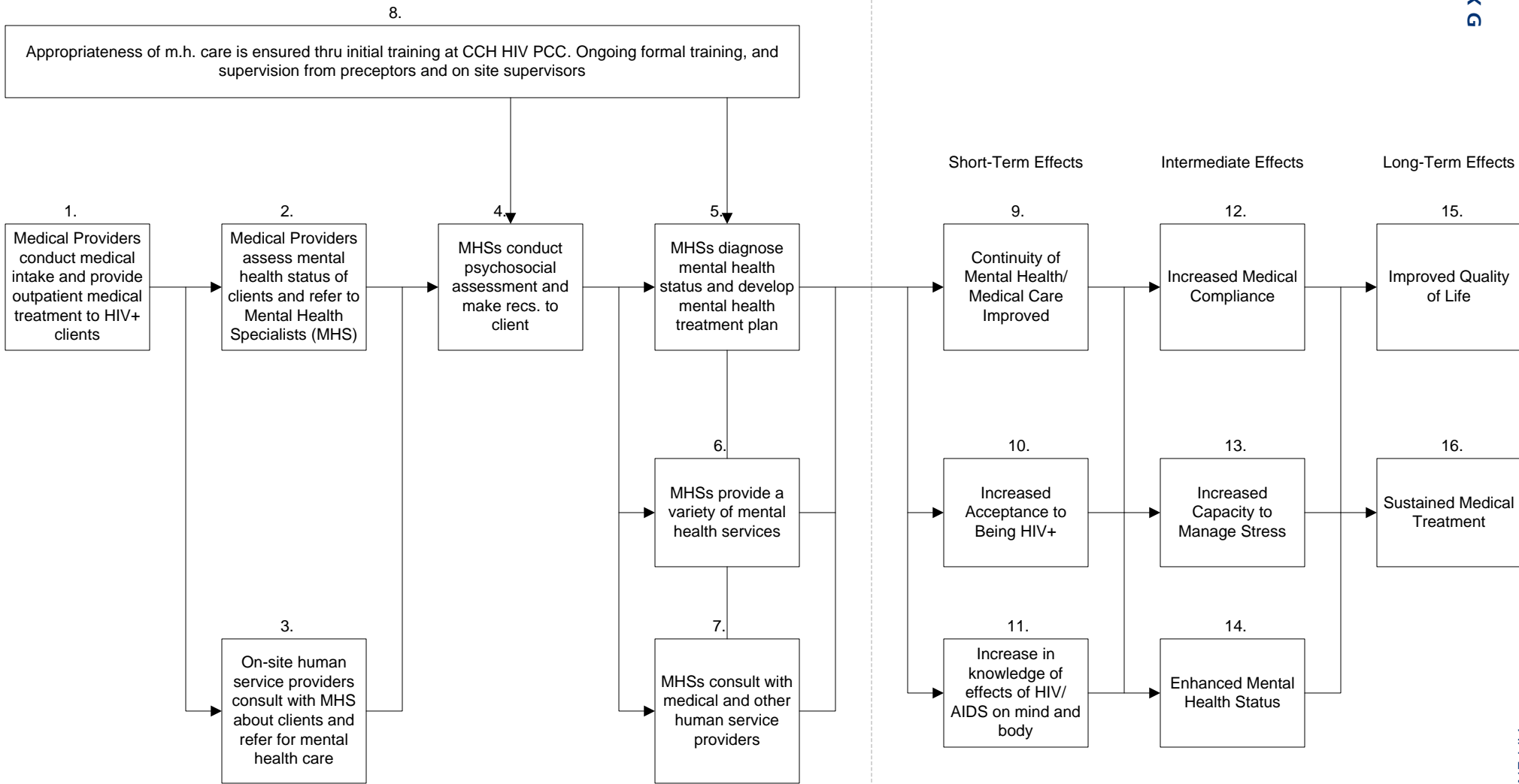
(Name of Evaluator)

DATE

DATE

Process Domain

Outcome Domain



CHHAPS Project: Logic Model of Integrated Care for Persons Living with HIV (Level II)

APPENDIX H

**CHHAPS PROJECT
SERVICE ENCOUNTER RECORD**

I. Client's First Initial and Last Name: _____

II. Staff ID: _____

III. Date(s) of Service Encounter(s): see table below

IV. Category of Provider Agency: _____

V. Service Provided (*more than one may be recorded for each date of service*):

III. Date of Service	A. Service Type(s)	B. Comp Status	C. Treatment Mode/Form	D. Duration	E. Location of Service
1.		08			
2.		08			
3.		08			
4.		08			
5.		08			
6.		08			
7.		08			
8.		08			
9.		08			
10.		08			
11.		08			
12.		08			
13.		08			
14.		08			

Office Use Only

Date Submitted to Data Coordinator or Administrative Assistant: _____

Date Entered into Computer: _____

APPENDIX H (Continued)

CHHAPS DCQC Manual; 12/1/96

SERVICE ENCOUNTER RECORD**PURPOSE OF THE FORM**

The purpose of the multi-site Service Encounter Record (SER) is to uniformly collect information about the services provided and activities conducted by demonstration-funded staff across all eleven project sites.

DEVELOPMENT OF THE FORM

The SER was collaboratively developed by interested members of the Steering Committee, Coordinating Center, and Local Evaluators. It has gone through a minimum of three iterations. The final SER was developed on August 1, 1996, and approved by the Steering Committee in mid-August. It is available in hard copy and in English. In the future, it may also be available in a computerized version and in Spanish.

Although the general outline of the SER is used across all sites involved in the Demonstration Project, there are individual variations in the forms and data specifications (e.g., definitions of each of the service categories used in the SER) used at sites around the country. These variations are due to differences in the target populations and type of services delivered at each site. For example, the Local Evaluator and Data Coordinator of the CHHAPS Project developed the CHHAPS SER in order to better fit the needs of the CHHAPS Project. Without compromising the intent of the multi-site SER, the following steps were taken in the development of the CHHAPS SER:

- The Local Evaluator and Data Coordinator compared and contrasted drafts of the final SER with the crosswalk that was developed for the previous iteration of the SER and the current service tracking form - 1009 - utilized by the Mental Health Specialists at Englewood and Lakeview. The fields which CHAAPS staff utilize on the final SER were highlighted by the four Mental Health Specialists and communicated to the Data Coordinator.

APPENDIX H (Continued)

- The Local Evaluator and Data Coordinator developed the CHHAPS SER, which encompasses the fields highlighted by the Mental Health Specialists and the intent of the multi-site SER.
- In mid-August, the Data Coordinator showed the Mental Health Specialists the first iteration of the CHHAPS SER. During the group training of the CHHAPS SER, suggestions were made by the Project Director and Mental Health Specialists regarding additional modifications to the data specifications and form.
- The CHHAPS SER was finalized by the Local Evaluator and Data Coordinator in late August, 1996. A copy of the CHHAPS SER data specifications and form was submitted to RTI in late August, 1996, for review and comment.

TRAINING ON THE FORM

The Mental Health Specialists were trained in late August, 1996, on the intent and use of the CHHAPS SER. The following protocol was used:

- The Data Coordinator provided a group didactic presentation of the CHHAPS SER at the August local evaluation meeting to the Mental Health Specialists, Local Evaluator, and Project Director. This involved going through the entire CHHAPS customized data specifications document, item by item, discussing the application of each code, and comparing 1009 codes to SER codes.
- The Data Coordinator met individually with Mental Health Specialists to answer site specific questions related to the CHHAPS SER. He documented the questions and his answers.
- At the September and October local evaluation meetings, the Data Coordinator led a discussion on “common errors” and resolutions. There is a standardization in definitions and use of the CHHAPS SER across all four Mental Health Specialists.

ADMINISTRATION OF THE FORM

During the didactic training on the CHHAPS SER, it became evident that there was a lot of redundancy between the CHHAPS SER and the 1009s. It was also noted, however, that the 1009s tracked services in a more “broad brush stroke” way compared to the CHHAPS SER. In order to avoid having the Lakeview Mental Health Specialist

APPENDIX H (Continued)

spend too much time doing paperwork AND in order to assure that the original intent of the multi-site SER is not compromised, the following procedures have been put in place:

- The Lakeview Mental Health Specialist adds the appropriate Service Type and Treatment Mode/Form codes at the end of each entry on their 1009s.
- If a referral is made during a case management activity, the Lakeview Mental Health Specialist adds the appropriate Service Type code at the end of their 1009 entry, asterisk (*) this code, and, under the “Staff Notes” section, writes the SER referral code and the agency to which the case management referral was made.

The Mental Health Specialists at the Cook County Hospital, Englewood, and Woodlawn sites are responsible to complete the CHHAPS SER as originally intended.

There are two periods of time at which all four Mental Health Specialists may decide to complete the CHHAPS SER or 1009s for each of their clients. The forms may be completed directly after the service/s are provided, or Mental Health Specialists may opt to complete the forms at the end of each week. Use of the CHHAPS SERs and new way to complete 1009s began on September 1, 1996.

DATA COORDINATION OF THE FORM

Because the original administration plan of the CHHAPS SER was modified at one site in order to lessen the paperwork time spent by the Mental Health Specialist (see previous section), the role of the Data Coordinator has expanded to include more intensive quality control procedures. In order to manage his expanding role related to the multisite evaluation, the Project Director and Local Evaluator are enlisting the efforts of the Administrative Assistant regarding: a) data transfer from the 1009s to the multisite SER, b) data transfer from the CHHAPS SER to the multisite SER; and c) data entry of the SERs.

The majority of SER data entry is conducted by the Data Coordinator. During October, 1996, the Data Coordinator trained the Administrative Assistant on SER data entry. Regarding the specific procedures for data entry, the Data Coordinator organizes hard copies of “to be entered” SERs by site in separate manilla folders. After an SER has been entered either into the Administrative Assistant’s computer or the main computer in the Project Director’s office, the hard copy of the SER is stamped with the date of

APPENDIX H (Continued)

entry, paperclipped with other “entered” SERs, and placed back in the folder. The Data Coordinator then files the “entered” SERs by date of entry into the computer. If the Administrative Assistant’s computer is used to enter SERs, the Data Coordinator downloads the latest SER data entries from this computer and uploads this information into the Project Director’s computer before the weekly polling to the Coordinating Center takes place.

QUALITY CONTROL PROCEDURES

There are several quality control procedures in place to ensure that the SERs and 1009s are completed, transferred, and entered as intended:

- On a monthly basis, the Data Coordinator copies the SERs and 1009s, and files them along with the other information collected on each client (i.e., Participant Log, Interviewer Tracking Form) in a locked file cabinet in the central office at Cook County Hospital. Mental Health Specialists keep the originals in locked file cabinets at their respective sites.
- On a monthly basis, the Data Coordinator and the Mental Health Specialists review the forms to assure that standardized definitions are used by each of them and to assess the need for more multisite SER service type categories. This review of the form is also an opportunity for Mental Health Specialists to provide feedback regarding use of the forms.

On a quarterly basis, during local evaluation meetings, the Data Coordinator randomly selects forms, and asks Mental Health Specialists how they use certain codes (e.g., crisis intervention vs. psychotherapy/counseling focused on HIV testing). Discussion is encouraged.

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