

GUIDELINES  
FOR  
PEER SUPPORT SERVICES

Massachusetts Department of Public Health  
Bureau of Infectious Disease  
Office of HIV/AIDS  
and  
Boston Public Health Commission  
Infectious Disease Bureau  
HIV/AIDS Services Division

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*The following individuals are responsible for the production of the document:*

**Linda Goldman**, Massachusetts Department of Public Health, Office of HIV/AIDS

**Sophie Lewis**, Massachusetts Department of Public Health, Office of HIV/AIDS

**John Ruiz**, JRI Health

*The BPHC and MDPH staff listed below provided content, insight, and thoughtful editing:*

**Michael Goldrosen**, Boston Public Health Commission, HIV/AIDS Services Division

**Jessica Kraft**, Boston Public Health Commission, HIV/AIDS Services Division

**Beth English**, Massachusetts Department of Public Health, Office of HIV/AIDS

**Benn Grover**, Boston Public Health Commission, HIV/AIDS Services Division

**Paul Goulet**, Massachusetts Department of Public Health, Office of HIV/AIDS

**Elizabeth Hurwitz**, Massachusetts Department of Public Health, Office of HIV/AIDS

**Eric Thai**, Boston Public Health Commission, HIV/AIDS Services Division

**Erin Wnorowski**, Boston Public Health Commission, HIV/AIDS Services Division

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## TABLE OF CONTENTS

<b>I. INTRODUCTION.....</b>	<b>4</b>
<b>II. DEFINITION OF PEER SUPPORT .....</b>	<b>5</b>
<b>III. CHARACTERISTICS OF PEER LEADERS.....</b>	<b>5</b>
<b>IV. ROLE OF PEER LEADERS IN SERVICE DELIVERY .....</b>	<b>5</b>
<b>V. BENEFITS OF PEER SUPPORT.....</b>	<b>6</b>
<b>VI. REQUIRED COMPETENCIES, SKILLS, AND CONTENT KNOWLEDGE.....</b>	<b>8</b>
<b>VII. SERVICE DELIVERY METHODS.....</b>	<b>12</b>
<b>VIII. ADMINISTRATIVE STRUCTURES AND SYSTEMS .....</b>	<b>23</b>
<b>IX. RECRUITMENT AND RETENTION OF PROGRAM PARTICIPANTS .....</b>	<b>27</b>
<b>X. EVALUATION AND QUALITY ASSURANCE.....</b>	<b>28</b>
<b>XI. APPENDICES .....</b>	<b>34</b>

## **I. INTRODUCTION**

In the early years of the HIV/AIDS epidemic, before services were in place, before the continuum of risk was understood, and long before highly active anti-retroviral therapy was developed, people living with HIV/AIDS had very few options. Many people had lost their families, partners, jobs, housing, and community; misinformation and biases fueled the stigma associated with HIV. But out of this bleak and desperate time grew a community. People had only each other, so that had to be enough. People supported each other by providing food, sharing information about which doctors were sympathetic, sharing experiences around disclosing to partners, families, and friends, and when AZT became available people reminded each other to not miss any doses. This early community of people living with HIV/AIDS laid the groundwork for our current service system; while huge strides and advances in medical and social services have been made, the basic components of peer support remain the same.

Peer support is based on the premise that no one understands the realities of living with HIV/AIDS better than someone who has been living with and managing it every day. Because they are coping with the daily challenges of HIV/AIDS, peers (hereinafter called peer leaders) have the power to serve as important role models. Peer leaders can help individuals cope with their HIV diagnosis and resulting grief, provide opportunities for people to share feelings, receive helpful ideas, reframe negative thoughts, change harmful behaviors, develop a sense of stability and hope, and adhere to health routines. The effectiveness of peer support is often associated with a positive form of peer pressure which can motivate a person to pursue things previously thought to be impossible. Peer programs also serve as a gateway to the service system for individuals who are not accessing health care, case management, or other needed services. Hence, peer support services serve a uniquely important role within the HIV/AIDS service system.

The purpose of these guidelines is to provide a framework for HIV peer support services funded by the Massachusetts Department of Public Health, Office of HIV/AIDS (OHA) and the Boston Public Health Commission, HIV/AIDS Services Division (HASD). The guidelines offer a blueprint for the operation of peer programs, as well as a range of ideas about the types of peer-led activities that have proven successful, including frameworks for individual and group services and the kind of organizational structure needed to sustain a peer program in both clinical and community-based settings. Programs can use these frameworks to construct the roles of peer leaders within their service mix, either to

enhance existing programs or to design new ones. The models are meant to be flexible and can be adapted to suit specific populations and local circumstances.

## **II. DEFINITION OF PEER SUPPORT**

Peer support is defined by OHA and HASD as a set of services provided *by* and *for* individuals living with HIV/AIDS that enable them to empower themselves and develop effective strategies for living healthy lives. Through one-on-one interactions and in groups, peer support promotes clients' engagement in health care and provides opportunities for education, skill-building, and emotional support in a respectful setting. With harm reduction as a foundation, peer support helps clients access health information, develop coping skills, reduce feelings of social isolation, and increase self-determination and self-advocacy, helping improve quality of life for both participants and peer leaders.

## **III. CHARACTERISTICS OF PEER LEADERS**

While all peer leaders are people living with HIV/AIDS, successful peer leaders have other characteristics in common: a peer leader is someone who has accepted his/her HIV diagnosis, has learned to live with the disease and manage its daily challenges, and has attained a level of personal growth and healing that gives him/her the understanding, insight, and motivation to help others. When recruiting and hiring peer leaders, agencies must assess these characteristics along with the Required Competencies and Skills described in Section VI. In addition to the characteristics, peer leaders are specially trained to deal effectively with a variety of issues and to provide a broad array of services.

## **IV. ROLE OF PEER LEADERS IN SERVICE DELIVERY**

Responsibilities of peer leaders vary depending on the focus of the organization or program. The growing range of peer titles reflects the vast spectrum of these responsibilities across clinical and community-based organizations. Some commonly used titles include *Peer Educator*, *Peer Advocate*, *Treatment Adherence Peer*, and *Peer Navigator*. While these titles define the *primary function* of the peer leader, they do not fully reflect the totality of the peer leader role. There are certain important roles regardless of title; these include the following:

- mentoring program participants;
- providing emotional and practical support around acceptance of status, disclosure, maintenance of care, and other challenges;
- acting in an empathic, open, and accepting way;

- sharing personal stories and providing opportunities for people to tell theirs;
- providing skills-based education and a range of harm-reduction options;
- assisting in clarification of thoughts and feelings, measurement of costs and benefits of personal behaviors or decisions, and help to resolve ambivalence;
- promoting the belief that healthy living and long-term survival are possible;
- focusing on empowerment and self-determination.

Peer leaders bring to their work the unique perspective of having had some of the same, or similar, experiences as their clients. What separates peer leaders from case managers and other staff is how they use their perspective and experience of being diagnosed and living with HIV/AIDS to inform the services they provide. For example, peer leaders' understanding of how clients experience HIV diagnosis and treatment can give them a heightened awareness of barriers to communication that impact the client/provider relationship. Because their interactions with clients are based on empathy and shared experience, peer leaders may glean more information than service providers about actual and potential challenges for clients.<sup>1</sup>

While there are times when the functions of case managers and peer leaders may overlap, the standard, core functions of these services are different. Case managers work with clients to conduct comprehensive bio-psychosocial assessments of the clients' needs and to develop service/action plans based on those needs. Peer leaders conduct needs assessments and help clients create service/action plans, but in the peer support context, those tasks are exclusively to determine the nature and scope of the peer support service that best meets the clients' needs. Peer leaders should not play the main role in coordinating a client's access to medical care, behavioral health services, housing, or social services. Peer leaders will, however, often play a critical part in helping clients develop the skills they need to access and maintain these services and in reinforcing efforts to accomplish action steps from their case management service/action plans. Agencies must be careful not to assign peer leadership roles to case managers who happen to be HIV-positive; the roles are intended to stay distinct.

## **V. BENEFITS OF PEER SUPPORT**

Unlike other services which a client may need on a time-limited basis, or in times of crisis, individuals across the spectrum of self-sufficiency and with varying levels of service-related need can benefit from

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<sup>1</sup> Boston University School of Public Health, Health and Disability Working Group, PEER Center

peer support. There may also be positive impacts on the lives of the peer leaders themselves. Additionally, there are clear advantages to organizations that choose to integrate peer support services into their models. Some of these benefits are described below.

### Program Participants

Participation in peer support is often associated with increased knowledge, coping skills, self-esteem, confidence, sense of well-being and control, and a strong social network. Depending on the nature of the service and its intended outcomes, other benefits can include (but are not limited to) the following:

- regular engagement in health care and support services;
- increased knowledge about HIV and HIV treatment;
- increased self-efficacy to manage HIV disease;
- improved adherence to medication regimens;
- enhanced self-efficacy to engage in risk reduction behaviors;
- decreased stigma and isolation; and
- increased self-sufficiency and life skills.<sup>2</sup>

A list of sample program outcomes and measurements is included in Section X: *Evaluation and Quality Assurance* below.

### Peer Leaders

Benefits for peer leaders include many of the same benefits derived by participants, as well as increased knowledge about HIV, improved self-care skills, increased sense of empowerment, leadership development, improved job skills, and enhanced career development opportunities.

### Organizations

An assessment of OHA-funded peer support programs in Massachusetts found that organizations view peer support as an essential component of reaching new clients, particularly those whom are hard to reach, and helping existing clients stay connected to regular medical care.<sup>3</sup> Other findings include the following:

- *Building and maintenance of the client-agency relationship:* peer support activities encourage clients to access services and get involved in the organization's programs through a less formal

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<sup>2</sup> Rajabiun, S., Abridge, A., Tobias, C. Assessment of Peer Support Activities: Keeping Peers in Good Health & Giving Them a Better Quality of Life. September 2006.

<sup>3</sup> Rajabiun, et al. 2006.

structure. Peer leaders become trusted contacts in the agency, help the agency be more responsive to client needs, and improve the organization's image with its clients.

- *Assistance to clients with navigating the service system:* peer support provides clients with important information about HIV and HIV-related services both within the organization as well as in the community. Further, participation in peer support programs increases client presence and involvement in the organization and makes it easier for clients to engage in other related care. In some communities peer support is an important mechanism for improving awareness about HIV and positive living.
- *Strengthening the service team through peer involvement:* peer leaders are part of a professional team that helps the client navigate the health and social service system in organizations that provide multiple services such as case management and health care. Peer leaders provide additional support to other program staff in following up with clients, especially when case managers have limited time. Finally, peer leaders can sensitize medical and service providers to the needs of marginalized populations and serve as examples to providers that clients can manage and overcome barriers to effectively adhere to care and treatment.

## **VI. REQUIRED COMPETENCIES, SKILLS, AND CONTENT KNOWLEDGE**

### **A) COMPETENCIES AND SKILLS**

Effective peer leaders must have a core set of particular competencies and skills, in addition to the characteristics previously described. While peer leaders may hone some of these skills on the job, they must have a basic level of competency before they are hired in order to be effective. The OHA and HASD require that peer leaders in funded peer support programs have the following competencies and skills:<sup>4</sup>

#### *Life experience with HIV/AIDS*

Peer leaders must have personal experience managing HIV in their own lives and employing effective self-care strategies. Someone who is not regularly in care, for example, cannot fully support others with regard to staying in care. Someone who has not accepted his/her diagnosis would have difficulty helping another achieve acceptance. This does not mean that peer leaders must have conquered every challenge, but management of the daily challenges of living with HIV is essential.

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<sup>4</sup> These competencies were developed by the *Greater Boston/Metrowest HIV/AIDS Service Coordination Collaborative Peer Support Work Group*, comprised of peer leaders, peer support program coordinators, and HIV-positive clients.

### *Ability to work with diverse groups*

Peer support participants come from many different backgrounds in terms of race/ethnicity, sexual orientation, gender identity, sex and drug cultures, age groups, religion, country of origin, disability, and economic status. A peer leader must have strong interpersonal skills and a level of cultural competency that enables the peer to render high quality services to *all* program participants with respect and compassion. Peer leaders must have an understanding of their own personal and cultural identities and how these characteristics influence their attitudes, reactions, and assumptions so as not to allow them to block their ability to listen and respond to clients in an open and supportive manner.

### *Willingness to provide services within a harm reduction framework*

Promoting a harm reduction philosophy and adhering to harm reduction practice are required of all funded services including peer support. Peer leaders must understand and be proficient in the goals, tenets, and strategies of harm reduction and be willing to give clients a range of options that reduce immediate harm, even when those options do not fully eliminate risk or represent what the peer leader would do in the same situation. Peer leaders must be comfortable discussing sexual and drug use behaviors with clients in a nonjudgmental fashion and must have the ability to strategize with clients about personal risks and harm reduction goals and strategies. Embracing and communicating a positive attitude toward sexuality and sexual health are essential elements of an effective harm reduction approach.

### *Ability to embrace and communicate a positive, self-affirming, empowering attitude toward the lives of people living with HIV/AIDS*

In order to promote the belief that healthy living and longevity are possible, peer leaders must believe this with respect to their own lives. Peer leaders must also demonstrate through assertiveness and action their own state of empowerment and their ability to challenge powerful barriers such as stigma, fear, and hopelessness.

### *Ability to share personal experiences of living with HIV/AIDS*

Sharing personal stories can help participants realize they are not alone and that there are other people with similar challenges who are managing them. Sharing should always be done within the context of a client encounter to help educate, provide emotional support, and give practical ideas based on real life experience. The sharing of stories should always include opportunities for the client to ask questions and share stories as well.

### Strong communication skills

The ability to communicate effectively is essential for relationship building between peer leaders and clients. Listening, expressing oneself, and asking questions while being genuine, accepting, and empathic can promote trust and openness. Peer leaders must have the ability to speak clearly, deliver information in a manner accessible to a range of clients, conduct formal discussions that are responsive to client needs, and elicit personal information and questions from clients in a respectful manner. Also, peer leaders must be able to write clearly in order to provide basic documentation of services provided. Written and verbal communication should reflect a high level of objectivity and professionalism.

### Ability to advocate for self and others

Depending on their role, peer leaders may be called upon to request services and benefits on behalf of clients. When advocating for clients it is helpful to simultaneously support them in developing the skills to advocate for themselves. Over time, this type of support enables clients to develop their own capacity for leadership, initiative, and self-sufficiency. Peer leaders should also be able to advocate for themselves, their clients, and/or their services when certain organizational structures or processes are not working well or are not supportive of their work.

### Ability to participate in required trainings

Peer leaders must attend all trainings required by their agency and funder(s). They must also have the ability to apply what they learn to their work as peer leaders.

## **B) CONTENT KNOWLEDGE**

In addition to the competencies and skills described above, peer leaders must be proficient in a variety of content areas that impact the lives of the clients they serve. Before they are hired, peer leaders must have a basic understanding of the issues that they will be addressing with clients, regardless of the type of peer program. Trainings sponsored by OHA and HASD (see below) will provide an additional level of information and skill-building support. In addition, funded agencies are required to provide ongoing training opportunities and consistent supervision so that peer leaders may enhance their knowledge and skills, while keeping current on updates in the HIV field.

Every peer leader will not need to be an expert in every content area but should have knowledge about each of these areas and expertise that is consistent with his or her particular role in the agency. The list

below describes OHA's and HASD's expectations for the content areas with which peer leaders are expected to be familiar.

### HIV 101/HIV Life Cycle

- Basic knowledge of HIV infection, disease progression, and physical impacts, including target immune system cells, role of viral load and CD4 cells in disease progression, and AIDS-defining conditions;
- Thorough knowledge of modes of HIV exposure and infection;
- Working familiarity with the range and role of antiretroviral medications and the treatment and prevention of opportunistic infections and conditions.

### Medication adherence

- Working knowledge of the importance of adherence to antiretroviral medication regimens for the prevention of disease progression and viral resistance;
- Ability to describe methods and strategies for ensuring or improving medication adherence;
- Knowledge about resources for adherence support in the community and ability to make appropriate referrals;
- Understanding of medication side effects and how side effects impact adherence.

### Harm/Risk Reduction

- Thorough knowledge of the relative effectiveness of various strategies to address risk and harm associated with a range of sexual and drug use behaviors.

### Sexually Transmitted Infections (STIs) and Hepatitis

- Thorough knowledge of STIs and viral hepatitis, their connection to HIV, their impact on HIV-positive health, how they are transmitted and prevented, and their symptoms and treatments;
- Working knowledge of STI and hepatitis screening and treatment sites and ability to make supported referrals to those sites.

### Ethics and Boundaries

- Thorough understanding of and commitment to core ethical principles and the ethics-based boundaries of the work, including timely and dependable attendance at assigned meetings and appointments, appropriate and inappropriate sharing of personal information, the confidentiality of

information gathered during the delivery of peer support services, appropriate and inappropriate contact with peers outside of a service context, and the need to observe agency-determined policies and relevant laws and regulations.

### Cultural Competency

- Working understanding of the mechanisms and negative effects of racism, sexism, and heterosexism as well as discriminatory attitudes and structures that oppress immigrants, drug users, transgender individuals, and other groups.

## **C) TRAINING**

OHA and HASD require peer leaders to participate in a specific set of trainings. These trainings address some of the aforementioned content knowledge areas and help peer leaders develop the skills they need to provide effective services. Below is a list of required trainings that are available through JRI Health:

- Peer Leader Competency Training;
- Fundamentals of HIV;
- Behavioral Risk Assessment and Risk Reduction;
- Positive Prevention in Practice;
- HIV Support Group Facilitation (for those facilitating groups);
- HIV Counseling & Testing Training: Core Standards and Practice (if included in peer role).

Funded organizations must provide training on any competencies or content areas that these trainings do not cover. Additionally, agencies must orient peer leaders in the following areas:

- mission, policies and procedures of the organization;
- peer leader job descriptions, including duties, responsibilities and other job expectations;
- other programs administered by the organization;
- the role of the peer leader in relation to other programs/employees of the organization.

## **VII. SERVICE DELIVERY METHODS**

There are many different ways to deliver peer support services; this document describes two categories of interventions supported by the OHA and HASD: individual-level peer support and group-level peer support. All funded agencies must offer individual-level peer support; agencies are strongly encouraged to offer both group-level and individual-level peer support. Services can be provided in

either clinical and/or community-based organizations (CBOs), and in some cases, in a client's home or in other settings. The OHA and HASD do not currently fund internet interventions for peer support, however agencies are encouraged to assess the population with whom they work and consider including internet activities offered in virtual settings (such as chat rooms, message boards, e-mail groups, etc.) as a component of their peer support service.

Agencies planning a peer support program must thoughtfully plan how they want peer leaders to be integrated into their service mix and organizational framework. Agencies must also consider what types of services are requested by the populations they serve and wish to serve. Agencies that already offer peer support services should reassess their service delivery methods on a regular basis. When thinking about expanding existing programs and/or adding new services, agencies should consult with their Consumer Advisory Board (CAB) and clients. They should also talk to other organizations in their area to identify opportunities for collaboration, coordinate on consumer needs assessments, avoid service duplication, and ensure that clients have access to a range of peer support services. Section X, *Evaluation and Quality Assurance*, provides more information on the specific steps necessary to develop an effective program model. This section includes some basic descriptive information about individual-level and group-level peer support. Detailed examples of program models are described in the Appendix.<sup>5</sup>

#### **A) INDIVIDUAL-LEVEL PEER SUPPORT**

Many clients prefer the confidential nature of individual-level or one-on-one support and benefit from its more individualized and often intensive focus. Individual-level peer support has been successful in engaging hard-to-reach populations and in supporting newly-diagnosed individuals as they adjust to their diagnosis and enter into the service and care system. Many other individuals can benefit from the service and may choose to participate to meet a discrete, short-term need, or to access more long-term support.

Client needs will determine which services a peer leader will provide at any given time. However, there are some basic roles and activities, described in section 1 below, which will be part of most one-on-one peer support work. These roles are essential whether the peer leader is providing the service as part of an interdisciplinary team or as part of a freestanding peer support service, the characteristics of

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<sup>5</sup> An excellent resource for agencies designing and implementing peer programs is "Building Blocks to Peer Program Success A toolkit for developing HIV peer programs." This guide was developed by the Peer Education and Evaluation Resource Center and is available at [www.hdwg.org/peer\\_center](http://www.hdwg.org/peer_center).

which are described in Section 2. Detailed examples of program models are included in Appendices C through E.

## **1. INDIVIDUAL-LEVEL PEER SUPPORT ROLES**

### **a. Supporting Client Access to Health and Support Services through Outreach**

Peer leaders can play an important role in helping individuals who are either newly-diagnosed or who have not yet entered care access medical and social support services. Peer leaders may conduct outreach within the agency, outside the agency, and in the community to find clients.

#### *Specific Knowledge Needs*

Peer leaders will need to have a knowledge of local HIV primary care and support services and knowledge of some of the barriers HIV-positive clients face in accessing care. Peer leaders will need to be familiar with the areas where clients may be located, including counseling and testing sites.

#### *Activities*

Activities will vary depending on the kind of outreach the peer leader is conducting, and whether the outreach is to counseling and testing clients, peer support clients, other agency clients, or other organizations. Agencies should provide the peer leader with a list of organizations with which they have a formal memorandum of understanding (MOU) or other collaboration and support the peer leaders' access to these organizations. Once a peer leader finds a client, s/he must be prepared to talk with the client about why the client is out of care, what barriers are keeping the client from re-entering care, how to work around the barriers, and other relevant issues. Other activities may include helping the client identify a provider (medical and/or social service), making an appointment for the client, and taking the client to an appointment. Some clients may want the peer leader to sit with them for all or part of the appointment as well. Many clients who are new to care may also need support in maintaining their care. The next role describes activities for working with clients on maintenance of care.

### **b. Supporting Client Retention in Health and Support Services**

This peer leader role supports people living with HIV who have dropped out of care or who are episodically in care, as well as people who struggle with maintaining their care.

#### *Specific Knowledge Needs*

Peer leaders will need to be familiar with the reasons why HIV-positive individuals drop out of care or find it challenging to regularly access care. These reasons may include practical concerns like lack of transportation and child care, and may also include more complicated issues like denial, fear, past

experiences with medical providers, stigma and not wanting to be seen at an agency known to serve people living with HIV, etc.

### Activities

Peer leaders will need to work with the client to understand why the client is not in care, and then strategize with the client about ways to overcome the barriers keeping them from care. This may include helping the client make an appointment with a provider, giving the client tips for communicating openly with the provider, assisting the client in preparing a list of questions to ask the provider, transporting the client to and from appointments, sitting with the client for all or part of the appointment, debriefing with the client after the appointment, helping the client make follow up appointments, and reminding the client about upcoming appointments.

### **c. Representing Client within the Agency**

Clients will often tell their peer leaders things they would not tell their case manager or medical provider. The peer leader may find him or herself in the position of knowing why a client is making certain decisions but not being able to share the reasons with the other agency staff. Peer leaders who are part of a team should strongly encourage the client to give permission for the peer leader to share any information that is applicable to the client's care with other members of the team – this will allow for the optimal service provision. It is important that peer leaders make clear to their clients what they cannot keep confidential (e.g., if a client is in danger), and it is important that agency staff respect the relationship that peer leaders have with their clients.

### Specific Knowledge Needs

Peer leaders must have a thorough understanding of agency policies and protocols around information sharing and confidentiality, and what information the peer leader is required to share. Peer leaders must also be knowledgeable about the other staff within the agency and their roles.

### Activities

Whether the peer leader is part of an interdisciplinary case management team or freestanding service, s/he should meet with other staff working with the client on a regular basis. These meetings are an opportunity for the team members to share information (as appropriate) about the client. While some of the suggestions and thoughts of the other team members may be in conflict with the information the peer leader is either sharing or is aware of but is not able to share, the team must work together to make recommendations about the client's needs based on all of the available information.

#### **d. Assistance Navigating Service Systems and Making Supported Referrals**

Though the role of a peer leader is different from a case manager, as described above, peer leaders can play a valuable part in helping clients navigate the service system. Peer leaders' understanding about accessing services from the client's perspective can be useful and reassuring for a client.

##### *Specific Knowledge Needs*

Peer leaders will need to know about local health care resources and support services and how to access them. This will require having contact names and being aware of eligibility criteria. However, it is extremely important that peer leaders know their own limitations, and that other agency staff understand their role as peer leaders and not as case managers or social workers. Therefore, peer leaders must also know how to make internal and external referrals. Agencies should make clear to peer leaders when they are to involve another agency staff and when outside referrals are acceptable.

##### *Activities*

Depending on the client's needs, the peer leader may explain a particular service, provide basic information about eligibility criteria, give the client contact information for the agency providing the service, give the client access to a phone to contact the provider if appropriate, call the agency for the client, transport the client to the agency, check with the client to make sure the service was accessed, find out what if any follow up is needed, and/or provide appropriate follow up. Some of the activities in this role will be similar to those described in *Supporting Client Retention in Health and Support Services* above.

#### **e. Supporting HIV Treatment Adherence**

There are many ways in which peer leaders can support client adherence to their medication regimens. With specialized training, peer leaders can be very effective in helping clients understand their medications and develop strategies for adherence that make sense in individual clients' lives.

##### *Specific Knowledge Needs*

Peer leaders will need an understanding of HIV medications and their side effects, as well as basic HIV labs (including CD4, viral load, and resistance testing).

##### *Activities*

In this role, peer leaders explain some basic medical information including how HIV medications work, how different classes of HIV medications work together, and how to read and understand lab results. Peer leaders engage clients in discussions to better understand the barriers the client is currently facing or might face that could impact the client's ability to adhere to medications. The peer leader can make a treatment adherence plan with the client and work with the client to identify specific

activities or adherence options that would assist the client, e.g., pill boxes, reminder calls/texts, weekly or monthly meetings, etc.

## **2. INTERDISCIPLINARY TEAMS AND FREESTANDING SERVICES**

Individual-level peer support services can be provided in two ways: as a fully integrated component of an interdisciplinary care team or as a freestanding service that is accessed independently of other care or support services utilized or available. Interdisciplinary teams may be located in both community-based organizations (CBOs) and medical settings. In community-based organizations the team may include case managers, housing advocates, social workers, benefits advocates, other social service providers, and/or clinical (e.g., licensed mental health) staff who work at the agency or who subcontract with the agency. In clinical settings the team may include doctors, nurses, social workers, registered dietitians, case managers, and other clinical or social service providers who work with the organization. Regardless of the composition of the team, each member of the team has a specific role with the client, and the team members work together to provide optimal support and services to that client.

Clinical sites are encouraged to offer individual-level peer support as part of an interdisciplinary team. The team approach works particularly well in clinical settings because the care provided will always involve at least one other provider (the doctor). Alternatively, in CBOs, some clients may wish only to access peer support services and may not be interested in or need any other services at that agency. In this case, there would be no need for the client to work with a team. CBOs can therefore offer freestanding peer support services either exclusive of, or in addition to, team-based services. Freestanding individual-level peer support services are usually located in community-based settings, but agencies offering these services may outpost peer leaders to clinical settings. While these peer leaders may work with other staff in the agency or clinic, and while they may communicate with other providers involved in the client's care and support, the services are not part of an interdisciplinary model.

The chart below highlights the different characteristics of individual-level peer support offered in an interdisciplinary team and as a freestanding service.

## Characteristics of Interdisciplinary Teams v. Freestanding Services

	<b>Interdisciplinary Team</b>	<b>Freestanding Service</b>
Enrollment	Client does not complete separate intake, assessment, or Individual Service Plan/Client Action Plan.	Client completes peer support assessment and peer support Individual Service Plan/Client Action Plan.
Coordination	Agency does not need to have a Peer Support Program Coordinator	Agency must have a Peer Support Program Coordinator. For some peer programs this person may also be the peer leader providing the services.
Experience and Background	Particular background, experience, and training may be required, especially in clinical settings.	Peer leaders must have the required competencies and skills described earlier in this document; additional experience and background is not necessarily needed.
File Access	Peer leaders have access to agency client files.	Peer leaders have access to the Peer Support section of a client's file or create separate client peer support files.

### **B) GROUP-LEVEL PEER SUPPORT**

Group-level peer support includes two categories: 1) support groups and 2) Peer Networking. HIV support groups, which OHA and HASD define as Traditional Support Groups and Educational Support Groups, are discussed in Section 1 below. Peer Networking (PN), a new category of group-level peer support that OHA and HASD are promoting is described in Section 2. Section 3 outlines some basic characteristics of group-level peer support models.

#### **1. SUPPORT GROUPS**

Support Groups are small gatherings of people who come together to share common experiences and challenges of living with HIV/AIDS. Support groups can bring about a powerful feeling of connection among members and have long offered companionship, information, and emotional support to people coping with disease. In the process of sharing, members show each other empathy, acceptance, and understanding. Typically, groups meet in person with eight to twelve participants. The small size of the support group promotes conversational interaction and gives each member an opportunity to participate. In support groups, effective peer support connections can be made between participants and between the facilitator and the participants. It is for this reason that OHA and HASD require that support groups be facilitated or co-facilitated by peer leaders. The OHA and HASD fund two sub-categories of support groups: (1) Traditional Support Groups and (2) Educational Support Groups. Each can be provided in a clinical or community-based setting.

### **a) Traditional Support Groups**

Traditional Support Groups offer participants both practical and emotional support and may focus on a wide variety of topics that impact people living with HIV. Discussions emerge from a range of issues that individuals raise or that the group as a whole decides to address. The facilitators prompt members to provide each other with help which may involve providing and evaluating information, relating personal experiences, listening to and accepting others' experiences, and providing empathic understanding. Some groups may be designed to bring together individuals with particular demographic characteristics, and other groups may choose to identify more broadly. Appendix A provides a full description of one model for a Traditional Support Group.

### **b) Educational Support Groups**

In Educational Support Groups, facilitators or invited speakers provide information about particular issues and increase awareness of the behavioral, medical, and psychological consequences of related behaviors. Participants are provided with concrete strategies for managing issues and solving problems and are supported in taking action to implement these strategies. While traditional support groups may include educational components, educational groups are designed around a particular educational topic or theme. Topics might include, but are not limited to, the basics of HIV treatment, HIV/STI/viral hepatitis transmission, disease prevention, disclosure, nutrition, working with your doctor, medication adherence, stress management, etc. Educational Support Groups are often appealing to people who are newly-diagnosed and who want and need support but who may not be ready to commit to a long-term group or case management. They may also work well for others who are interested in a short-term intervention that addresses a discrete, very specific need.

Educational Support Groups are different from educational presentations in that they are designed to offer some of the same psychological benefits as support groups, to provide a comfortable setting for participants to ask questions and share concerns, and to create an intimate environment that facilitates learning and sharing about skill-building strategies. Participants can derive emotional support from hearing the personal stories of other participants and experiencing the empathy exhibited by group members toward each other. As such, these groups should always incorporate opportunities for group discussion. Appendix B provides a full description of one model of an Educational Support Group.

## **2. PEER NETWORKING**

While support groups are an excellent way to address the feelings of isolation and loneliness that are experienced by many people living with HIV, the support group structure does not appeal to everyone. The goal of Peer Networking is to engage individuals who are not comfortable with the formalities of a facilitated group or who feel that they do not need more intensive or long-term services. It is an intervention that aims to promote health and wellness by bringing people with common interests together in a relaxed environment to build social networks and develop relationships. PN emphasizes the mutual or communal aspects of living with HIV/AIDS and the goals achieved through the sharing of personal experience and socialization.

Twenty-five years into the epidemic, many people living with HIV still face isolation and stigma and want a way to meet, spend time with, and learn from their peers, and for a number of reasons the typical support group model does not meet their needs. PN can be an excellent alternative as it has a less formal and more flexible design than support groups. Like support groups, PN brings people together to share experiences and learn from each other. Unlike support groups, PN is not limited in size, offers much more flexibility in venue, and emphasizes the importance of creating, building, and maintaining social networks. PN may be particularly appealing to long-term survivors; however models can be designed for any community.

Peer Networking activities must be designed to complement an agency's other peer support services (Individual-Level Peer Support, Traditional Support Groups, and Educational Support Groups).

Models must be developed as part of a peer support program strategy to meet a defined need, achieve a particular set of outcomes, and engage particular populations or sub-populations. PN programs must address clearly defined outcomes and must incorporate an educational component and/or a specific product. While this requirement may draw comparisons with Educational Support Groups, there are some concrete differences between Peer Networking programs, and support groups in general, listed in the table below.

### Components of Support Groups v. Peer Networking

Component	Support Group	Peer Networking
Size	Most groups include eight to twelve participants.	The nature of the activity determines the number of participants; groups may be small or large.
Service Methodology	Outcomes are achieved through intimate discussions that are promoted by the group's small size.	Outcomes are achieved through networking, social interaction, and education.
Venue	Groups are usually held in community-based or clinical settings.	Activities can take place in a variety of settings. The venue is carefully chosen to engage the intended community.
Enrollment	Participants are required to complete an agency intake and peer support assessment.	Participants may or may not be required to complete an agency intake and peer support assessment, depending on the model.
Facilitation	Groups must have at least one facilitator.	Activities must have a coordinator; a facilitator may or may not be involved, depending on the activity.

Below are some examples of Peer Networking activities. Agencies are encouraged to be creative when thinking about Peer Networking opportunities that would appeal to the specific communities of people living with HIV using their services.

1) A clinic identifies a need for consumer-friendly treatment brochures (including classes of medications, adherence tips, etc.). Clients design the brochures and write text that includes their personal experience. The project is coordinated by the clinic's peer leader with clients referred by the nurse and other medical providers. Clients sign-up to participate and meet twice monthly until brochures are completed.

2) A community-based organization hears from a number of clients who are men who have sex with men (MSM) that they want a way to connect to other HIV-positive MSM, but that they are not interested in support groups. The peer leader works with the clients to identify topics that would be interesting and useful to the community and a culturally-appropriate venue. A monthly meeting is started, open to anyone living with HIV but geared toward MSM. The group does not require people to sign up and meetings are held in a night club. Each meeting includes an educational presentation with time for discussion and an opportunity for informal networking.

### 3. CHARACTERISTICS OF GROUP-LEVEL PEER SUPPORT

Once a type of Support Group or Peer Networking activity has been selected, specific models must be chosen and characteristics must be determined. Agencies should work with their CABs and/or potential participants to make these decisions. Below are descriptions of some options for additional basic characteristics of group-level models:

#### Membership

Group-level interventions are often designed for HIV-positive individuals from a particular community or of a specific demographic. Examples include groups for newly-diagnosed individuals, women's groups, groups held in languages other than English, groups for people in recovery, etc. Agencies should work with their clients to create the appropriate group(s). While there is a requirement that all clients of peer support services be documented as HIV-positive, there is an exception for group-level interventions: upon request, agencies may create groups for discordant couples where one person is HIV-positive and the other HIV-negative or of unknown status. Reporting practices for individuals who are not documented to be HIV-positive will be tailored to the funding stream used to support the service, and agencies must work with their funders to develop a reporting plan. This also applies to PN activities which may include projects or events that are open to HIV-negative individuals.

#### Open vs. Closed

*Open groups* allow new members to join at any time and usually have flexible policies about participating. Members can typically participate at their convenience without having to attend every meeting. *Closed groups* do not allow new members to join once the group has reached maximum capacity (usually twelve individuals for a support group; for PN the maximum will vary depending on the activity). New members are added through attrition. Closed groups are generally designed for members to attend every session.

The flexibility of the open group makes it suitable for many kinds of PN activities. Alternatively, since closed groups often foster greater familiarity, bonding, trust, and friendship among group members, they are usually preferable for Traditional Support Groups. Similarly, participants in an Educational Support Group may find more opportunities for learning and sharing in a closed group format. Facilitators of both Traditional and Educational Support Groups will have an easier time managing groups with a closed format.

### Time-Limited vs. Long-Term Groups

*Time-limited* groups can last from a few weeks to several months depending on the program model. *Long-term* groups can extend indefinitely. Most Traditional Support Groups are long-term, while Educational Support Groups are often time-limited. Peer Networking activities may be either short-term or long-term, depending on the program model.

### Facilitation

Support Groups may be exclusively peer-led or peer-led with a mental health professional (i.e., clinical social worker, psychologist, etc.) as a co-facilitator. Ideally, exclusively peer-led support groups will have two facilitators; professionally-led groups must always have two facilitators: the professional and the peer leader. The facilitators may offer different experiences and perspectives and may have complementary expertise. Together, the co-facilitators should be able to identify and intervene in a greater range of situations and with greater skill than one facilitator. From an administrative perspective, this arrangement also ensures coverage of meetings when one facilitator is absent. PN activities must have a coordinator but are not required to have a facilitator. If PN activities are facilitated, it is recommended that at least two facilitators are used, one of whom must be a peer, and the other may be a mental health professional or another staff person from the agency.

### Meeting Frequency

Meeting schedules vary depending on the program model, but all Traditional Support Groups and Educational Support Groups are required to meet at least once a month. Each agency must decide upon the frequency of meetings based on client need and available resources, while being mindful that scheduling meetings too far apart can cause groups to lose momentum. In many programs, support groups are scheduled weekly or bi-weekly. PN activities will develop schedules that are based on the program model offered.

## **VIII. ADMINISTRATIVE STRUCTURES AND SYSTEMS**

High quality peer programs have administrative and operational systems in place that support both the program and the peer leaders in delivering effective and sustainable services. Careful planning, clear objectives and expectations, appropriate supervision, strong evaluation mechanisms, and good communication will support peer leader performance and successful programming. Regardless of the type of peer support being provided, whether the peer leader is full time, part time, or stipended, and whether the peer leader is part of an interdisciplinary team or a freestanding program, peer leaders are

an important part of the agency or clinic, and should be shown the same respect given to any other staff person. Peer leaders should not be asked to take on tasks that are not part of their job description; peer leaders are there because of their expertise and experience as people living with HIV, they are not there to provide low cost administrative support. Peer leaders should be recognized, integrated, and supported as the vital human resource that they are.<sup>6</sup>

The OHA and HASD require that peer programs maintain sound administrative structures and systems which include the following:

- clearly *written* policies and procedures with well-defined channels of communication and clearly understood expectations of both peer leaders *and* staff;
- well-organized and clear documentation of peer work;
- detailed peer leader job descriptions with clear lines of authority;
- stable mechanisms for compensating peer leaders;
- administrative supervision policies that include regular meeting times;
- clinical supervision policies that include regular meeting times;
- mechanisms to ensure the safety of peer leaders when doing off-site work.

### Policies and Procedures

In addition to a description of the agency's mission and scope of work, written organizational policies and procedures should be included in the peer leader's employee orientation. These policies and procedures should include, but are not limited to, client rights and responsibilities, employee confidentiality agreements, client consent for funder file review, client releases of information, client grievance procedures, and personnel policies. It is the agency's responsibility to ensure that peer leaders are familiar with all of the agency's policies and procedures.

### Documentation

Peer support activities must be documented in accordance with the Boston Public Health Commission/Massachusetts Department of Public Health Standards of Care for HIV/AIDS Services (SOC). The SOC describe the minimum level of documentation required by these funders. Beyond this requirement, organizations may have their own, additional documentation policies and must decide what method or level of documentation will work best for its peer support program.

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<sup>6</sup> Harlem Adherence to Treatment Study, Harlem Hospital Peer Support for HIV Adherence, 2003

The SOC state that individual peer support activities must be documented by the peer leader and must include the date and duration of a client encounter, and the general topic areas discussed.

Documentation methods vary from one organization to the other. Some agency policies require peer leaders to document their work following the same procedures used by everyone else in the organization. In other programs, peer leaders simply fill out a checklist and make brief comments on a standard form specifically designed for this purpose.

For support groups, the SOC require documentation to include the following information:

- date of the support group meeting;
- name of group;
- number of participants; and
- general topics discussed;
- documentation of participation in each participant's client file.

Documentation protocols should never require peer leaders to violate the confidential and trusting nature of the peer-client relationship. Program participants often share very personal information with a peer leader that they would not necessarily share with anyone else. Therefore, progress notes should not be a full account of every detail a participant has shared with the peer leader. If the peer leader feels that a certain behavior or situation shared confidentially can have adverse effects on the health and well being of the participant, he/she should encourage the person to tell his/her doctor or case manager and even offer to help with the communication. But ultimately, the program participant decides what information the peer leader can and cannot share. Funded organizations are responsible for training peer leaders on how to write notes that capture required information without violating the trust program participants have placed on them. Documentation responsibilities should be articulated in the peer leader's job description. Supervisors should regularly review a random sample of peer leader progress notes and provide guidance as needed.

### Job Description

However peer leaders are used within an organization, it is essential to define their roles and responsibilities. The job skills and activities required by a peer leader position are different in nature than professional positions, so it is necessary to be more explicit in defining peer roles and the type of organizational structure that can support them. Agencies must also determine how the work of the peer leaders will intersect with the work of the agency's other staff.

Ideally, plans are made prior to hiring peer leaders although it is never too late to review and redefine peer leader expectations and responsibilities. An effective supervisor will provide each peer leader with a clear job description based on established peer objectives and expectations. Peer leader objectives, expectations, and responsibilities should also be communicated to other staff of the organization. Peer leaders themselves might be asked to help shape the role that they are intended to fulfill, bringing attention to issues faced in the field and suggesting creative ways to address them. The job description should be reviewed during the job interview, employee orientation, administrative supervision, and performance evaluation. Each peer leader should have a copy and clearly understand the requisites of the job he or she has been hired to do.<sup>7</sup>

### Compensation

Peer leaders must be offered compensation of some kind. Individuals providing individual-level peer support must be offered a full-time or part-time salaried position with the agency. Individuals providing group-level peer support must be offered either a salaried position or a cash stipend/cash alternative (e.g., gift card). Agencies must offer all peer leaders reimbursement for work-related travel and must offer non-salaried staff reimbursement for child care expenses. Agencies must ensure that they follow applicable federal laws and regulations with regard to compensation policies and practices.

Prospective peer leaders should analyze how earned income can affect their disability payments, if any. Entities issuing disability payments are the best authorities on how changes in income and/or physical activities can affect those payments, and peer leaders should consult with those entities on their most current *financial* and *categorical* eligibility requirements. Peer leaders who are offered salaried positions may decline this offer in favor of a stipend arrangement, however, OHA and HASD strongly encourage salaried positions when possible.

### Administrative Supervision

The purpose of administrative supervision is to ensure that peer leaders are executing the duties of their position, evaluate job performance, provide guidance, prioritize work load, strategize on job challenges, and monitor attendance. Scheduled individual supervision allows the supervisor to help the peer leader identify training needs, information gaps, or other areas of knowledge and skill development. Hence, regular individual meetings between supervisor and peer leader must be

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<sup>7</sup> Harlem Adherence to Treatment Study, Harlem Hospital Peer Support for HIV Adherence, 2003

established. In the case of new hires, supervision should be conducted more frequently, either weekly or bi-weekly, at least during the initial three to six months of employment. Additionally, peer supervisors should shadow new hires for a period of time, or should have experienced staff shadow them, to observe how they communicate with and react to clients, the accuracy of the information they provide, and the range of their knowledge and skill set.

### Clinical Supervision

Clinical supervision refers to supervision provided by a licensed mental health professional. This supervisor focuses on job stressors, burnout or potential burnout, dealing with conflict, dealing with difficult clients, transference and counter-transference, and other job related issues affecting the mental and emotional health of the peer leader. This type of supervision must be provided a minimum of one hour per month individually, in groups, or both, depending on the needs of the peer leader and the organization's resources. The information shared with the clinical supervisor is confidential and is not shared with the administrative supervisor, unless there is a mandated reporting issue involved.

## **IX. RECRUITMENT AND RETENTION OF PROGRAM PARTICIPANTS**

Organizations administering peer programs play an important role in the recruitment and retention of clients. Peer leaders do not and should not carry the full burden of recruitment and retention, although they can play an integral role in the process and may have a great deal of influence over how clients engage with the program. Agencies are responsible for using appropriate and tailored outreach methods that motivate clients to become involved. Peer leaders can work with other staff to consult the agency's Consumer Advisory Board and clients about marketing strategies and messages that will resonate with the intended client population. Particular attention should be paid to creating low-threshold access to services, considering creative approaches to recruiting participants who resist associations with particular groups or labels, and referencing confidential space, when applicable.

Attending to the needs of peer support participants *and* peer leaders can go a long way in client retention. Agencies must ensure that the peer support services are fully integrated, supported, and marketed as part of the comprehensive framework of client care and service. For example, program staff can follow up with participants who have stopped coming to sessions and offer them help in overcoming obstacles they may be facing; help resolve conflicts between a participant and a peer leader; ensure that all agency staff are aware of and understand the peer support services; market the

services; and help clients understand how participation in the peer program can enhance their health and quality of life. Agency staff should also ensure that strong internal and external referral mechanisms are in place. Agencies are also responsible for the provision of logistical support, such as:

- securing meeting space;
- providing food and beverages for support group meetings;
- disseminating information to participants about meeting place and time;
- sending reminders; and
- offering incentives.

Incentivizing is one of the most effective methods of recruiting potential participants for a peer program. Once engaged in the program, the incentive often becomes the *value* of the services they receive, and tangible incentives become less important in retaining program participants. Incentives need not be costly or in cash. Raffle items, gift cards, fitness center passes, movie tickets, and door prizes are examples of incentives typically offered to peer support participants. Agencies must ensure that any incentives distributed are done so in accordance with applicable laws, regulations, and agency policies.

## **X. EVALUATION AND QUALITY ASSURANCE**

The overarching goal of peer support is to improve the health and quality of life of people living with HIV/AIDS. Program evaluation furthers this goal by providing ongoing, systematic information that can be used to strengthen program design and delivery and assess the extent to which clients have changed by participating in the program. Evaluation can be used not only to demonstrate that a project worked, but to also improve the way that it works, leading to more effective programs, greater learning opportunities, and better knowledge of what works and why. Evaluation should not be seen as a stand-alone process, rather as an integrated and valuable part of program planning and service delivery. Knowledge gained through thoughtful evaluation will enable program staff to make decisions that ultimately lead to stronger programs and more effective services. The Office of HIV/AIDS does not require a specific type of evaluation. Programs are afforded the flexibility to choose the client outcomes they wish to measure and determine what information to collect and the method by which it will be collected. The following are suggested steps to follow in measuring program outcomes:

**STEP ONE: GET READY.**

Identify the members of your evaluation team. Involve key stakeholders including consumers, peer leaders, and staff. Discuss your peer support model and determine how you see the program effecting change with clients. Identify the program's key goals and the specific programmatic activities that are designed to bring them about. Be realistic, and think about what changes are clients likely to experience as a direct result of the components of your intervention.

**STEP TWO: CHOOSE THE OUTCOMES YOU WANT TO MEASURE.**

Outcomes are benefits for participants that occur during or after their involvement with a peer support program. Outcomes generally relate to a change in knowledge, skills, attitudes, values, behavior, or condition. Outcomes should be specific, realistic, and measurable expectations of change. An important question to consider when determining which one or two client outcomes you wish to evaluate is: what are the key issues we are working on with our participants (e.g., disclosure, stigma, service system navigation, medication adherence, knowledge of HIV and behavioral risks, self-care, etc.)? Define your outcomes precisely; vague outcomes will be hard to measure and even harder to respond to if you learn that you are not meeting them. Consider that new skills and knowledge often precede changes in behavior and health status. It may be more realistic to measure these, especially if your program is relatively new. Sample outcomes for peer support programs are listed in the table below.

**STEP THREE: SPECIFY MEASUREMENTS FOR YOUR OUTCOMES.**

Once a program has identified an outcome or outcomes it wishes to evaluate, the next question to ask is: how will we know if our clients are making changes we have identified? There are many ways to measure the changes that clients are making. Some of the commonly used tools are knowledge assessments, surveys, client interviews, focus groups (with participants or with peer leaders), direct observation, and chart reviews. Programs need to identify the type of tool to be used to measure outcomes, the time frame for collecting information, the clients they will assess and the parties responsible for collecting and interpreting the data. Programs should identify a threshold number of sessions or months participation through which they would expect a client to demonstrate some benefits from the program and assess only those clients (e.g., those who have been in the program for at least six months, who have attended at least four sessions in the fiscal year, etc.). Sample measurements are included along with the examples of outcomes in the table below. Programs are encouraged to use these outcomes and measurements and adapt them to fit their needs.

#### **STEP FOUR: PREPARE TO COLLECT INFORMATION.**

Develop the appropriate tools that your program will use to measure client outcomes. Keep it simple and concrete. Design specific questions for knowledge assessments, focus groups, surveys, or interviews, and consider planning direct observations that directly relate to the outcomes that you will measure. Decide who to sample: will you evaluate every client who meets certain criteria or a random sample of a number of clients? If you choose to ask only select clients, invite clients based on a random factor (every third name in alphabetical order, for example). Do not only choose the clients who are most responsive or seem to have had the best—or worst—experience in the program. Below are some aspects to consider:

*Validity:* How close does your question get to assessing what the client is experiencing? Suppose you wanted to know whether a program had improved a client’s self-advocacy skills. You could ask, “the last time you went to the doctor, did the doctor answer all of your questions?” Clients’ responses might be interesting and important, but may not give an indication of self-advocacy skills. What if the doctor happened to touch on the client’s concerns while the client sat silent and listened? What if the client brought a friend to advocate on his or her behalf? What if the client did not ask any questions, so felt he or she couldn’t say that the doctor failed to answer questions? To be valid, a question has to measure what it is intended to measure. A better question may be, “the last time you went to the doctor, did you ask the questions that you wanted to have answered?”

*Reliability:* If you ask a question multiple times or multiple ways, do you get the same answer? Does everyone interpret the question the same way? To maximize reliability, avoid asking questions with response patterns such as most of the time, some of the time, rarely, or never. Instead, ask this type of question: how many times in the last month did you have sex? How many of those times did you or your partner wear a condom?

*Bias:* Does something about the question or the way it is asked lead people to respond in a certain predictable way, regardless of the truth? If conducting interviews, ask all questions of all clients, and phrase them consistently. Try not to lead participants to think one response is ‘better’ than another. Make every effort to have a focus group conducted by someone outside of the program.

Appropriateness: Think about reading level, linguistic proficiency, and cultural relevance.

**STEP FIVE: IMPLEMENT YOUR EVALUATION PROCESS.**

Pilot test your data collection methods with a small group before introducing them. This will help you determine if the questions are clear and easy to understand, if the length of the tool is appropriate, and if clients are willing to participate. Ask pilot participants for feedback. Revise the tool as necessary.

**STEP SIX: ANALYZE AND INTERPRET YOUR FINDINGS.**

Consider the information you have collected and start to draw conclusions: are you meeting your outcome goals the way you expected? Include consumers, peer leaders, and staff in the process of interpreting findings. Conclusions should not be drawn based on patterns in the data alone; it is important to consider contextual factors as well. For example, in analyzing the data, ask: why do these patterns exist? What do they mean? Are there other possible explanations for the results we are finding?

Investigate both successes and concerns as both are important. For successes, understanding what works and why can help you to refine the focus of your program and develop best practices that can be useful for your program and others across the state. If the program is not achieving the intended results, it is vitally important to understand why in order to adapt the program. Some questions in order to identify why a program may not be achieving its intended outcomes include the following:

- Are the people using the program those anticipated? (Review demographic and utilization data.)
- Is the program being implemented as intended? (Consider the elements of the intervention described in Step One as essential to bringing about your outcome; are they taking place?)
- Is the content relevant to client needs? (Conduct focus group or interviews.)
- Is the program culturally competent? (Conduct focus groups or interviews.)
- Is staff adequately trained? (Conduct staff knowledge assessments, participant focus groups, or interviews.)
- Are health messages clear? (Conduct focus groups or interviews.)
- Are there external factors at play? (Conduct focus groups or interviews.)

**STEP SEVEN: USE YOUR FINDINGS TO REFINE YOUR APPROACH.**

Now that you have identified and explained your challenges and successes in meeting program outcomes, you are ready to adapt your programming according to those findings. Now begins the

process of planning for immediate and future change. Convene consumers, peer leaders, and staff and share your findings with them—both successes and challenges. Strategize around a plan to reinforce and build upon successes and to combat challenges. What program-level changes will be needed to meet your outcome goals even more fully in the future? Once you have a plan, set it in motion.

### Sample Outcome and Measurement Statements

Outcome	Measurement “as measured by”
Clients know about HIV/AIDS and treatment	The proportion of clients who know specified information (e.g., modes of transmission, opportunistic infections, treatment options, etc.) regarding HIV/AIDS and treatment <u>Method of data collection:</u> knowledge assessment <u>Time frame:</u> to be conducted after every six week peer support session <u>Population to assess:</u> all clients who have participated in at least 4 group support sessions
Clients know harm reduction techniques associated with sexual and/or drug using behaviors	The proportion of clients who know how to reduce the harm associated with specified sexual and/or drug using behaviors <u>Method of data collection:</u> knowledge assessment <u>Time frame:</u> to be conducted annually (March) <u>Population to assess:</u> a sample of 50 clients who have participated in at least 4 group support sessions
Clients feel a sense of community	The proportion of clients who express feeling part of a community as a result of attending peer support groups <u>Method of data collection:</u> client survey <u>Time frame:</u> to be conducted annually (June) <u>Population to assess:</u> all clients who have participated in at least 4 group support sessions
Clients reduce feelings of isolation	The proportion of clients reporting feelings of isolation <u>Method of data collection:</u> pre- and post- intervention survey <u>Time frame:</u> pre-intervention survey to be given at the beginning of the intervention (September) and post-intervention survey to be given at the end of the intervention (December) <u>Population to assess:</u> all clients who participated in at least 7 of 10 sessions
Clients are involved in the community	The proportion of clients who report attending two or more community events/groups/meetings (*not counting the support group itself*) during the fiscal year <u>Method of data collection:</u> chart review <u>Time frame:</u> end of fiscal year (June) <u>Population to assess:</u> all clients who participate in three or more sessions
Clients are able to negotiate disclosure (specify: with friends, doctors, sexual partners, family, etc.)	The proportion of clients who show mastery of disclosure discussions <u>Method of data collection:</u> role play scenarios observed by a peer leader <u>Time frame:</u> end of programming year (June) <u>Population to assess:</u> all clients who participate in three or more sessions
Clients feel confident in their ability to successfully disclose HIV status	The number of clients that report feeling confident in their ability to successfully disclose their status <u>Method of data collection:</u> survey following role plays <u>Time frame:</u> monthly <u>Population to assess:</u> all clients who participate in role plays

## Sample Outcome and Measurement Statements, continued

<p>Clients disclose HIV status</p>	<p>The proportion of clients who report disclosing their HIV status to someone new during the fiscal year  <u>Method of data collection:</u> client interviews  <u>Time frame:</u> end of fiscal year (June)  <u>Population to assess:</u> A sample of 20 clients who participate in three or more sessions</p>
<p>Clients feel a decreased sense of stigma</p>	<p>How clients describe experiencing stigma  <u>Method of data collection:</u> focus groups  <u>Time frame:</u> to be conducted at the end of the program year (June)  <u>Population to assess:</u> a sample of 10 clients who have participated in at least 4 group support sessions</p>
<p>Clients engage in self-care behaviors</p>	<p>How clients describe integrating stress relieving behaviors into their lives  <u>Method of data collection:</u> focus groups  <u>Time frame:</u> to be conducted at the end of the program year (June)  <u>Population to assess:</u> a sample of 10 clients who have participated in at least 4 group support sessions</p>
<p>Clients possess self-advocacy skills</p>	<p>The proportion of clients who demonstrate self-advocacy skills such as asking questions at doctors visits, requesting services for which client is eligible, etc.  <u>Method of data collection:</u> direct observation by peer navigator accompanying patient to medical and social service appointments  <u>Time frame:</u> to be conducted once a year  <u>Population to assess:</u> all clients who participate in three or more sessions</p>
<p>Clients develop personalized plans to improve adherence to medication regimens</p>	<p>The proportion of clients that develop a personalized adherence plan  <u>Method of data collection:</u> chart review of progress notes  <u>Time frame:</u> to be conducted November and May  <u>Population to assess:</u> all clients who attended at least 3 sessions</p>
<p>Clients have knowledge of strategies to improve adherence to medication</p>	<p>The proportion of clients who are able to list 3 or more adherence strategies  <u>Method of data collection:</u> written assessment (survey)  <u>Time frame:</u> end of programming year (June)  <u>Population to assess:</u> all clients participating in peer support for at least 6 months</p>
<p>Clients adhere to medication regimens</p>	<p>The proportion of clients who report adhering to their medication regimen at least 5 days a week to their one-on-one peer support provider  <u>Method of data collection:</u> chart review of progress notes  <u>Time frame:</u> to be conducted twice a year (December and June)  <u>Population to assess:</u> all clients who participated in one on one peer support for at least 3 months</p>
<p>Clients believe in their ability to navigate the HIV service system</p>	<p>The proportion of clients expressing feelings of confidence in their ability to get their needs met at a social service organization  <u>Method of data collection:</u> client interviews  <u>Time frame:</u> to be conducted quarterly by staff outside the peer program  <u>Population to assess:</u> a sample of 15 clients who participated in a minimum of three one-on-one peer support sessions</p>

## XI. APPENDICES<sup>8</sup>

### Appendix A: Traditional HIV Support Group: Health Promotion Model

<b>Outcomes</b>	<ul style="list-style-type: none"> <li>▪ Engagement in self-care behaviors</li> <li>▪ Self-efficacy to manage HIV disease</li> <li>▪ Decreased feelings of isolation</li> </ul>
<b>Settings</b>	<ul style="list-style-type: none"> <li>▪ Community-based organizations, including AIDS Service Organizations (ASOs)</li> <li>▪ Hospitals, clinics, community health centers</li> </ul>
<b>Description</b>	<p>This model is intended to serve individuals who are interested in coming to a safe, nonjudgmental space where they can share common experiences and challenges as people living with HIV and talk about strategies for promoting health. Discussions emerge from a range of issues that members raise about topics such as sexual health, relationships, communication, stigma, substance use, nutrition, isolation, and mental health. This model is designed to be low-threshold, flexible, and welcoming and offers both practical and emotional support.</p>
<b>Activities</b>	<ul style="list-style-type: none"> <li>▪ Facilitated discussions about experiences, feelings, and issues related to health and HIV</li> <li>▪ Exchange of ideas and self-care strategies that support physical and emotional health</li> </ul>
<b>Agency Inputs</b>	<ul style="list-style-type: none"> <li>▪ Peer leaders trained in support group facilitation</li> <li>▪ Meeting space</li> <li>▪ Client recruitment and retention</li> <li>▪ Administrative and clinical supervision</li> <li>▪ Internal and external referral mechanisms</li> </ul>

<sup>8</sup> Appendices D and E include content adapted from program models described in “Individualized Peer Support Program Assessment: Six Case Studies,” by Donna M. Bright, MSPH, ABD, JRI Health, September 2007.

## Appendix B: Educational Support Group: Psychoeducational Mental Health Model

<b>Outcomes</b>	<ul style="list-style-type: none"> <li>▪ Self-efficacy to manage mental health issues as they relate to HIV</li> </ul>
<b>Setting</b>	<ul style="list-style-type: none"> <li>▪ Hospitals, clinics, community health centers</li> <li>▪ Community-based organizations, including ASOs</li> <li>▪ Substance use programs</li> <li>▪ Mental health facilities</li> </ul>
<b>Description</b>	<p>The Educational Support Group that uses a psychoeducational mental health model educates participants about one or more mental health issues such as depression, addiction, stress, grief, loss, and anxiety. In this type of group, participants discuss how the experience of these issues impacts their lives as people living with HIV. Participants not only develop an understanding of the issues, but how to recognize and manage them as well. The theory behind psychoeducation is that the greater the understanding of the problem, the better control a person has over that problem. These groups create an environment that promotes information transfer and emotional support.</p>
<b>Activities</b>	<ul style="list-style-type: none"> <li>▪ Education about selected types of mental health issues and how to identify them</li> <li>▪ Facilitated discussions about how these mental health issues affect life and health</li> <li>▪ Development of strategies and skills for managing mental health issues</li> </ul>
<b>Agency Inputs</b>	<ul style="list-style-type: none"> <li>▪ One facilitator who is a mental health professional</li> <li>▪ One facilitator who is a peer leader</li> <li>▪ Meeting space</li> <li>▪ Administrative and clinical supervision</li> <li>▪ Internal and external referral mechanisms</li> <li>▪ Client recruitment and retention</li> </ul>

## Appendix C: Individual-Level Peer Support (Freestanding Service): Positive Prevention Model

<b>Outcomes</b>	<ul style="list-style-type: none"> <li>▪ Understanding of harm reduction techniques associated with sexual and/or substance use behaviors</li> <li>▪ Self-efficacy to engage in harm reduction behaviors</li> </ul>
<b>Settings</b>	<ul style="list-style-type: none"> <li>▪ Hospitals, clinics, community health centers</li> <li>▪ Community-based organizations, including ASOs</li> </ul>
<b>Description</b>	<p>The prevention model can be highly structured with a specific, reputationally strong curriculum, or can be more formative. Either approach must have a particular focus on behavior change and must use harm reduction as a framework. Peer leaders work with clients to complete detailed client assessments, increase awareness of behaviors and their impacts, consider client goals, explore client motivation for change and barriers to change, provide factual information, discuss risk reduction and health promotion strategies, and engage in skill-building activities. Topics addressed may include, but are not limited to, risk reduction skills and practices, disclosure, relationships, experience of stigma, treatment adherence, engagement in medical care, etc. Peer leaders should be trained in the use of risk reduction materials and should have the capacity to offer these supplies to clients. Some prevention programs include follow-up sessions after the main intervention is complete.</p>
<b>Activities</b>	<ul style="list-style-type: none"> <li>▪ Service-specific behavioral risk assessments</li> <li>▪ Individual sessions including education, discussion, and skill-building</li> <li>▪ Provision of risk reduction supplies</li> <li>▪ Supported referrals to HIV Partner Services and other services</li> <li>▪ Emotional and practical support</li> </ul>
<b>Agency Inputs</b>	<ul style="list-style-type: none"> <li>▪ Trained peer leaders</li> <li>▪ Curriculum, if applicable</li> <li>▪ Meeting space</li> <li>▪ Administrative and clinical supervision</li> <li>▪ Client recruitment and retention</li> <li>▪ Internal and external referral mechanisms</li> </ul>

## Appendix D: Individual-Level Peer Support (Interdisciplinary Team): Linkage to Care Model

<b>Outcomes</b>	<ul style="list-style-type: none"> <li>▪ Access to and regular engagement in medical care</li> <li>▪ Self-efficacy to manage HIV disease</li> </ul>
<b>Settings</b>	<ul style="list-style-type: none"> <li>▪ Hospitals, clinics, community health centers</li> <li>▪ HIV counseling, testing, and referral programs</li> <li>▪ Community-based organizations, including ASOs</li> </ul>
<b>Description</b>	<p>This model helps clients engage in care by providing support to individuals who are newly-diagnosed, who are aware of their HIV status but have not entered care, who have dropped out of care, or who are episodically in care. Peer leaders are trained to recognize common barriers to engagement in care such as substance use, mental health issues, poverty, and homelessness. HIV-positive individuals are referred to peer leaders upon learning of their HIV diagnosis, or when medical providers, case managers, or other providers determine that they would benefit from additional support to stay connected to care. After a linkage to care is firmly established, the program provides ongoing services related to engagement in care (practical and emotional support, reminder phone calls, etc.). This model works best using an interdisciplinary team approach.</p>
<b>Activities</b>	<ul style="list-style-type: none"> <li>▪ Community outreach, focusing on venues where target populations are likely to be found</li> <li>▪ Informal assessment of client’s immediate needs</li> <li>▪ Supported referrals to medical care and support services</li> <li>▪ Basic HIV education</li> <li>▪ Emotional and practical support</li> <li>▪ Case conferencing and communication with interdisciplinary team</li> </ul>
<b>Agency Inputs</b>	<ul style="list-style-type: none"> <li>▪ Trained peer leaders</li> <li>▪ Client recruitment and retention</li> <li>▪ Administrative and clinical supervision</li> <li>▪ Internal and external referral mechanisms</li> <li>▪ Strong internal service coordination mechanisms</li> </ul>

**Appendix E: Individual-Level Peer Support (Interdisciplinary Team): Treatment Adherence and Self-Care Education Model**

<b>Outcomes</b>	Self-efficacy to manage HIV disease Self-efficacy to adhere to medication regimens Engagement in self-care behaviors
<b>Settings</b>	<ul style="list-style-type: none"> <li>▪ Hospitals, clinics, community health centers</li> </ul>
<b>Description</b>	This is a structured, curriculum-based intervention in which peer leaders orient clients to adherence services, engage clients in discussions about their needs, provide basic HIV treatment education, develop individualized adherence plans in conjunction with clients, monitor the plans, and provide the practical and emotional support necessary to implement the plans. This model works best in a clinical setting where there is team-based collaboration between peer leaders and medical providers, case managers, nutritionists, social workers, and other staff.
<b>Activities:</b>	<ul style="list-style-type: none"> <li>▪ Client assessment</li> <li>▪ Treatment education and treatment plan development and monitoring. Topics are tailored to the individual client and may include the following: <ul style="list-style-type: none"> <li>-<i>HIV 101</i>: the peer leader discusses areas such as HIV terminology, HIV transmission, and the importance of adherence.</li> <li>-<i>Understanding Basic Labs</i>: with the client’s lab results, the peer leader helps the client understand the purpose of each test, how to interpret the results, and potential strategies for improvement (e.g., better adherence, nutrition, etc.).</li> <li>-<i>Medications</i>: this topic addresses drug classes and medications, why drugs are taken in combination, potential side effects and strategies for their management, etc.</li> <li>-<i>Resistance/Adherence</i>: the peer leader explores the connection between adherence and resistance and works with the client to explore barriers to adherence and potential adherence strategies.</li> <li>-<i>Miscellaneous</i>: the peer leader may cover additional topics as relevant such as HIV and pregnancy, lipodistrophy, disclosure of status or other topics particularly relevant to the client.</li> </ul> </li> <li>▪ Help preparing for appointments, thinking of questions, thinking of role plays, accompanying clients to appointments, and modeling effective communication.</li> <li>▪ Case conferencing and communication with interdisciplinary team</li> <li>▪ Emotional and practical support</li> </ul>
<b>Agency Inputs</b>	<ul style="list-style-type: none"> <li>▪ Trained peer leaders</li> <li>▪ Administrative and clinical supervision</li> <li>▪ Reputationally strong curriculum</li> <li>▪ Access to medical records</li> <li>▪ Internal and external referral mechanisms</li> <li>▪ Strong internal service coordination mechanisms</li> <li>▪ Client recruitment and retention</li> </ul>



