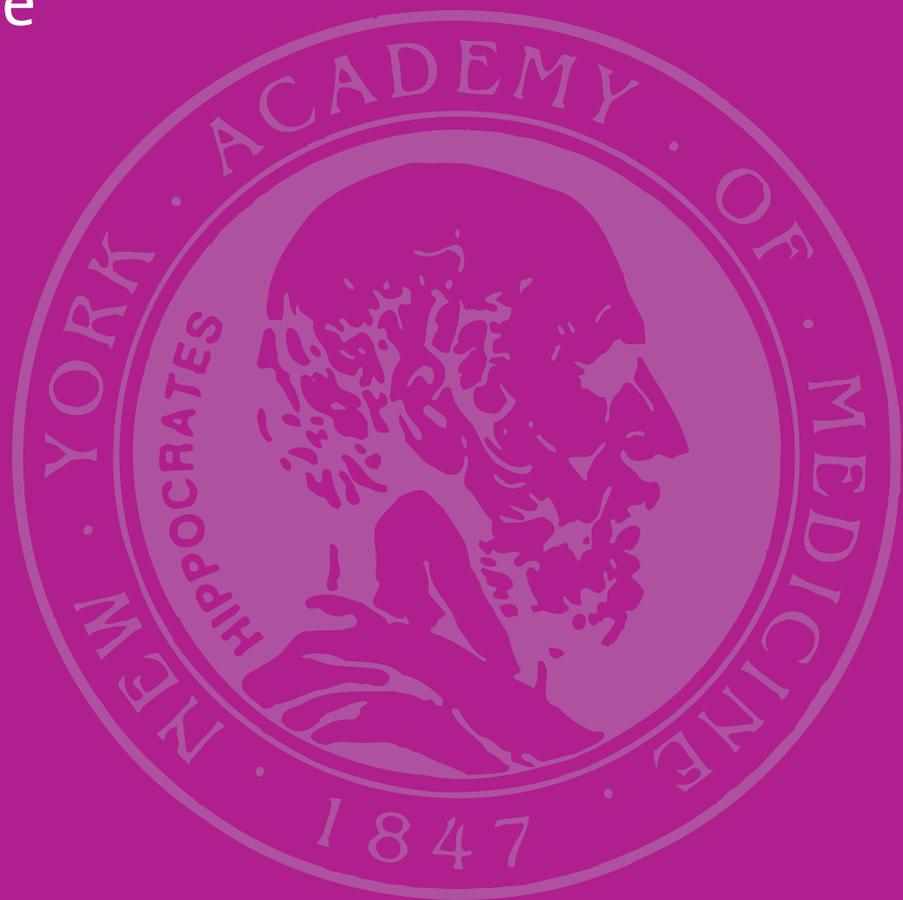


Breaking Barriers:

A Toolkit For Getting
and Keeping People
In HIV Care



New York Academy of Medicine

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What is This Manual About?

THIS MANUAL IS A COMPILATION OF STRATEGIES USED BY 23 NEW YORK PROGRAMS designed to serve people living with or at high risk for HIV infection, and who are inadequately connected to medical care or not receiving it at all. Our programs aim to eliminate barriers to care and to provide access to or strengthen a weak connection to medical care. What is unique about our programs is that we seek out and work with populations that often “fall through the cracks” in a regular case management setting. Although we mainly target people of color, our approaches will be relevant to serving a wide range of people who are not in care or poorly connected to care. The manual is geared for providers who would like to work in or start a program similar to the Access-to-Care (ATC) and Maintenance-in-Care (MIC) programs featured here; and for providers who are looking for new ideas about how to reach and retain these vulnerable populations in medical care. The topics that will be covered in this manual are the following:

- Planning your program
- Hiring, training and supporting providers who will work on staff
- Conducting outreach and connecting clients to medical care
- Maintaining clients in medical care
- Working with special populations
- Evaluating and updating your program

About the ATC and MIC Programs

About the ATC and MIC Programs

Based in New York City and Westchester County, our ATC and MIC programs are located in 23 agencies that receive funding through the Congressional Minority AIDS Initiative. The Minority AIDS Initiative (first known as the “Congressional Black Caucus Initiative”) began in 1998 in response to the disproportionate HIV/AIDS crisis in racial and ethnic minority communities. Through this initiative, supplemental funds are provided to HIV/AIDS service agencies for the purpose of connecting HIV+ or at-risk people of color to medical care, or to strengthen a weak connection.

ATC programs and MIC programs are housed in three different types of settings: community-based organizations (CBOs), hospitals, and community health centers (CHCs). Our programs are located in the Bronx, Brooklyn, Manhattan, Yonkers, and Mount Vernon. Some are stand-alone programs within their institutions, and others are integrated into larger programs. The larger programs within which the programs are integrated include HIV specialty clinics, HIV case management/social services programs, harm reduction programs and drug treatment programs.

The 23 ATC and MIC programs that have participated in compiling this manual have amassed a wealth of expertise in serving HIV+ or at-risk people of color over the past seven years. Many of the programs are housed in agencies that have served this population for much longer. Together, the 23 programs serve more than 3,500 clients each year providing them with more than 50,000 services. An outcome evaluation that all the programs participate in shows that they are successful in helping clients achieve important goals that impact health, such as entering into stable housing, stopping or reducing drug use, and initiating HIV medical care and anti-retroviral medication. The evaluation also shows that overall, clients in these programs experience significant improvements in health-related quality of life.

ATC and MIC program staff are people who have been trained to engage clients, and to assess and help remove barriers to care, in order to help clients connect to and stay in medical care. Often each staff person has a different specialty, and staff members work together as a team – for example some staff members may specialize in engaging clients, while others may specialize in navigating the health care system. MAI program staff consist of (but are not limited to):

- Outreach workers
- Peer workers
- Social workers
- Case managers
- Mental health specialists
- Nurses
- Nurse practitioners
- Physician’s assistants
- Project coordinators
- Substance use counselors

If you already have a program that has been set up to provide services for clients, but you want ideas on how to identify, reach, and engage clients who have a poor or non-existent connection to care, turn to “Conducting Outreach and Connecting Clients to Care” (page 36) for a description of our strategies. If you haven’t started a program yet, or are still setting it up, the next section describes how to plan a successful program.

Planning Your Program

Planning Your Program

Your program, like any complicated but worthwhile effort, is more likely to be successful if you do your planning and groundwork carefully before starting to deliver services. While it is important to be flexible and adjust your approach based on your real-time experiences once you get started, a solid foundation helps any structure to “get off the ground.”

In this section, we will take a look at the four legs that support a successful program: (1) an understanding of the **population(s)** you plan to serve; (2) an understanding of your **funding source** and your **agency**; (3) an understanding of **legal issues** related to serving your population; and (4) an understanding of the available **resources** (financial, material, personnel, intra-organizational and community) you have to work with. Please note that while we focus on programs that serve HIV+ or at risk clients because that is our area of expertise, our strategies may have applications for programs dealing with different types of populations,.

Understanding the **POPULATION** you are serving

Planning whom to target for your program starts with the question, “Who is in the community?”

If you want to design a program that offers access-to-care services for people previously undiagnosed with HIV, or maintenance-in-care services for people who are already diagnosed with HIV, you must first identify who are the high-risk and most heavily affected populations in the area you wish to serve.

Let's start with risk factors.

HIV is most prevalent among groups of people who, for reasons that vary from group to group, engage in high-risk behaviors. Just who those people may be will vary from community to community, and they may be representative of more than one ethnic or behavioral group in any one community. For example, in less heavily populated areas, or in smaller single-ethnicity neighborhoods within a larger catchment, there may be a single heavily affected population. In large urban catchments there may be many ethnic groups with a number of behavioral risks within a few square blocks. Groups of people who are HIV+ vary from place to place and it is important to assess which groups in your local area engage in high risk behavior. Your local population with high-risk behaviors may include, for example, injection drug users of several ethnicities; recent immigrants with little HIV prevention information available in their language(s); men who have sex with men; women; and adolescents. Of course it's important not to make assumptions about who is doing what. But a data-based assessment may help you target your program.

Remember that HIV is spread by risky behavior, and not because one is part of a particular ethnic group. Affected persons within any one ethnic group will reflect a range of behaviors. There is as much diversity of behavior within any single ethnic group as there is within any other, and within society at large.

Planning Your Program

“Groups” also have looser boundaries than we sometimes realize. The two greatest transmission factors for HIV, sexual fluid transmission and blood exchange through needle sharing, involve human social and sexual behavior that is very basic and often crosses religious, socioeconomic, racial/ethnic, sexuality, cultural and language and other group-defining lines.

i

In sizing up your population, the companion question to “Who is in the community?” is “What are they doing, and with whom?”

Once you have a good idea of your target community and with whom the people in it interact, it is important to understand the cultures, values and traditions of the community. Your understanding and the proper use of it will be your admission ticket to the group of people you want to reach. While all human beings have similar survival needs and common vulnerabilities to sickness and suffering, we all have different ideas about how we should conduct our lives in order to survive and to avoid illness and suffering. If you present your program in a way that is contrary to what your target population believes will help it, it will reject your help. You do not need to pretend to be a cultural “insider,” or to adopt ways that are foreign to you, but you will need to understand the culture and beliefs of your clients. That way you will know what is important to them, and you will be able to form a bridge between what they believe and what you want to offer them. Some aspects of your program can be geared to deliver services in a context that is familiar and comfortable. Some aspects of your program may not be. However, conveying your understanding of their discomfort and how the new situation may feel to them could be all that is needed to put potential clients at ease and to establish trust. For more information on cultural competence and on different populations that we encounter in our work, see “Cultural competence, client-centeredness and a non-judgmental approach” on page 50 and “Working with Special Populations” on page 97.

Understanding your **FUNDING SOURCE** and your agency.

The second leg supporting a successful program is an understanding of your funding source and the mission and values of your agency. If your program’s mission does not fit in with the goals of your funding source, you will lose your funding. If your program’s mission or design runs counter to how the agency functions as a whole, it will be difficult for your program to survive.

While you have some leeway in creating your program, you must be sure to include what your funder has contracted you to do, and whatever documentation is required to demonstrate to your funder that contracted work has been accomplished. It is important to be aware of the terms of your contract – requirements, for example, such as how many services you are to provide, how many clients you are contracted to see, how you are budgeted to spend the money – and to **share relevant information with each service provider**. If there are no guidelines, front-line service providers may unwittingly provide the services they feel are important, while losing sight of what they have been funded to do. Also, staff need to document services in a way that will give you credit from your funder. It is important to agree on how your program’s work will be documented, how you expect your staff to do this work, and how often you expect them to do it. It is also useful to have someone in a supervisory capacity in your program monitor how your work is being documented and do an independent assessment about whether your targets are being met, without waiting for the end of a reporting period. You can also use program audits conducted by your funder as a guide for what your program should

Planning Your Program

contain, but it is important to know before a site visit from your funder if you are meeting contract requirements. If you don't identify and correct problems proactively, before the site visit or the end of the reporting period, problems identified at the end of the reporting period or at the site visit may have already progressed to the point where they can have a negative effect on your funding. Have periodic meetings with staff to update them on how they are doing. Your work depends on your funding, and you must prove to your funder that you are doing what you were contracted to do.

Your program's mission and policies should reflect not only your funding requirements but also your agency's ethics, values and policies. In selecting staff for your program or planning to work as staff in a program it is important to be aware of the policies and ethical standards of the agency, plus any relevant local legal requirements (see "Understanding legal issues related to serving your population" on page 15).

The following steps can help you to stay abreast of agency policy:

- If you are a policy leader in your agency, clarify the ethical and legal standards to be met, and develop clear Policies and Procedures for your program to reflect this
- If you are unsure what your agency's policies and procedures are, ask your supervisor. Consult the Human Resources Department regarding personnel policies
- If you have a quality improvement/assurance component in your agency, consult people in that department. It's their job to improve what the agency does, and they should have information on important guidelines to adhere to
- Keep yourself up to date on issues affecting your agency, your clients, and your staff. Be aware that things are always changing. Policies change, drugs of choice change among substance users, HIV meds change and so on. Your program's needs may conflict at some point with the values of the agency even if they don't right now. An awareness of what agency policies are combined with openness to dialogue can help you negotiate the need for change more effectively

Sometimes your views may differ from those of your agency's leadership, and in some cases, the leadership's views will impact how you are able to work with clients. One area in which this often occurs is in working with clients around substance use, since agencies' philosophies regarding substance use among clients span the range from harm reduction to zero tolerance. A useful question to ask is, "What is my agency's philosophy towards substance users?" For instance, does your agency require that they completely stop using before you provide services for them, or does your agency encourage you to use a harm reduction approach? Some agencies require sobriety as a prerequisite for services, while others use a harm reduction approach. Providers who do not embrace harm reduction may be more comfortable working in an agency that follows abstinence-only guidelines. (For more information about harm reduction, please turn to Appendix A, "Harm reduction versus zero tolerance" on page 123). Both approaches to addressing substance use have their strengths and limitations. If there are certain issues that you feel strongly about, or an approach that you have been trained in, it is important to know what the agency's stance is, to ask yourself how flexible you are (or are not), and to make decisions from there.

Planning Your Program

Understanding **LEGAL ISSUES** related to serving your population

It is crucial that you understand the legal issues surrounding providing services to your target population. Failure to comply with legal requirements may compromise your clients, your job as a service provider, and can do damage to the institution you work for. In extreme cases, your license to do certain types of work may be revoked, or you may have to pay a fine or serve jail time.

Legal requirements vary by state and municipality, and they change over time. For this reason, it is important to inform yourself about your local laws, and to keep up to date with the legal requirements for your program. Your local department of health and your funder may have information about these laws.

An associated concern, risk management, refers to managing liability you may have as a result of program activities. The following are some examples of the legal and risk management issues that affect our programs and ways we have addressed them. Please note that they serve only as examples, and that you should check locally about your legal issues and requirements.

HIV Confidentiality

New York State Confidentiality Law and HIV

Public Health Law, Article 27-F

“No person who obtains confidential HIV related information in the course of providing any health or social service or pursuant to a release of confidential HIV related information may disclose or be compelled to disclose such information, except to the following:

the protected individual or, when the protected individual lacks capacity to consent, a person authorized pursuant to law to consent to health care for the individual;

any person to whom disclosure is authorized pursuant to a release of confidential information;

an agent or employee of a health facility or health care provider if 1) the agent or employee is permitted to access medical records, 2) the health facility or health care provider itself is authorized to obtain the HIV related information, and 3) the agent or employee provides health care to the protected individual, or maintains or processes medical records for billing or reimbursement;?

a health care provider or health facility when knowledge of the HIV related information is necessary to provide appropriate care or treatment to the protected individual or a child of the individual...”

Laws were put in place to protect client confidentiality because a breach of confidentiality can seriously endanger clients' mental health, physical health, work, housing, relationships and other important aspects of their lives. Confidentiality therefore plays a substantial role in clients' trust and work with providers. HIPAA (the Health Insurance Portability and Accountability Act of 1996) is an example of federal regulations that protect client confidentiality. While the New York State HIV Confidentiality law is local, HIPAA is national in scope and applicable wherever in the US your program is located.

Planning Your Program

How you maintain client confidentiality will be specific to your institution and how it handles information, and to the laws that are in place in your state. However, that said, our agencies have found the following steps useful in trying to ensure client confidentiality.

- 1) Speak with clients in a private space so that others cannot hear. If a private space is not possible, items like a noise machine can help drown out your conversation with clients and can help them feel like the space is more private
- 2) Have all personal information about your clients locked up. If information is contained in a computer, only authorized users should be able to access it – information is often protected through the use of passwords
- 3) If information is to be released to third parties, clients must sign a consent form showing that they give their permission for this to happen. Usually the consent form states what type of information will be released, to whom, and has an expiration date for the release of information
- 4) Do not talk about clients with people who are not authorized to have confidential information about the clients. People who are authorized to have confidential information are usually people such as other medical providers, insurance companies, and parents or legal guardians of children under 18. Check your local confidentiality regulations for who authorized people are and when a signed consent form from clients is necessary for you to talk to others about their health. When talking about clients with people who are authorized to have confidential information about them, it's important to speak about them in a private place where no one can overhear your conversation. Speaking in hallways about clients, for example, runs the risk of others overhearing your conversation, and jeopardizes the confidence clients have in you and in the institution
- 5) If you receive confidential information about a client from another provider, do not share this information with others unless you are authorized to do so
- 6) When working on a client's medical or other chart, put it face down when other people walk by or come into the vicinity. The names and medical record numbers on the charts must not be revealed to others
- 7) Have a grievance procedure in place. If clients have any complaints about confidentiality not being maintained, have them file a grievance. Document and address the complaints and outcomes

Planning Your Program

Some scenarios you may want to watch out for

Clients' partners, family and other people in their social circle sometimes come in and demand to know information they have revealed to their providers. Guard against people saying they are authorized to know information about your clients because they are a husband, wife, girlfriend, boyfriend, mother, father, friend, boss, etc. Someone may try to convince you of his or her right to know based on his or her legal relationship to your client. One of our agencies, for instance, had a case of a husband bringing in his marriage certificate to prove that he was the client's husband, and that therefore he had a right to know anything he wanted.

A way to handle such situations is to tell the people who ask that you cannot verify whether the person they are asking about is a patient or not; and any information you have about your patients is confidential, and by law, you cannot talk about it. If they want to obtain any information, they should ask the person they are referring to directly.

Sometimes clients will disclose information that they don't want shared with their medical doctor or other service providers on the treatment team. They may believe that confidentiality includes keeping medically relevant information off the record even within the team. The way to handle this is to avoid it in the first place by being very clear from the beginning about how you define confidentiality. For example, we tell our clients that while we will not share any information they tell us with their family, friends, boss, landlord, or anyone else in their social or professional circle, within the Access-to-Care/Maintenance-in-Care program, a team approach is employed. We further explain that we work together as a team with other providers to get clients the care and the help they need, which means sharing the information we have within our team.



Beware of questions or statements like:

- *Do you know a particular client? (the person asking will make assumptions based on your answer)*
- *Why does the client come to this program?*
- *Did the client have an HIV test?*
- *What are the results of the HIV test?*
- *I know all about her HIV status; how's she doing now? (fishing for HIV status or other information by convincing you he or she knows personal information about the client already.)*

Be sure when you develop your policies and procedures that you clearly identify the need for sharing relevant information with insurance companies so that they can pay for services the client needs, the legal obligation to do it, and the mechanism for doing it.

Informed Consent Procedure for Getting an HIV Test

New York State requires that certain procedures be followed if individuals would like to get tested for HIV. One such procedure is that individuals must read and/or be counseled about, understand, and sign the New York State Department of Health form, *Informed Consent to Perform HIV Testing*, before taking the test. The following is an excerpt of concepts discussed in the consent form and in-person with an HIV pre- and post-test counselor before the test:

Planning Your Program

- *HIV is the virus that causes AIDS*
- *The only way to know if you have HIV is to be tested*
- *HIV testing is important for your health, especially for pregnant women*
- *Anonymous and confidential HIV testing is available*
- *State law protects the confidentiality of test results and also protects people who have been tested from discrimination based on their having been tested and their HIV status*
- *Methods of preventing transmission*
- *Persons who test positive are asked to cooperate with partner notification efforts to let those exposed to HIV become aware of their need to have an HIV test. Help notifying partners is available. The name of the person who tests positive, or any other identifying information, is not revealed to the partner*

Many localities have similar procedural requirements for obtaining consent for HIV testing. Be sure to know your local legal guidelines when offering HIV testing as part of an Access-to-Care program.

Some risk management considerations related to HIV antibody testing

- Clients agree to be tested, but do not want to go through the informed consent procedure required to take the test. Either they don't want to sit through listening to information about HIV/AIDS, or they do not want to sign any documents, or they don't want to answer questions or give out any personal information. We generally handle these types of clients by telling them that we are legally required to follow HIV testing procedures, otherwise, we cannot administer the test. We also tell them that while we do not provide anonymous testing, their information will be kept strictly confidential. Generally clients consent after hearing about our procedures regarding confidentiality. If clients prefer to remain anonymous, we refer them to a department of health testing site for anonymous testing. Where applicable, your clients should be counseled about the availability of anonymous testing and the benefits, in terms of accessing follow-up care, of confidential testing.
- Sometimes clients want to take the HIV test, but indicate that they would not be able to handle a positive diagnosis when we ask them questions such as, "how would you react if you found out you were HIV+?" They say that they will kill the person who gave it to them, for example, or that they will kill themselves. **In these cases, we cannot give them the HIV test.** We refer them to counseling until they are emotionally ready to handle the results. Some approaches to assessing suicidality or homicidal intent are given below. Your Policies and Procedures should include an assessment and follow-up process similar to those described below as part of a plan to limit the liability of your agency if a client responds adversely to the test result.

Planning Your Program

Dealing with a suicidal or a homicidal person

Suicide

In this section, we will include guidelines from the Depression and Bipolar Support Alliance on responding to an emergency situation, and we will share some of our procedures for handling a suicidal client. Please note that, as with other areas we have discussed, legal and procedural requirements surrounding suicidal clients vary according to the agency you work with, professional affiliation and state regulations. We urge you to acquaint yourselves with your agency policy, professional standards and state laws surrounding this issue.

Responding to an Emergency Situation

If someone is threatening to commit suicide; if someone has let you know they are close to acting on a suicidal impulse; or if you strongly believe he or she is close to a suicidal act, these steps can help you manage the crisis.

- *Take the person seriously. Stay calm, but don't under-react*
- *Involve other people. Don't try to handle the crisis alone or jeopardize your own health or safety. Call 911, if necessary. Contact the person's doctor, the police, a crisis intervention team, or others who are trained to help*
- *Express concern. Give concrete examples to the person of what leads you to believe that he or she is close to suicide*
- *Listen attentively. Maintain eye contact. Use body language such as moving close to the person or holding his or her hand, if appropriate*
- *Ask direct questions. Find out if the person has a specific plan for suicide. Determine, if you can, what method of suicide is being considered*
- *Acknowledge the person's feelings. Be understanding, not judgmental or argumentative. Do not relieve the person of responsibility for his or her actions*
- *Offer reassurance. Stress that suicide is a permanent solution to a temporary problem, reminding the person that there is help and things will get better*
- *Don't promise confidentiality. You may need to speak to the person's doctor in order to protect the person from him or herself*
- *Make sure guns and old medications are not available*
- *If possible, don't leave the person alone until you are sure they are in the hands of competent professionals. If you have to leave, make sure another friend or family member can stay with the person until they can receive help*

(Excerpted from Depression and Bipolar Support Alliance, www.dbsalliance.org.)

Planning Your Program

There is a useful mnemonic device to help practitioners remember common risk factors, “SAD PERSONS”:

S ex:	Males more often complete, females more often attempt
A ge:	Teenage years and age > 45 years
D epression:	Hopelessness, despondency, muted affect
P rior attempts/ prior mental illness:	Personal or family history
E mployment:	Change or loss of job, retirement
R ecent stressors:	Multiple losses, or separation, severe anxiety, irritation, violence
S ubstance abuse:	Especially alcohol dependence
O rganic disease:	Failed medical treatment or first hospitalization for organic disease, chronic pain from organic disease
N ote written stating intention of suicide	Or similar behaviors such as having and stating a means of suicide and/or giving away possessions
S ingle, widowed, or divorced	

(from Patterson WM, Done HH, Bird J, Patterson GA. Evaluation of suicidal patients: The SAD PERSONS Scale. *Psychosomatics* 1983; 24:343-345.)

If there are mental health professionals in your agency use them as a referral source for further psychological assessment. If you don't have a mental health worker at your agency, the suicidal client should be brought to the nearest emergency room. If your agency provides escort and advocacy services, arrange for the client to be brought to the hospital; otherwise call 911 and explain the situation.

After the client is safe make sure the incident is well-documented in the client's chart and make sure to process the situation with your supervisor.

Homicide

Our agencies don't have many homicidal clients. Some agencies do not deal with clients who have a propensity towards violence, while others sometimes see clients who are violent or who have a history of violence. When we have a client we suspect is an immediate danger to others, we call the police, we call our own security system, and we try to get the client out of other client and staff space. If the signs are more ambiguous, we alert all staff to keep an eye out for that particular client. We also check to see if the client has a history of violence. This gives an indication of whether the client is likely to be violent now. Again, if we suspect the client will be an immediate danger to him/herself or others, we call the police.

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Child abuse and domestic violence

We have taken the following definitions on child abuse and domestic violence from Understanding Violence Against Women (www.kwmc.on.ca/html/abuse.html), the Kids First Foundation (<http://www.kidsfirst.com.au/page.php?partid=68>) and My Sister's Place (<http://www.mysistersplacedc.org/whatis.asp>).

What is abuse?

Any act which puts another person down, any act which degrades or reduces a person's sense of self-worth; any act which mistreats and denies others' respect and dignity as valued people; any act which frightens another; any act of a physical nature including: pushing, grabbing, hair-pulling, hitting, kicking, punching, pounding tables and walls; any act of a sexual nature that is unwanted; any act which attempts to coerce using power and control over another human being.

Understanding Violence Against Women (www.kwmc.on.ca/html/abuse.html)

Child Abuse

Child abuse is any action (or lack of) which endangers or impairs a child's physical, psychological or emotional health and development. Child abuse occurs in different ways. All forms of child abuse and neglect are detrimental to the child, both physical and sexual abuse are crimes.

Child abuse may be physical, emotional, sexual, or the result of neglect.

Physical abuse *is any physical injury to a child which is not accidental and includes severe beating, shaking, burns, human bites, strangulation.*

Emotional and psychological abuse *occurs when a child is not nurtured and is not provided with love and security, or is not provided with the necessary environment to develop mentally, and includes constant criticism, belittling and persistent teasing.*

Sexual abuse *occurs when the child is involved in any sexual activity with an adult and includes fondling, exhibitionism, sexual intercourse, incest and pornography.*

Neglect *is depriving a child of their essential needs. These include nutrition, clothing, warmth and shelter, emotional security and protection, medical and dental care, hygiene, education, and supervision.*

Adapted from Kids First Foundation (<http://www.kidsfirst.com.au/page.php?partid=68>)

Domestic Violence

Domestic violence is a pattern of behavior used to establish power and control over another person through fear and intimidation. It happens between people who are or have been in an intimate relationship, and often includes the threat or use of violence. It happens when one person believes they are entitled to control another...and it is a crime. Domestic violence can take many forms. It can include emotional abuse, such as name-calling and put-downs, and economic abuse, when one person uses money and finances to control the other. Often an abusive partner may be sexually abusive, use or control the children, or threaten, isolate, or intimidate the other. All of these behaviors are used to maintain fear, intimi-

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ation and power. Not all of these behaviors — such as emotional abuse — are against the law, but none of them is acceptable...and no one deserves abuse.

My Sister's Place (<http://www.mysistersplacedc.org/whatis.asp>)

Reporting Child Abuse

As an example, we include below the policy on reporting child abuse from the Institute for Urban Family Health, one of our MAI agencies. As with every issue in this section, please inform yourself of your own agency's policy before taking any action.

New York State Law requires that all cases of suspected or actual abuse or maltreatment of children be reported. All clinical staff, or anyone who examines, attends or treats children are obligated to report these cases. The kinds of situations to report in addition to physical abuse or neglect are sexual abuse, medical neglect, or parental behavior indicating alcoholism, drug abuse or impairment of emotional health, the latter to the extent that it is believed that the safety of the child is seriously jeopardized.

When reports are made in good faith, the reporter is immune to prosecution. Health professionals need only to have reasonable cause to suspect abuse/neglect. In order to make a report, call the A Hotline: 1-800-635-1522.

Institute for Urban Family Health, Policy on Reporting Child Abuse

Identifying and addressing Domestic Violence

Indications of Abuse

Characteristics of partners who are abusive include wanting to accompany their partners to their appointments, jealousy, seeming overly concerned about a partner's whereabouts or fidelity, preventing their partners from going places or seeing people, answering questions for their partners or being overbearing.

Clients who are being abused will often miss many appointments, be anxious to leave at certain times, may describe their partner as jealous or overly concerned, may express fear of a partner or describe a partner as having anger problems. Most times clients with physical injuries will not have them in places we can see. They may appear as migraines, increased asthma attacks, gynecological problems, and generalized body aches.

Addressing Domestic Violence

It is never advisable to address abuse between individuals when they are both in your presence. It is dangerous for the worker, and almost always has consequences for the abused partner when they leave the office. It is advisable to address the abuse with the abused partner when they are alone. Asking very direct questions is best, for example,

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- “I am concerned for you and worry that you are being hit or hurt by your partner. Can I help you?”
- “I ask all my patients about whether or not they are being hurt in their relationship and I am concerned that you may be.”
- “I noticed that your partner is very jealous. Sometimes partners who are very jealous are hurtful at home. Is this happening to you?”
- “Does your partner ever say things to you that hurt your feelings, or about how you look or dress?”

Counselors should not ask if someone is being “abused” because what is abuse to one person is not abuse to another. Counselors should also not ask vague questions like, “are things OK at home?” It is better to be very specific.

When the client is the abuser, we work with the client on coping skills, anger management and understanding the damaging effects of abuse.

Staff often feel that they have to “do something” once someone discloses abuse. It’s important to recognize that choices for survivors are difficult. Offer choices, but never insist on them or pressure someone into services. Just give them the information, tell them about programs that can help, develop a safety plan with them, and have them come back. Also, know that simply listening to someone’s story can help.

Reporting Domestic Violence

While knowing that our clients are in abusive relationships and in danger is very upsetting, we are not required or mandated to report this abuse in NYC unless the client is a minor. If a worker knows that a client is abusing his/her partner, unless the client threatens to kill him/her, this information is also confidential and is not required to be reported. We must, however, report any stabbing or gunshot wounds clients may have received or been responsible for. Except when we are legally required to report, our policy is to honor clients' wishes regarding reporting their abuse. Be aware that your local regulations may differ from ours, or that New York may adopt a different policy at a future date.

Public Ordinances

There will be laws in your locality governing public behavior, such as sexual solicitation; drug possession, trafficking, sale and use; etc., which may affect your target population. There may also be some regulations affecting such benign activities as street outreach, leafleting, public gathering, and so on, that affect your ability to carry out program activities within the law. Be sure you know what public ordinances apply to you when you go out in the community, and follow them.

Undocumented immigrants

A 1986 federal law states that hospitals must treat all patients, including undocumented immigrants, in their emergency rooms. Regarding non-emergency care, policies vary by local area.

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Common fears of undocumented immigrants include the following:

- obtaining medical care at a healthcare facility will mean their undocumented status will be revealed and they will be deported;
- evidence proving they have a serious illness will lead to their deportation;
- applying to the AIDS Drug Assistance Program will compromise their position in the US.

In New York State, such fears are generally unwarranted. But protection for undocumented immigrants seeking medical care varies by state and local area.

Some of us who work with undocumented immigrants note that while many are eager to apply for Permanent Residence Under Color of Law (PRUCOL) because they think it will help them, they should learn about possible negative ramifications it could have for them, including closing off the option to apply for a green card at a later time. They should discuss these issues with a lawyer who is knowledgeable about these issues.

Addressing Client Concerns About Immigration Status

At our agencies, we are not mandated to share any information the clients give us with any federal office. Therefore, we can guarantee that all of their information will stay with our agency unless they sign papers giving their consent for us to do otherwise. We find that it is important to stress this over and over again with clients to allay their fears. In addition to being afraid they will be found out by a federal office, they are afraid of being exploited in general because many have experiences of being taken advantage of in the US. Therefore, we concentrate on establishing a relationship of trust with them, and helping them feel that this is a safe place for them to come.

If clients test positive for HIV, they are likely to be eligible to receive HIV medications and HIV primary care through the AIDS Drug Assistance Program, regardless of their undocumented status. It is often a challenge to get them to apply for this, however, because it requires that they disclose their HIV status to a separate agency. We address their concerns by telling them that ADAP does not share information regarding their undocumented status, or their HIV status, by law (in New York, executive order #41, and by the New York State law protecting confidentiality). Check the laws in your local area.

Some clients, on the other hand, are eager to disclose their undocumented status in the interest of applying for Permanent Residence Under Color of Law (PRUCOL). Once this status is obtained, clients can become eligible for additional financial support. They often will ask you to help them apply for this. However, in our experience, it is best to refer them to a lawyer who is experienced in these matters and who can counsel them regarding whether this is actually their best option. If clients have a history of substance use, or if they have been arrested, applying for PRUCOL means telling the government who they are, and where they live, making it easy for the government to deport them if it wants to. In addition, after September 11th, 2001, PRUCOL status is given much less liberally than it was before, and only after much scrutiny of the applicant. If clients do want to stay and live in the US, the best course of action is to assess their history, the likelihood of their getting approved for PRUCOL given the factors involved, and to speak with a lawyer experienced in these matters.

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Understanding the available resources you have to work with.

Knowing what resources are available, both outside and inside your organization, is useful for two reasons: first, so that you get a sense of who else is doing the work that you are doing. If not many people are doing the same kind of work, your program is likely to be necessary. If others are doing the work you are, but those programs are concentrated only in certain areas, your program is likely to be necessary in other areas. Even if other agencies are providing the same services, your program may still be necessary if available services are not adequate to meet the level of need. If you find that the work you would like to do is duplicative in some way, you may want to consider modifying your program accordingly to make sure it responds to an unmet need. Second, it's important to know what resources are available because your program will only provide a piece of what the client needs. In order to accomplish the goals of your program, it is very helpful to establish linkages and relationships with other agencies in your community that can help your clients in areas that your program does not address. Here are some suggestions that may be helpful in assessing resources that are out there.

- 1) Get directories and manuals from your area that will help acquaint you with the community and the population you want to target. For example, you can look at
 - Resource manuals or social service directories that list agencies in your community along with their address and what they specialize in
 - Information provided by your local health department
 - Information provided by your funding source. See what other programs are being funded in this area, for what clientele
 - The internet
 - Resource manuals that address a particular issue your clients may be facing, like HIV or Hep C. These manuals may contain important resources for the clients and for you to be aware of

- 2) Talk to relevant people and get involved in your community. This will not only help you to familiarize yourself with resources that exist and further assess the need for your services and the optimal way for them to be provided, but it will also let you familiarize the community with your program.
 - Join local coalitions and networks, and attend local community forums (gather and give information at these events)
 - Talk to neighborhood programs and community boards
 - Form a connection with your local police department. Participate in police meetings
 - Get in touch with neighborhood hospitals. See what they offer, find out about other programs they are aware of, and let them know about yours
 - Go out and talk to regular people in the community. Ask questions about your target population — what their needs are, where they reside, what their habits are. Pass out information about your program
 - Ask your clients about other programs they go to and what is helpful to them

Setting Up Your Program

Setting Up Your Program

Once you have a grasp of who you are trying to serve, your funder's requirements and agency's policies, the legal issues surrounding your target population, and the service and institutional environment around your program, it is time to make your program's mission a reality. You will want to staff your program; create an environment which will encourage staff to be productive and to communicate with each other and their supervisors; set up linkages with programs that provide services you do not; figure out the enrollment criteria for potential clients; and develop guidelines for their participation in your program.

STAFFING Your Program

The primary goal of our Access-to-Care and Maintenance-in-Care programs is to identify, engage, and retain HIV-infected persons in treatment, especially those who are hard to reach, have social and economic barriers to care or are in other ways at risk of “falling through the cracks” and not accessing and utilizing health care. We provide services and hire staff who will help us accomplish this goal. In developing your program design, all of the services you offer should be selected because they support your central goal. Program design and staffing go hand-in-hand; the program you design will determine the skills and qualifications you will need in staffing your program. In this section we will look at strategies for selecting staff and developing a good team.

Selecting Your Staff

Establish what qualities you need in a worker

Beyond job titles and credentials, it is important to know what kinds of people can fulfill the mission of your program and uphold the values of your agency. We all seek honest, trustworthy, and competent staff. The complexities of HIV also require that we explore people's values in some controversial areas in making staff selections. For example, an agency that supports zero tolerance with regard to substance use will not embrace a worker who feels strongly in favor of a harm reduction model. Similarly, a low-threshold drop-in center offering syringe access and bowls of condoms on the magazine tables may not be the right work environment for a counselor who promotes an abstinence-only model.

Aim for a well balanced staff

Within the bounds of agency culture and program design, it is helpful to select staff that provide you with a range of counseling and advocacy skills and experience and a balance of men and women, language skills and cultural knowledge that match as fully as possible the population(s) you plan to serve. “Balance” corresponds to the degree of need; if your clientele is 75% Spanish-speaking you may need more Spanish than English-speaking workers; if your program serves only male ex-offenders, you may want a preponderance of male outreach workers who know the correctional system. Of course people can and do successfully cross gender and cultural lines in delivering services, but sometimes gender, cultural identity and other points of similarity are valuable tools in building trust with disenfranchised persons. Make sure that you do not violate any equal employment laws in your hiring process.

Setting Up Your Program

Some things to ask about in the interview

- **Work history and experience:** Ask questions about the positions described in the applicant's resume. What did all those "duties" actually consist of? What did the applicant enjoy? Dislike? Ask about any unexplained long gaps in employment. Depending on your agency personnel practices and your program model, you may choose to hire "peers," people representative of the populations you are trying to reach. Although they may not have a high level of formal education or extensive professional work experience, they may offer a combination of life experience, specialized peer educator and other paraprofessional training, and volunteer or internship experience, which must be given fair weight. Many skillful counselors at all levels, from peer to licensed professional, are in recovery from some form of substance use themselves, and their life experiences are part of what equips them to provide services for similar populations. Still, an applicant who is stabilized in recovery for a year or more, has attained and maintained stable housing and has been working or acquiring work skills steadily is likely to be a better choice for your program than someone who has been sober for only as long as he or she has been in residential treatment and is just about to transition back to community living.
- **Knowledge base:** Does the applicant have a basic understanding of HIV and other issues that are important to your target population; does he or she know about risk factors and transmission, disease process, treatment and adherence issues? Does the applicant understand the social framework within which HIV exists in your community? What level of understanding does this staff person need in order to carry out his or her job? If specific knowledge is lacking, do you plan a staff training program that can supply the necessary learning? Does this applicant seem like someone who will absorb and apply the necessary information? If he or she is expected to provide broad supportive counseling, does the applicant have counseling skills and experience? What training are you prepared to provide? Depending on the services you plan to offer, what educational credentials does the job require?
- **Comfort with diverse groups of people:** If you expect to serve an ethnically, culturally and/or behaviorally diverse clientele, it is important that your staff be at ease with the full range of clients they will see. If you are concerned about an applicant's comfort level with any of the populations you serve, discuss it in the interview. That way you are clear from the beginning what your expectations are from staff, and you have an opportunity to size up the applicant's attitudes.
- **Ask about specific "issues":** We all have our tripwires. Some constitute more of a barrier to providing services than others, and an otherwise qualified candidate should not necessarily be disqualified because he or she has one. It is also a good measure of the honesty and insight of applicants if they know, and can discuss, their own tripwires candidly. Some examples of tripwire issues are the counselor who cannot objectively counsel a pedophile, which may not present a daily obstacle to delivering program services, or the substance abuse counselor who regards HIV infection as punishment for not curtailing drug use, which can prove to be an insurmountable barrier to providing services in an HIV service program.

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- **Assess problem-solving abilities:** Describe one or two case scenarios that are typical of what your program is likely to encounter and ask applicants how they would handle the situation you describe. Look for resourcefulness, insight and the knowledge and values reflected in the applicant's response. Your policies and procedures can be learned; the applicant's un-coached problem-solving will tell you a lot about the person you propose to employ.

Creating a Good Work Environment for Staff

Supervision

In addition to daily observation and direction of the work of your program, it is important to meet periodically for private one-on-one supervision with staff. This is an opportunity for communication, teaching, and relationship-building. Staff members should be encouraged to bring their own agenda items to supervision meetings, to express concerns and to ask questions. This is also an opportunity to express any concerns you have, reinforce expectations and express positive feedback.

Staff meetings

It is important to acknowledge your staff as individuals but integrate them as a team. Full staff meetings are one way to promote this. This is a chance to invite contribution and collaboration, share information and resources, and keep everyone in touch. Opportunities should be made to air group issues (keeping the radio at an acceptable level, leaving the bathroom clean, etc.). Staff meetings can be designated for particular purposes or a number of purposes can be met at a single staff meeting.

Open-door policy with staff

In addition to scheduled, structured supervision and staff meetings, it is sometimes necessary to address a problem or issue as promptly as possible. Every supervisor knows how essential it can be at times to be able to close the door and focus. Every supervisor also knows how essential it can be at times to open that door and address a problem as soon as feasible. The real issue here is *accessibility*: is the supervisor available as a resource for staff, or to troubleshoot and/or address problems that exceed the scope or skill of line-staff when needed?

Establish reasonable and appropriate boundaries

It is not always possible to be a friend and a boss at the same time. It is not always possible to make a clean, simple transition from friend to boss when the need arises. For this reason, it is important to establish clear workplace boundaries, maintain them carefully, and assure that mutual respect and an understanding of each other's differing roles is the foundation of the work relationship. You are also modeling boundaries for your staff, who must in turn establish boundaries with each other and with the clients they work with.

Staff motivation and appreciation

Let people know that you value them! Invite their input. Let them run with their best ideas. Praise success, and recognize when someone has gone above and beyond. Let people participate in the planning of their own work and the development of the program, so that they can enjoy ownership of their own efforts and the results they achieve. Every once in a while, buy your staff lunch or coffee and donuts.

Setting Up Your Program

Staff training

One way to support your staff is to provide them with good quality, interesting, useful ongoing training. The following is a list of typically required and recommended staff training topics and is by no means exhaustive.

1. Confidentiality (annual)
2. Service site safety (annual)
3. Safety in the field (annual)
4. Mandated reporting, i.e. child welfare, domestic violence, suicide risk, etc. (annual)
5. Client assessment and service plan development
6. Counseling and communication skills
7. How to take good case notes
8. Networking within the agency
9. Networking within the community
10. Case studies
11. Cultural sensitivity/competence
12. Cultures of behavior, i.e. sex, drug use, etc.
13. Discussing sexual behavior
14. Increasing comfort with “uncomfortable” topics
15. Handling “difficult” clients
16. Adherence case management
17. Distinguishing between and addressing program and client goals
18. Tracking clients over time
19. Reducing stress and avoiding burnout
20. Issues of transference and counter-transference
21. Population-specific training
22. Evaluation, research and better program design

Reducing staff stress and preventing burnout

Direct client services work is notorious for causing staff stress and burnout. Factors that often cause stress and burnout are: internalizing difficult situations of clients and taking them home; taking on too much work at once; not taking enough vacation; wanting clients to make changes faster than they can handle; not having enough time/resources to grieve over the death of a client; and not getting support for current responsibilities or for new responsibilities.

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We suggest addressing these issues through some of the trainings we just mentioned, such as the ones on transference and counter transference, handling “difficult” clients, and reducing stress and avoiding burnout. In addition, we’ve put into place some measures that seem to help reduce staff stress in our programs:

- **Make sure staff take their vacations.** Look at how much time off each staff person has taken each year. If staff have not taken enough vacation, sit and discuss the matter with them and strongly recommend that they take time off.
- **Give staff the opportunity to take mental health days.** Make a certain amount available for staff each year.
- **Create a team ethic among your staff.** Some of us do this by making rounds each morning or by having case conferences every week. These meetings keep us all in touch with each other and in touch with what each client needs. If one of us is sick or needs some time off, other people on the team can do that person’s work for him or her while he or she is away.
- **Let staff know that you can help them if they get overwhelmed.** Keep an open door policy where staff can come and talk if they are overwhelmed with their workload or anxious about it. If they need hands-on help, reassign some of their workload to other people who have lighter loads, help them prioritize the work, or even step in as a supervisor to help out until they catch up.
- **Create a support system for staff if a client dies.** If a client passes away, gather together as a group to mourn the client and to discuss any feelings staff may have. We also recommend that staff get outside help, such as from a therapist. If staff continue to have a hard time with the death of a client, offer support as a group or welcome staff to come talk to the supervisor individually.
- **Support staff when they are promoted.** A scenario we have seen is staff promoted to a new position but not given enough support regarding their new responsibilities. They can get overwhelmed, feel inadequate to the new task and even relapse from recovery if substance use was part of their coping methodology in the past. While we want our staff to improve and advance in the workplace, it’s important that we don’t set them up to fail. Be sure candidates for promotion are ready for the responsibilities of a new position. Prepare them by giving them the proper training. When they start their new position, check in on them often to see how they are doing. As they continue, let them know you are available to them should they get overwhelmed or need help. A team ethic in your workplace will also help staff as they get promoted.

Setting up LINKAGES with Other Programs

As we mentioned earlier, it is important to set up relationships with other programs that provide services your program doesn’t so that your clients can get the full range of services they need. If they are lacking resources in a certain area, such as housing for instance, this can slow down their response to the help you are providing them in other areas.

One way to set up a linkage between your program and another is to hold a meeting attended by program directors, department heads, community liaisons, or others authorized to sign agreements on behalf of each agency. If they agree on terms, a Linkage Agreement, Memorandum of Understanding or other formal documentation of an agreement is set up. Typically this document will specify the purpose of the partnership, what each agency will provide in the partnership, mechanisms for cross-referrals, and the duration of the partnership. Alternatively, in the absence of a formal agreement, you may proceed informally by getting to know the program and then referring your clients to that program using their standard referral process.

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It is preferable that staff have some relationship with the places where they refer clients. Ideally, one of the staff should take time out to investigate referral sources. It's good to know where your referrals are located, what services they provide, and in what type of environment they provide them. If you investigate beforehand, you can verify that the program is still active and talk about the referral with authority, and the client may better respond. It's also important to know about the quality of the services provided there and if there is a possibility your client will encounter any obstacles. For example, there may be long wait times, or providers may not have the capacity to understand the issues your client is facing. Or it may be difficult for your client to navigate the system once they get there. You may prevent frustration for the client if you notice problems beforehand. After considering obstacles, you may realize that it would help to provide the client with an escort or an advocate. It's important to know where you are sending your clients because the quality of your referral is a reflection on you as well.

If it is impossible for you or your staff to do any research on your referral and you must refer the client to that agency, tell your client that you've never been there and that you would like him/her to tell you about it once the appointment is over. Get to know the agency through your client so you can help him/her through any difficulties, and so you can decide whether you would like to send other clients there.

ENROLLMENT and SCREENING Criteria for Potential Clients

Your program's enrollment and screening criteria will be based on a number of things. First, your criteria should take into consideration who you are contractually required to enroll. Second, your program criteria should consider your agency criteria for enrolling clients. This will differ from agency to agency. Some agencies will not enroll active substance users for example or those with violent criminal records, while others do enroll these clients. Last, you should consider your program's mission and your staff capability for handling certain kinds of clients.

The following is an example in a staff person's own words of how one of our agencies, The Bridge, Inc., screens clients. Their contract requires them to target people of color who have HIV or who are at high risk for it, and are not connected to health care.

"We look to see

- if this client meets contract requirements (for example, currently we cannot work with minors)*
- if clients are dangerous*
- if they have a medical condition that could endanger others or themselves*
- if they are able to connect to any staff person at The Bridge*

My personality is one that takes risks . . . My view is, 'If nothing changes, nothing changes.' But enrollment guidelines and screening criteria are important for safety purposes. Safety is important. For example, during the initial assessment, it's important to ask for all the documents the clients have that can give you information about themselves. Check for a criminal history. Is there violence? A parole officer around? At The Bridge, we have an open door policy. We ask them 'what brings you here?' 'How did you hear about us?' 'From whom?' 'What type of help do you want?' Then we ask a series

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of questions about their mental health. We ask them whether they have ever hurt anyone? Themselves? Do they have a criminal record? Do they have a parole officer? Can we have a character reference? They understand that no weapons are allowed. We take away any that we may see. We get their background, and we try to get a contact person. With difficult clients, we try to see who they connect to. If they connect to no one, then we have to choose someone for them. If that doesn't work, then I handle them personally. If that doesn't work, then I have to refer them to somewhere other than The Bridge."

David de la Rosa, Project Director, The Bridge, ATC Program

GUIDELINES for Client Participation in Your Program

Once you have come up with enrollment and screening criteria, determining which clients you can serve in your program, you will want to come up with a set of guidelines they must follow in order to participate. The guidelines should be based on what you need from your clients to be able to help them, and at the same time run your program effectively so that you can help others. Because program needs and staff capabilities differ, guidelines vary from program to program. They can include behavioral rules detailing how clients are to behave while in the agency; program rules such as stipulating that clients must undergo an intake process or go to a support group to participate in your program; or any other guideline that will help you do your job effectively. Some agencies have contracts for clients to sign, while others post these guidelines using large print on their walls. Below are some examples of how different agencies set guidelines for client participation.

Settlement Health, ATC Program

Program Participation Rules and Regulations (contract)

*In order to ensure the safety of clients and staff, individuals who participate or are enrolled in the Settlement Health Access-to-Care Program **MUST** follow these rules.*

- 1)** *All clients must sign an attendance sheet when entering the building*
- 2)** *Instructions from agency staff must be followed. Clients who refuse will be asked to leave the building*
- 3)** *Disruptive or provocative behavior (Ex. fighting, aggressive or hostile confrontation, sexual harassment of staff or other clients) will result in immediate termination from the program*
- 4)** *Violence or threats of violence are grounds for immediate termination from the program*
- 5)** *Weapons of any kind are not allowed in our building. Anyone observed in possession of a weapon will be terminated from the program*

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- 6) *Drug use in the building will not be tolerated and it will result in suspension or immediate termination from the program*
- 7) *Theft of staff, program or other client's belongings will result in termination from the program*
- 8) *Clients or groups of clients should not loiter outside in front of the building*
- 9) *All clients' records and charts are the property of the agency. Client cannot ask for information to be destroyed. Client may request a copy of the records in their chart. The request has to be made in a timely manner and client must take into consideration staff availability to complete the task*
- 10) *The following are not allowed in the building:*
 - *Smoking*
 - *Use of cellular phones*
 - *Radios/CD Players*
 - *Audio Beepers*
- 11) *Clients have the right to utilize our grievance process if they feel they have been treated unfairly by any staff in our agency. Grievance must be submitted in writing and clients will be provided with a copy of the grievance protocol. Grievance forms are available upon request*

I hereby acknowledge that I understand the rules and regulation of this program and I agree to follow them.

Client Signature

Date

Staff Signature

Date

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The Bridge, ATC Program

Program Rules (posted on wall)

No fighting

No sex

No weapons

No foul language

Bathe if you want to go to a particular section (ex. napping section)

Ask permission to use the phone

Stay out of places you are not supposed to go to

If you have any problem relating to the Bridge, we have a grievance process. Don't handle it yourself

Conducting Outreach, and Connecting Clients to Medical Care

Conducting Outreach, and Connecting Clients to Medical Care

Now that you have set up the structure of your program, it is time to carry out the work your program is designed for. Our programs are designed to conduct outreach, engage clients in medical care, and maintain them in care. The following section will describe the strategies we use to identify and recruit clients and engage them in medical care.

IDENTIFYING and RECRUITING Clients

Typically, we identify and recruit our clients in four ways:

Inreach

Outreach

Community referral

Self-referral

Inreach and outreach are the most common strategies we use. First we will give a brief description of each recruitment strategy, then we will discuss our inreach and outreach procedures at greater length.

Inreach

This method is used by all of the Maintenance-in-Care programs, and by some of the Access-to-Care programs. It is called “inreach” because programs engage clients from *within* their hospital, clinic, or CBO rather than from outside. The programs that use this method have set up a system within their larger organization where other departments who come into contact with HIV+ clients alert them that they have candidates for their program, and they refer clients over to them to see if they meet the enrollment criteria. Programs that get their clients through inreach specifically target clients who do not come to their appointments regularly and have difficulty staying in care. Once they enroll clients, programs then investigate why those clients are having trouble coming to their appointments by locating them, assessing what the problem may be, and attempting to help remove or reduce any of the obstacles.

Outreach

Most of our Access-to-Care programs perform outreach in order to find and recruit clients. Their target population is people of color who are either are HIV+, do not know their status, or are HIV- and engaging in high risk behavior, and are not receiving medical care. Because these clients are not connected to a program or clinic, it is impossible to find them through inreach. To conduct outreach, outreach workers go to places outside the agency that are likely to be frequented by members of the target population. While doing outreach, trained staff try to engage potential clients, assess their needs, and enroll eligible candidates into their program if there is a good fit.

Community Referral

Clients are sometimes recruited through community referral, a process where a client is referred to an agency for services by a member of the community, such as friends of the client, family members, acquaintances, other clients, or by

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other community agencies. One of our programs, for example, has a linkage with a drug treatment center. Through the agreement, the drug treatment center sends clients to the program upon discharge from drug treatment so that the program can help connect them to medical care.

Having clients become community activists and recruit other clients can be particularly helpful. Clients can build trust with and provide support to potential clients by talking to them about their own HIV experience and letting them know they are not alone. Client involvement in recruiting is helpful not only for the program, but also for the clients' own positive self-image, making them feel like they are able to do something useful for the community.

You can also get members of the community to become activists and recruiters. If people are not infected with HIV, often they are affected by it. In our experience, it is effective not only to do outreach to HIV+ people, but also to people who say they are negative because they can be at high risk themselves, or they might know others who need help. During outreach activities, people often say they are HIV-negative and want to walk away, but we don't let them leave without having them take our card and letting them know that if they are concerned about a family member, a neighbor or a friend, they should tell them about us. We also talk to people who seem to know about what is going on in the neighborhood. Sometimes there's a man or a woman who sits outside all day and just knows what is going on. We ask them if they know anyone who might need our help. As a result, we often get calls from people who say "Listen, somebody gave me your card and told me you could help me."

Often you can reach greater numbers of people if you find out who different leaders are in the target group and spread the word through them. As Duane Ronen from one of our MAI agencies puts it, *"every clique has a leader. If you get to that leader, you get to the rest of them. Don't pastor everyone. Find out who the little pastors are. Pastor them and they'll pastor others."*

Self-Referral

People who refer themselves to the program and just walk in are "self-referrals." Often clients who refer themselves have seen a friend going through the same difficulties they have and then improve by participating in the program. They are inspired to help themselves as well, and so they seek out one of our programs.

More about **INREACH**

We have found the following strategies to be effective when setting up an inreach system within a larger health care setting or CBO. As with all the suggestions we offer, please modify them to fit your hospital, clinic or CBO's system and culture. Get to know the place that houses your program and work with it. If you disregard how your organization customarily does things, other departments may have difficulty coordinating with your efforts.

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Suggestions for setting up an inreach system

- Coordinate and network within your agency to get a complete list of HIV+ clients served by your agency
- Get medical and other providers to routinely identify clients who miss their appointments and refer them to your program
- Make presentations and attend other people's presentations to see if there are any prospective clients for your program
- Have a monthly meeting between the departments in your agency where each unit does "show and tell." See if you can foster collaboration with other departments using information you get from this meeting
- Hold case conference meetings with doctors, medical staff, and HIV specialists at your agency
- If your hospital, clinic, or CBO uses electronic medical records, see if your Information Technology (IT) department can program it to flag all clients who miss their appointments. Brainstorm with your IT department about other ways the system can be used to aid with inreach
- If your hospital or clinic uses epidemiologic tracking software to keep track of the HIV+ clients served, this can help you identify persons known to be positive who are not accessing care
- Do rounds of other departments to find potential clients. If this is too burdensome for one person, share or rotate this duty with others. Clients can often be recruited from hospital inpatient units and emergency rooms. People who are not connected to routine health care are more likely to come to emergency rooms when they get sick
- Coordinate with inpatient discharge planners at your hospital or clinic, if you have them. Ask them to alert you when someone with HIV or related illnesses checks in. Follow those clients and enroll them in your program if appropriate
- Speak with discharge planners in other units. Do you have a substance use treatment unit, or a methadone maintenance program? See if there are HIV+ clients in those units that you are not aware of
- Coordinate with your hospital or clinic's laboratory department. Monitor clients' viral load and CD4 count. Their lab work could be an indication of whether or not they need your help
- If you have an HIV counseling and testing program, collaborate with staff in the program – ask them to direct any HIV+ persons identified to your program
- Set up a system with registration office of your hospital, clinic, or CBO to direct all HIV+ clients to your program. Also ask staff in the registration office to be on the lookout for people with HIV-related illnesses and to direct those individuals to you as well

More about **OUTREACH**

Outreach is an especially challenging and time-intensive method for recruiting clients who experience a large number of barriers to care. (A list of common barriers can be found on page 56.) Because the outreach worker is the first person to approach these potential clients, he/she needs effective skills to break down initial resistance and inspire confidence. If the outreach worker is not successful in recruiting a person in need, none of the other service providers will have the opportunity to see that person and help him/her. Because this is such an important job, we discuss outreach at great length in this section. We will talk about:

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The importance of knowing the **habits** of your population

The importance of establishing an effective outreach **method**

How to effectively **engage** your target population

How to know when your outreach method is **not working**

The **personality** of the outreach worker, and **basic outreach skills**

The importance of a **safety plan**

Learning about the routines and customs of your population

In order to reach members of your target population, it is important to know their routines, their culture, and what they value. Once you understand these, you will have ideas about where to find potential clients, you will be able to better understand them and their needs, and they will feel more comfortable with you. The following strategy, used by Project Street Beat, is an example of how to take a population's routines into account when doing outreach:

"I do a lot of outreach to sex workers and drug users. This population is not going to be found at places like 125th Street in Manhattan, a street with high visibility. They're going to be found in-out-of-the-way places. They are concerned about who sees them, so, they congregate behind Pathmark [grocery store], under elevated train tracks and in more deserted places.

Another thing I do is I pay attention to what times people go where. For instance, many people may attend a certain program (i.e., a methadone program), and afterwards, a whole group may stand outside McDonald's for a while when it ends. Or, the 1st and 15th of each month, many people go to public assistance. This is a great time to outreach to many people at once."

Duane Ronan, Outreach Worker, Project Street Beat, Planned Parenthood, ATC Program

Here is a list of sample questions you could ask yourself about the people you plan to outreach to:

- What types of things or activities are important to them?
- What motivates them to do what they do during the day? For example, are they motivated by:
 - Their kids?
 - Money?
 - Having a good time?
 - Surviving today?
 - Drugs?
 - Employment?
 - Food?
 - Help for physical or mental pain?
 - Approval from peers?
 - Changing their immigrant status?
 - Safety?
 - Socializing with a group of people?
 - Pleasing a spouse or significant other?

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- What actions will they take to get what they want?
- What places do they frequent?
- What times do they go to those places?
- What types of people do they spend time with?
- What are their needs and problems?
- What are their strengths?
- What types of actions, gestures, people do they mistrust?
- What types of people are they most comfortable with?
- What are they especially sensitive to?
- What can you offer them?
 - Are your services important to them from your point of view?
 - From their point of view?
 - When should you **not** approach someone? For example, is the person dangerous or unable to listen and communicate at all because of alcohol or drug use?

It is ideal to employ outreach workers who have ties to the community you are outreaching to, or who have experience with community members' needs and ways. It is not always possible, however, to have someone on staff with this type of background or experience. Therefore, if you are outreaching to a group of people other than one you are familiar with, it is important to learn about the group's norms, values, beliefs, and traditions. Do some research beforehand so that you start off on the right foot with your potential clients. You can learn about a group of people in a number of different ways:

- Talk to anyone you may know from that group and ask him or her questions about lifestyle, values, religious or other beliefs, etc. First-hand information from the community will allow you to identify sites for street outreach and effective methods for outreaching to your population
- Go to places where people you are trying to learn about congregate. Observe them, and pay attention to things you can learn about who they are and what is important to them
- Speak with workers from other agencies or institutions that deal with this population. See what information you can get from them
- Read any literature, books, or articles you can find on the population

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Because life is a learning process and we can't know everything about everyone ahead of time, it's important to keep an open mind and to know that you are continually learning as you go along. Don't assume you know everything about how a person thinks or his/her culture even when you do know a lot. When communicating with someone from a different culture than yours, and you don't know him/her that well, check in every so often and see if he/she is comfortable.

You may find that while you are trying hard to be culturally sensitive, you will make some mistakes. Do not feel badly about this. We all make mistakes in understanding others no matter how much we learn. If clients are not patient with you as you learn about them, don't take it personally. Just apologize (it might be useful if you explain your good intentions), learn for next time about what makes them comfortable, and move on.

Please refer to "Understanding the population you are serving" on page 12 for more information on how to understand the population you are serving. Please see "Working with Special Populations" on page 97 for descriptions of some of the target populations we work with.

Knowing your outreach zone

Your outreach zone, often specified by the agreement with your funder or by your program's mission, is the first thing to consider when you look for your target population. Find out in what areas you are supposed to do outreach. Make sure each person on your outreach team knows this information and keeps it in mind at all times. In addition, familiarize yourself with local laws pertaining to trespassing or private property.

Examples of places where we do outreach are:

- Street
- Single room occupancy housing (SROs)
- Shelters
- Soup kitchens
- Prisons
- Shooting galleries
- Detox programs
- Outpatient drug treatment facilities
- Churches
- Bottle/can redemption machines
- HIV testing facilities (or we provide the testing ourselves)
- Places where immigrant populations are likely to congregate – hair braiding salons, for example

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Mobile vans

Use a mobile van, if one is available to you. Mobile vans are very useful, because they can go to any part of an area relatively quickly for outreach purposes, they allow programs to provide a range of services in a private environment, and they can be used to transport clients to medical care or other appointments. The ability to provide services in the van or to transport clients to services is an integral part of some of our programs' success in connecting clients to care. Clients often drop out when there are many steps to take between where they are and their medical appointment. Providing services right away is one way to combat the problem. Agencies that do not have a mobile van to bring clients to and from appointments try to address the same issues by giving clients carfare or transportation passes to go to their appointments.

Marketing your program

Marketing and spreading the word about your program will make your outreach work much easier. If you put information out there before you go into the field, you increase public understanding and support for your program; you increase the chances for people you approach to have heard of you first and you'll have less ice to break; and, you make it easier for people who are really motivated to come to you to find you. You can spread the word through:

- Newspaper, magazine, radio and television ads
- A website
- An open house
- Presentations at
 - Health fairs
 - Prisons
 - Homeless shelters
 - Drug treatment facilities
 - Faith based organizations
 - Other organizations where you can reach your target population, or people connected to them
- Coordinating with your local
 - Social service agencies
 - Hospitals
 - Businesses
 - Police department
- Word of mouth

Working with the police department

It is especially useful to develop a working relationship with the police precinct that is local to the areas where you are conducting outreach. Police can tell you about areas within the community that are frequented by high risk populations. In addition, police can help with staff safety, they can alert you ahead of time if they plan to do a raid so that you can avoid the area, and they know to leave you alone if you come across each other in the street, instead of suspecting you are soliciting anything (make sure your ID tag is visible at all times).

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When developing this relationship:

- Contact the Community Affairs Office of the police department or equivalent for your locale. This is the department that facilitates the relationship between the community and the police department. Arrange to meet with police officers in this department
- Attend Community Police Meetings. These meetings can be an effective vehicle for establishing ties with the community affairs representative from the local precinct
- Work with the community affairs representative for your area. He/she may be able to make arrangements for all your outreach workers to come in and introduce themselves to officers that are on duty during the hours outreach is scheduled

Staffing your outreach team

Designate a team uniquely devoted to outreach at your agency. Outreach can be at its most successful when a team's purpose is strictly about outreach. It is difficult to ask staff to be consistent and keep relationships in the community with the police, other community groups, drug dealers, and sex workers when they are also expected to conduct extensive follow up and paperwork. For programs that rely heavily on successful outreach, there should be some delineation between the people who do recruitment and the ones who provide follow-up services. Funding constraints may be a barrier to having separate outreach and service teams. Utilizing peers and volunteers to assist in ongoing and consistent outreach in the field can expand the capacity of programs while reducing some financial burdens.

Have at least 2 people, preferably 3, people on your outreach team. At least two people on a team is recommended — if community members don't connect with one person, you give them a chance to connect with the other. Also the work of handing out materials, taking down names and talking to people requires at least two people. Outreach workers should also go out in groups of at least two for safety reasons (for more on safety during outreach, see "The importance of a safety plan" on page 48). Having three people on a team is ideal because with this set-up, one person can hand out materials, the second person can take down names, and the third person is freed up to do more counseling and connecting with the people who walk by.

In general community outreach (not targeting one gender specifically), at least one man and one woman should be on each outreach team. Many clients feel more comfortable talking with someone of the same gender. Some clients feel more comfortable talking with someone of the opposite gender. When you give them a choice, you increase the chances that all people will feel comfortable enough to come and talk to your team.

Outreach team members should be culturally and linguistically sensitive to the target population. Ideally, at least one member of the outreach team will know the language, norms, values, cultural beliefs and traditions of your target population from being or having been part of the culture. If there is a heavy Spanish-speaking population in your community, for instance, you should have some Spanish-speaking outreach workers.

Setting outreach goals

Establish a target for how many people you have to outreach to per day to meet your program goals. If possible, slightly over-estimate your daily goals to make sure you reach your overall target. Allocate a specific amount of time for conducting outreach in a specific place. A time-frame keeps outreach workers more focused. When outreach workers know they only have 2 hours to reach a certain amount of people, for example, they tend to focus their efforts more.

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Outreach materials

Distribute materials pertinent to your program and items that can be useful to your target population. If you are distributing written materials, make sure they are at literacy levels your potential clients can understand. Our programs often distribute condoms, bleach kits, educational materials, brochures, “dignity packs” containing deodorant, toothbrush, toothpaste, and soap, food and beverages. Some of us do needle exchange or distribution of clean syringes. Having items not connected with HIV on hand can be useful so clients are not afraid of being suspected of having HIV when they are seen talking to you.

How to effectively engage your target population

Engaging your target population may be easy or difficult depending on how much they recognize what you are offering as fulfilling a need and on the number of obstacles they face in order to respond. We have found several engagement methods to work especially well for us. The following section provides direct quotes and examples from the field from our outreach workers.

Being non-judgmental and respectful toward potential clients *“I just do what I do naturally. I go into the community. And I know behaviors... so I can see a person...I know if the person is under the influence of drugs and alcohol and stuff like that -- if they are high-risk -- by their behaviors, because they have tell-tale signs. And what I do is I confront them, like the human beings that they are. ... I treat them as human beings, tell them who I am, ... what services my program has to offer. And I try to find out if they are interested. One of the things I do is I let them know that I'm not there to judge them. I'm not telling them to stop using drugs and alcohol. But I am saying ... whenever you are ready to give yourself a break... we have a car, we have a mini-van, we have an office. And we have a very concerned staff that's here to advocate for you and help you reach your needs—to access you to the care that's being provided in the community. And the good thing about it is ... the services that we provide are at no cost to you. So you don't have to have the Medicare, you don't have to have any type of insurance, you know. Our staff members help you work with getting that. And I think that ... when you meet people like that, then they feel you. When they look in your eyes they can see that you're concerned.”*

Ronald McBurney, Outreach Worker, Project Street Beat, Planned Parenthood, ATC Program

Respecting clients' assessment of their own needs Assess what you think are the client's needs, but also ask the client what he/she needs right now. Clients are faced with many challenges in their lives and sometimes they are not concerned about issues we may think are important. Many clients may feel they have priorities that are higher than seeing a doctor and getting health care. In the long run, we want clients to prioritize good health; however, we recommend that you work take seriously what the client thinks is important for best results. You may want to start by asking clients what is the greatest need they have *now* and what things they would like to change for later. You may not be able to satisfy all needs but by being resourceful enough to try and empathetic enough to care, you may gain your client's trust and attention.

Persistence and assertiveness Our outreach workers emphasize that persistence and assertiveness are key to engaging clients. Pick places frequented by your target population, and go there at times they are most likely to show up. Visit those places regularly. When you visit places reliably and regularly, people in the community can count on you being there at certain times. While they may not feel that they need you the first time they see you, perhaps they will realize they need your help at a different time. If they know when and where you'll be, they can make plans to see you. When

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you show up consistently, you also give people who had a reluctance to approach you right away an opportunity to observe you and to see what you are all about. This can give them the confidence to eventually approach you.

Settlement Health, one of our agencies, goes to a certain homeless shelter every week, for example. While they have some potential clients who come and talk to them right away, they also know that there are people at the shelter who are thinking of enrolling, but are not yet ready to approach them. Because these people know that workers from Settlement Health come every week, they watch them for a while, and then they approach them when they are ready.

We also recommend an assertive manner when approaching clients. *“You’ve got methadone clinics... and you have drug areas. You have different parks and blocks in the target areas that people congregate in that are HIV-positive. And they know they are sick and whatnot, but they don’t know how to access services. ...if you are not going to step into that crowd and let them know what you do, they’re not going to come to you! ... I mean a lot of agencies call themselves [an] outreach [program] by handing out flyers ... in the community. How do you know this person can read? How do you know this person doesn’t have a language barrier? ... And the person walks away because nobody is going to show their ignorance by saying they can’t read...! That’s not outreach! ...[An example of my] street contact [is]: ‘How are you doin’? My name is Ron. Can I have a word with you?’ And you know, you start advocating your program.*

Ronald McBurney, Outreach Worker, Project Street Beat, Planned Parenthood, ATC Program

Confidentiality

Assuring potential clients of confidentiality is very important in this work. Many people are up against stigma of all kinds, and this prevents them from addressing health issues and seeking the health care they need. For more on confidentiality, see “HIV confidentiality” on page 15. For more on stigma see “Assessing and addressing barriers to initiating medical care” on page 55.

Incentives

Offering incentives are a good and quick way to get someone interested in your program. Because people need these things and benefit from them right away, they can be a draw. Examples of incentives are transportation passes for public transportation, cash, food vouchers and food, movie tickets, dignity packs (a kit containing personal care/hygiene items), condoms, and so on. For more discussion on incentives, see “Use incentives” on page 54.

When your outreach method is not working

It is important to evaluate your outreach method from time to time in order to make sure you are getting the maximum benefit from the time and effort you are expending doing outreach. Certain signs may cause you to wonder whether your method is working:

- You have trouble meeting your targets
- You are unable to recruit people
- It takes you a long time to recruit people
- People just take your materials or incentives and keep walking

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Before you jump to conclusions, we want to give you a word of caution: **DO NOT GIVE UP RIGHT AWAY!** Potential clients may need to watch you for a while before they approach you, or before they let you approach them. Also, they may be testing the waters by taking your incentives first before talking to you. They may open up after some time. Finally, they may come back, but it might not be to you. In doing outreach, you are educating potential clients about the services available to them issues and raising awareness. While they may not come back to your particular agency, they may get the help they need after talking to you, because of the seed you planted.

We suggest that before you give up on the outreach location you have chosen, study it over time and after repeated outreach attempts. Our agencies end up enrolling about 40% of all the people we talk to. We suggest that you give yourself a few months to try an outreach location. Give yourself and the community some time to get to know you and to warm up to you. If after 3 months you have trouble reaching your target, then that location may not be suitable.

The personality of the outreach worker

Outreach work requires that workers be visible, deal with masses of people, engage people's interest, and talk about issues that are often private and sensitive. It is not a job for the meek! If you are wondering whether outreach work is for you, or if you are hiring an outreach worker, this list of personality traits and skills we have found common to our outreach workers can help you decide if you or someone else is right for this job.

An outreach worker should be:

- Confident
- Outgoing
- Interested in people, and interested in helping them
- Optimistic
- Non-judgmental
- Knowledgeable and comfortable with the subject matter promoted by your agency
- Not intimidated by crowds or attention
- Able to handle requests of many people at once (not necessarily to respond to them at the same time, but to deal with that situation effectively)
- Someone who has healthy boundaries with others
- Someone who does not take other people's behavioral problems personally
- Sensitive to stigma people may feel when them and sensitive to some people's discomfort with the subject matter
- Comfortable with all types of people (for example, people of different ethnicities, different sexual orientations, previously incarcerated, people who have health problems, people with mental health issues, different economic situations, etc.)
- Good at drawing people out and engaging them
- Reliable
- Responsible
- Someone who loves this type of work

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The importance of a safety plan

Unfortunately, people's problems sometimes lead them to commit violent acts. This is why a safety plan is very important while doing outreach. Look at your agency policy for the safety guidelines you are required to follow, and talk to your local police department for additional information. Here are some things we have found to be helpful:

- All outreach should be conducted in a safe environment for the outreach workers
- Meet with your local police precinct periodically to:
 - Inform them of what you are doing
 - Find out about any local tensions in the area
 - Find out about upcoming police activity or raids
 - Consult with them about safety precautions
- Prominently display your agency picture ID at all times so participants and police know who you are
- Always do outreach in teams of at least 2. **Do not do it alone.** While doing outreach with your partner:
 - Don't walk alone
 - Don't walk too far from each other
 - Check up on each other at certain intervals, even if you can see one another
 - If you have to go to the restroom or leave for a brief moment, inform your partner
- Some programs permit home visits to clients, while others do not for safety reasons. If your program requires that you conduct home visits,
 - do not go alone
 - leave at the first sign that something is not right
 - carry your cell phone close by – if you feel uncomfortable, perhaps have your supervisor stay on the phone with you while you conduct the home visit
- If you observe tension or violence near you, leave immediately. Go back to your agency, or to a safe area
- Avoid having a group of people surround one outreach worker. If one person on the team has a group surrounding him or her, the other partner should step into the circle so that the group sees the worker is not alone. If the situation does not feel safe, leave the site
- Before entering private or public institutions, agencies or businesses, get permission from the proper authorities to do outreach there
- Do not approach cars
- Avoid wearing expensive clothes, uncomfortable shoes or jewelry
- Do not carry valuables, or large amounts of money. Do not take out your wallet or purse
- Use your cell phone only in case of emergency, to make a referral, or for an otherwise work-related phone call. Conceal it if you are not using it
- Do not carry weapons
- Do not use a beeper. It makes addicts nervous, and the police may think you are a runner

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- Do not hold, carry, handle, or sample any kind of controlled substance or other merchandise such as works or other drug paraphernalia
- Do not buy stolen goods, or engage in any criminal activities with clients

The following behaviors may not lead to direct violence, but they are inappropriate and can cause problems. We therefore advise against them.

- Avoid non-work-related relationships with people you are doing outreach to - social, sexual or otherwise. Keep your personal and professional life separate
- Be yourself. While you should be aware of local attitudes and slang, don't affect manners or use language that is foreign to you
- Don't come on too strong to the participants by pressuring them to change their behavior, or to accept a safety kit, or other information you are offering. Offer them what you have, and take no for an answer, if that's what they say
- Use your referral network to direct clients to extended services rather than providing services you are not qualified to provide. Don't counsel in the streets if you are not qualified for this, and don't play doctor by trying to diagnose HIV or other illnesses
- If you and your partner disagree over how to proceed with outreach while off-site, come back to the agency and get guidance from your supervisor about how to proceed

Connecting clients to **MEDICAL CARE**

Once you have recruited clients through the process of inreach, outreach, community referral, or self-referral, it is time to connect them to medical care. This involves engaging the clients beyond the initial engagement, building a relationship with them, and assessing and removing barriers to care. First, we will discuss methods we have used to strengthen connections with our clients, and second, we will go over the most common barriers we have come across with our clients, and how we have addressed them.

Strengthening connections with clients

Strengthening connections with clients involves showing the client **how the program can help** him or her, ensuring **confidentiality**, building a **relationship** with the client, and using **incentives**.

Throughout our lives, we have been developing our skills at building relationships. The relationships we work on are usually with family, friends, classmates and teachers, teammates, co-workers and others. They are based on mutual trust, respect, confidence and commonality. What we need to remember about members of our "hard-to-reach populations" is that although they may have attempted to develop their own skills at relationship building, many of them feel let down by their own families, friends, community support systems and society as a whole, making it difficult for HIV service providers to gain patients' confidence and trust.

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During your first visit with the client, orient him/her to what your program is about. Be sure to include what the program involves, how the program can help, and what can be expected at first and over time. People function better if they know what to expect. If their energy is spent on unrealistic expectations, or fear of the unknown, they will have less energy to expend on getting better. Also, by telling your clients what your program is about and how it will benefit them, you include them in the process of evaluating the program, evaluating their needs, and deciding what is best for them. You are not trying to control them by telling them you know what is best for them. This process is important for them if they intend to gain better control of their health and their lives.

Confidence in yourself and in your program will also help the participant trust you. Be sure that when you talk about your program, you talk about it knowledgeably, with pride. It's difficult to convince someone to buy into something if you haven't bought into it yourself.

Talking about confidentiality will also be key in gaining your client's trust, and in engaging them in the work you are about to undertake together. Try to talk about confidentiality as soon as possible -- at the first intake. Make clear what is confidential and what is not confidential according to your program's rules. For example, we tell our clients that we are bound by law not to tell anyone outside of the agency any information about them, without their explicit, written permission. However, our goal is coordination of care, and therefore, we sometimes have to talk to other providers within the agency about them. Coordination of care helps us better respond to their needs.

Other topics you may have to address while talking about confidentiality with your clients are whether others can learn anything about them simply by seeing them in your waiting room and confidentiality regarding undocumented immigrant status (see "HIV confidentiality" on page 15 and "Undocumented immigrants" on page 23).

In building a relationship with your clients, it is also important to:

- Be culturally competent to the degree possible, and to use a client-centered, non-judgmental approach
- Be honest and strongly encourage getting honesty in return
- Meet clients where they are and help them make changes from there
- Use a harm reduction approach, agency policy permitting
- Continually reach out to clients and not give up on them, unless it's clear they no longer want to participate in the program
- Offer incentives

Each one of these points is discussed in more detail below.

Cultural competence, client-centeredness and a non-judgmental approach

When providing care to clients from different cultural backgrounds it is ideal to have some knowledge of their cultures (see "Learning about the routines and customs of your population" on page 39 for the importance of this and how to get information). Because that is not always possible, it is necessary to approach clients with the knowledge that your own values and behavior may be interpreted differently by people from different cultures. We must be open to listening and learning.

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It is especially important to be sensitive to trigger words and behaviors for the population you are working with, what stigmas people may endure, and what prejudices they encounter. Being careful to avoid further stigmatizing your clients or using words or actions they might find offensive helps to build their confidence in you and shows them you respect them

If you come across a language barrier, give clients materials in their own language whenever possible and identify language interpreters, either within your agency or outside. If you have to provide spoken interpretation for written materials, try to be aware of the words you are using. Try to stick as closely to the meaning of the information as possible. After you are done, ask the client to repeat the information so you can see how well the client understands. Also, ask him/her “how do you feel about what I’m saying?” to be sure he/she has a chance to express any concerns.

A non-judgmental, warm environment where clients feel comfortable is also integral to increasing their involvement with your program. We try to make clients feel as comfortable and at-home as possible. Sometimes it helps to have staff who used to be peer workers or clients. When clients come in, clients can see people who have been where they are, who are looking good and doing well now. They see that people can change, and they feel inspired. Paying attention to how the agency environment looks and feels also helps the client feel that you respect them.

Finally, a non-judgmental approach when talking to clients is important. As David de la Rosa, the director of one of our programs, illustrates, “When clients share the different places they’ve been, their experiences, and perhaps distorted thoughts, I don’t ridicule them. I listen. If clients are not articulate, shy, or not willing to talk, I just ask questions, tell them ‘answer what you can, and if you don’t want to or can’t answer, that’s OK.’ I get trust by being as sensitive as I can, by role modeling.” Speaking to clients respectfully, even if they are acting in a difficult or suspicious manner, is also important. David’s approach is the following: “I trust the clients first. If I suspect the client is high, rather than say ‘come here, I want you to take a urine test’ I ask them. I say ‘you look different today. Have you done anything different?’ If they are in a restricted area, I don’t yell, I don’t accuse them of purposeful wrongdoing, I don’t say ‘what are you doing there?’ I just say ‘that area is off-limits, can I help you with what you are looking for?’ I don’t come down on the clients too hard. People understand at different levels, and sometimes you have to explain things more than once. I have the 3-point rule. I tell them once, twice, then 3 times. If after the 3rd time you don’t understand, then we have to sit down and talk. Is there a language barrier? Do you think rules don’t apply to you? Do you believe you cannot trust the rules? Let’s look at them together!” In this way, David gets trust by giving it to clients first. “The key to healing,” he says, “is through relationships.”

Honesty

Be honest with clients, and strongly encourage honesty in return. In order to build trust participants need to know their provider. This involves being authentic. If you try to present yourself as someone you are not, it will eventually be noticed by participants, and you will lose your credibility. To avoid this situation, learn about your organization and what it can and cannot provide, and tell clients about it during their first service orientation. Let them know all that’s positive and all that’s negative, without hiding anything. If there is something you cannot do, let them know. Don’t make promises you can’t keep. When you give them honesty, it’s easier for clients to deal with you.

It is also necessary that clients be honest. We let them know that if they lie to us, we cannot help them. For example, if they are using drugs and they can’t stop, lying about it guarantees that they will be handling the situation alone. If they

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tell us, we will be there for them, and perhaps we can help. Also, if a problem is left alone and not addressed for some time, it can become deadly, such as HIV. Andre Williams, at one of our agencies (Health People), says he tells his clients “in order to get perfect care, you have to be perfectly honest. Lying is like committing a crime, lying to the lawyer who could have gotten you clemency, and then going to jail when you don’t have to.” Assuring them that we will not look down on them for whatever problem it is they share with us helps give them the confidence to be honest with us. Many clients are tempted not to be honest about certain things such as substance use in order to escape the stigma it carries, and/or to escape the usual reaction providers have, which is that they should stop.

Meet clients where they are

It’s important to let clients define themselves when they come in for help, and for us to meet them where they are. They must tell us what is wrong, because we don’t know what is wrong and how it feels to them. This is not our treatment, but theirs, and they will have to make it happen and live through the consequences of it afterwards. Therefore, whatever is meaningful to them should be meaningful to us. When providers impose their treatment plan on a client who is not ready for it, it can backfire, because the provider is not dealing with the client as he or she is, but as an imaginary person. If this persists, goals will not be met, and the client will get discouraged and may not come back.

We may not be able to give clients exactly what they want, when they want it. Our job is to remove barriers to care, teach them about health care, and move them to a better place. However, most likely, what they want is connected to improving their lives in ways we think is important as well. In explaining to them how things work and using their goals as a target in addition to what we think is valuable (if our goals differ), their buy-in and participation are more likely. We give two examples from our agencies below. The first is about a client who wants a job and housing right away without taking care of other important needs, and the second is about a woman who refuses a psychiatric evaluation when she seems to need one.

“For example, the client is unemployed, not housed, and thinks that once they get a job and housing, their problems are over. I tackle the problems using a point system. There are points I need to make, with all due respect. So, dealing with the work situation, I say to the client, first we need to answer these questions: how will you get to and from work? Can you work one week with no food? Some paychecks come 2 times a month. How will you survive? Do you have clothes to wear to work? A change of clothes? Do you have clothes for the interview? A job will come, but we need to take care of these things first. Or, for example, with housing, I ask them: how will you pay for rent? How about furniture? Will you sleep on the floor? I give this information to the client so that they can think about it. Are clients good planners? Sometimes clients are so desperate, they don’t think about these things. I tell clients I will help them reach their goals, they will come in time, but first things first. We need a treatment plan. But all that the clients want is important to me.”

David de la Rosa, Project Director, The Bridge, Inc., ATC Program

“What I do is always appease the client, steer them in the right direction, look at things from all points of view (mine and the client’s), and use a form of negotiation. For example, I had a client who had psychiatric problems. She didn’t see it and didn’t want to address it. She was paranoid schizophrenic. She would rob, steal, and manipulate situations. I wanted her to get a psychiatric evaluation, but she didn’t want to, and I knew she wouldn’t get one if I just presented it to her that way. I knew though that she had a big thing about getting money. I told her that if she got evaluated and if they came up with a diagnosis, SSI would send her a check every month. Whereas before, she disappeared all the time, now she calls regularly to ask when is her appointment, and to check up on the progress of this.”

Andre Williams, Case Manager, Health People, ATC Program

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Use a harm reduction approach (agency policy permitting)

Most of our agencies concur that a harm-reduction as opposed to a zero-tolerance approach for drugs and other behaviors is an important way to build trust with clients. Just as we discussed in the previous section on meeting the client where he/she is at, in harm reduction the goals are set by the client, and the provider helps the client to reach his/her goal rather than imposing the provider's goals on the client. Harm reduction case management also encourages incremental progress: this means that work progresses only when the client is ready for it. As a result, the client feels in control of his/her life. The client also trusts that the worker views him or her as a person, and with respect. Clients get unconditional positive regard from their providers as opposed to positive regard only if they meet certain conditions. Our programs that endorse the harm reduction philosophy have minimal criteria that will disqualify clients from their programs. They usually help the client whenever he/she needs help, even if the client does not follow an optimal service plan. This does not mean that they enable behavior that is harmful to clients, but rather, help clients identify their strengths and weaknesses, and based on that assessment, help clients pursue incremental goals that are appropriate to their readiness. This can involve making a referral to needle exchange or clean syringe distribution programs, providing condoms and education on safer sex, allowing the client to choose if and when he or she stops using drugs, and promoting other tools to help the client work at his/her speed. The purpose of this approach is to keep clients connected to medical care, despite their barriers to care. Harm reduction advocates that problems are often improved not by solving one after another, but by working with a few at the same time. The successes a client will have in one area often encourages success in another area, and gradually the client does better overall.

Zero tolerance imposes goals on the client and is more provider-centered. It uses "conditions" for providing services, which may limit the chances of building a strong relationship with the client. A zero-tolerance approach means, for example, that clients can be seen by appointment only; if they are late, they cannot receive services; they must get off drugs to receive services; and they must follow other rules or achieve other goals in their service plan to be seen at that agency. The risk of this approach is that if the client is not capable of functioning at that level, he/she may not come back.

While most of our agencies feel that harm reduction is a major reason they have had success getting or keeping clients with many barriers to care, our agencies endorse the harm reduction approach at different levels. Some agencies warn that failing to challenge clients enough can be counter-productive. According to one agency, "it's the behavior of the client that got them in that state in the first place, so it's unrealistic to keep catering to that behavior." While they acknowledge that if the clients don't agree to the goals in their service plan, they cannot achieve them, they strongly advocate that the service plan be a combined effort between client and provider. Firm advocates of the harm reduction approach among us, however, do not agree. They say that when the provider gets involved in making the service plan with the client, it is a negation of the client, and will lead to failure. As a provider, you will need to explore what works best for you since there is no consensus on the standard of care in this area.

For more information on harm reduction, from a harm reduction advocate's point-of-view, please see Appendix A, "Harm reduction versus zero tolerance" on page 123.

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Don't give up on clients

An important component of the Access-to-Care and Maintenance-in-Care models is continual, persistent effort to keep clients engaged, without being dissuaded by clients who don't respond. When clients tell us they are not interested, we tell them they may not need us right now, but they might need us later. Then we give them our card. We find that it helps clients to know that we are not giving up on them, and that we are **not** people who are just going through the motions of our jobs. When clients meet people who give up on them, it's easier for them to give up on themselves. They are often mistrustful because no one has really been there for them. We suggest using the following methods to reach out to clients, keep in touch with them, and make it easy for them to keep in touch with you:

- Give them your card and contact information
- Once a client is enrolled, call regularly to check-in
- Write letters if a client doesn't respond to calls – if you want to see if the client still lives there, you can send the letter certified mail and ask that he/she signs it upon receipt
- Make home visits if your program thinks it's safe for you to do this
- Have walk-in times and flexible agency hours and appointments

If your focus is to stay in contact with clients before, during, or after their medical appointments

- Provide the services on site, if possible
- If the appointments are outside your agency, escort them to the appointments
- Follow up on referrals you make for the clients if you don't escort them yourself

A problem we run into when continually reaching out to and trying to engage clients, is determining how much effort should be expended on clients who resist engagement, and how much effort should be directed towards clients who are more responsive. We tend to prioritize clients who need the most help and are most responsive first. It's a difficult balance to achieve, but a necessary one when there is only a certain amount of time and resource available.

Use incentives

Incentives are useful because they can be a part of providing clients with things they may need, while also helping to create a stronger bond to your program. A variety of things can be called an "incentive." An incentive is basically a draw for the client to come to your agency. Your program itself and the help you offer can be all the incentive that is needed. However, as previous discussions in this manual demonstrate, many times clients are not at a point where they can recognize the true value of what your program offers. Clients may want gratification right now, especially at first when they are not fully aware of how much they are benefiting from the services of your program. Our agencies each have their own set of incentives offered. They include:

- Nutritional snacks
- Cooking supplies
- Appointment planners
- Public transportation cards or passes
- Packs with hygienic supplies, also called "dignity packs"

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- Movie tickets
- McDonald's coupons
- Clothes
- Space for peers to network and socialize, celebrate holidays and birthdays
- Certificates for completing workshops
- Computer-generated charts illustrating their progress in certain areas, for example, with their viral load or CD4 count

We should also mention that there is a certain amount of debate surrounding the psychological impact incentives can have on the client, and the degree to which they should be used. Some staff members worry about being “used” by the client to obtain incentives. They note that clients are enrolled in many programs and come just to get incentives. On the other hand, incentive advocates feel that if clients are not yet at the point where they care about their own health, incentives are important because they help clients stay connected to care, which is the goal of our programs.

We suggest that you offer incentives, and then evaluate the situation over time. If at some point it appears that the incentives no longer help the client – if the client seems stuck, in a rut, or is no longer progressing – you may want to consider referring the client elsewhere. We also suggest that if you do provide incentives, try to be sure that you can provide them for some time to come. If at some point, you stop the incentives, or if you are unreliable about giving them out, clients who ordinarily may be satisfied with the program and trust their providers, can feel cheated and resentful. They can lose perspective that the incentives are a gift to them. If you start resenting or suspecting the client of using you, review your program's policies both alone and with the client. Discuss your concerns with your supervisors and co-workers so that you can get guidance.

Assessing and addressing **BARRIERS** to initiating medical care

As we have often mentioned, the clients we work with have many barriers to initiating health care. If we want our program participants to seek medical care, we have to remove or address the barriers they face so that they no longer prove to be obstacles. Some of these barriers are specific to clients' issues with medical care itself and the health care system, while others are psychological and life situation barriers that keep clients from initiating medical care. These barriers and suggestions for addressing them are described in more detail below. While this section is on initiating medical care, many of these barriers also affect a client's ability to stay in care. Issues of having clients stay in care, or be maintained in care, are discussed separately in more detail in later sections.

A word of caution: when you are confronted by a clients' problem, only address what you are qualified to address. If you are not trained to handle your client's problem, refer the client to the proper person or agency. You may cause harm to the client if you try to handle things you have not been trained for.

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Clients' ignorance about their own health and health care in general

It's a barrier because ...

- when people are not informed about the state of their own health, or have limited information about health issues, they may not recognize a need to see a doctor

You can address the barrier by ...

- providing health education: it empowers people with an understanding of their current condition, and available options for prevention and treatment

Clients' feeling intimidated by medical providers and the medical system

It's a barrier because ...

- clients fear they won't be able to navigate the health care system
- it is difficult for some people to communicate with medical providers
- people worry they will be stigmatized by doctors

You can address the barrier by ...

- orienting clients to the medical system beforehand: show them where they need to go, make the necessary appointments, arrange transportation if necessary (or give them the fare for transportation), and follow up with them afterwards
- if clients need escorts or advocates, go with them or set them up

Denial

It's a barrier because ...

- people are too scared to address the possibility that something may be wrong with them
- people don't want to accept limits on what they can and can't do
- people believe even if they have unsafe sex or use drugs that they will be spared problems like HIV
- people believe if they feel good, nothing can possibly be wrong with them

You can address the barrier by ...

- providing health education
- providing mental health counseling
- providing counseling on self-care

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Homelessness

It's a barrier because ...

- medical facilities require that clients have an address for mail and to apply for benefits to pay for services
- homeless people can be self-conscious about their hygiene and general presentation, and they may worry about being stigmatized
- medical and mental health problems that led to homelessness may be too incapacitating for them to seek care

You can address the barrier by ...

- helping them with their most immediate need first, even if it's not medical care, in order to stabilize them
- getting them housing and shelter; this will (in addition to helping the homeless person) give them the "address" required by medical facilities
- helping them get benefits (if they don't have any) so they can pay for care
- getting an escort/advocate to go with them to their medical appointments to advocate for them in the event of stigma and inability to communicate well, and to alleviate any fears

Substance use

It's a barrier because ...

- substance users often prioritize drugs over medical care
- the physical and psychological need for the drug makes it difficult to go through the wait time for the appointment and the process of the appointment
- there is a fear of stigma and discrimination by doctors (often with good reason)
- they want the doctor to see them in a favorable light, so they don't want to admit to being a substance user and perhaps to having other problems

You can address the barrier by ...

- connecting the client with drug treatment, if he/she desires it
- helping connect the client with medical care anyway, even if he/she does not desire drug treatment
- encouraging clients to be honest about their drug use with their doctor
- escorting clients to doctors' offices to advocate for the clients in the case of stigma or other problems
- assuring clients that if they are not happy with their doctor, they can always change doctors. Their comfort is important
- calling doctors' offices ahead of time to see if there is a long wait that day
- finding doctors' offices that have flexible hours, drop-in times, less extensive wait times and are nonjudgmental about drug use

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Substance use (continued)

You can address the barrier by ...

- counseling clients by telling them that legally, doctors are not allowed to deny them medications they need because they are getting high. Tell them, however, (or ask the doctor to tell them) about any medication interactions they may have with the drugs they are currently taking

Poverty

It's a barrier because ...

- poor people may not be able to bathe, shower or wash their clothes regularly due to homelessness or lack of resources, and may fear stigma, or just be self-conscious
- they must prioritize their resources due to the shortage of them, and may see food and shelter as more important than medical care
- poor self-esteem can result from being poor, and they may neglect themselves medically or avoid social situations due to feelings of unworthiness

You can address the barrier by ...

- helping them address their issues, whether it means finding a place for them to shower, helping them apply for benefits that would increase their level of resources, or providing counseling to improve self-esteem
- providing health education and stressing the importance of medical care

Undocumented immigration status

It's a barrier because ...

- clients fear being deported if the government finds out they have a health problem, or simply gets information about their immigration status from a medical facility
- undocumented immigrants (and sometimes even some documented immigrants) are ineligible for many public entitlements and benefits

You can address the barrier by ...

- telling your client about your local laws or policies that may protect them when they are seeking medical care
- building a relationship of trust with clients so they feel comfortable sharing their immigration-related problems with you
- knowing which entitlements and benefits the client is actually eligible for; sometimes government workers themselves are poorly informed about eligibility requirements related to immigration status

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Undocumented immigration status (continued)

You can address the barrier by ...

- helping to find the client legal help to legalize immigration status

Language

It's a barrier because ...

- clients do not understand their medical provider

You can address the barrier by ...

- connecting them to a doctor who speaks their language
- providing an interpreter for the client, or referring them to an agency that can provide an interpreter
- providing written materials in the client's primary language whenever possible

Lack of needed services at your agency or in the service system

It's a barrier because ...

- clients cannot find the services they need

You can address the barrier by ...

- making a proposal that your program add the service
- seeing if the providers in your network can work together to provide what the client needs
- educating community members in your area about the problem so they can advocate to get the necessary funds to create those programs
- raising consciousness among the clients so they can advocate for funding for the services they need. Go with them to public hearings and other venues for educating decision-makers about the lack of needed services

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Client's priorities do not include medical care

It's a barrier because ...

- clients may not seek medical care until it's too late

You can address the barrier by ...

- providing them with health education emphasizing the importance of ongoing, consistent medical care
- combining their medical appointment with activities that address something they do feel is important, such as applying for benefits that will get them financial assistance or food

Culture/religion

It's a barrier because ...

- clients may not want to see a doctor of the same culture for fear of gossip within their community
- clients may not want to see a doctor from a different culture for fear of misunderstandings
- a client's culture or religion may not permit that he/she sees a doctor of the opposite sex
- a client may only feel comfortable with doctors within his/her age range
- a female client may be from a culture that does not permit her to go to the doctor without her husband or father
- the client may not believe in Western medicine

You can address the barrier by ...

- helping to accommodate a client's culture or religion, for example, providing him or her with a doctor of the same culture or a different culture, someone of the same sex or same age range, or accompanying the client as an escort to help deal with cultural misunderstandings.
- providing health education discussing both the pros and cons of Western medicine
- when possible, working with the client's medical provider to integrate medical practices that are more culturally familiar or acceptable to the client

Lack of insurance

It's a barrier because ...

- many health care facilities will not accept clients without some form of payment

You can address the barrier by ...

- helping the client get benefits. Eligibility will vary by state and local area. For example, in NY, ADAP Plus will cover HIV-related medications and HIV primary care for HIV+ people who are undocumented or otherwise ineligible for Medicaid

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Lack of insurance (continued)

You can address the barrier by ...

- networking and seeing if anyone has any resources that can help. For example, hospital-based pharmacies may provide meds to undocumented immigrants
- encouraging the client to relocate to a catchment area where they are eligible for more benefits
- helping the client to enroll in clinical trials. Some clinical trials offer routine health care for persons who enroll. There are of course risks in participating in clinical trials; advise your client to be cautious
- checking emergency care policies in your area; emergency rooms in your area may be required to provide care to anyone who walks in, regardless of ability to pay

Lack of child care

It's a barrier because ...

- clients have no one to watch their children when they go to an appointment

You can address the barrier by ...

- helping connect them to a child care service or with your agency's service if you have one

Recently incarcerated

It's a barrier because ...

- the recently incarcerated may not be aware of services available
- sometimes they are let out of prison without documentation of their HIV status, which makes seeking HIV-related services more difficult
- although they may have been receiving medical care in prison, they might have been released without a transition plan in place

You can address the barrier by ...

- going to prisons, meeting with potential clients, and telling them of services that exist on the outside
- meeting with discharge planners in prisons, before or after people are discharged. In New York, discharge planners have 60 days to follow up with people once they have been released. If you are looking for recently released inmates, discharge planners can communicate information to them

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Recently incarcerated (continued)

You can address the barrier by ...

- writing to people in prison or working with a program that writes to prisoners
- getting in touch with legal service agencies, probation offices, and parole offices to get an idea of how to make contact with people coming out of prison
- identifying other post-incarceration services or agencies in your area and creating a procedure where they refer people to you once they are released

Mental health issues

It's a barrier because ...

- clients may not have the mental capability to understand their health issues or to address them

You can address the barrier by ...

- providing health education
- providing mental health treatment (or referring them to it)
- escorting clients to medical appointments

Domestic violence

It's a barrier because ...

- a relationship with the provider and consistent follow-through with appointments are often disrupted by attachment to and fear of the abuser. Clients may miss appointments, they may have to leave suddenly during an appointment, or they may not follow their treatment plans, because of fear of repercussions from their abuser
- abuse in a relationship can also often be a cause of depression, alcohol and substance abuse, physical ailments and anxiety. Most of these factors interfere with follow-up on case management needs and one's ability to adhere to treatment

You can address the barrier by ...

- directing the client to an agency qualified to deal with domestic violence. Do not attempt to handle a domestic violence situation yourself if you are not trained to do so. (See "Identifying and addressing domestic violence" on page 22 for more details on handling domestic violence.)

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Stigma

It's a barrier because ...

- clients feel that, for whatever reason (HIV status, sexual orientation, homelessness, race/ethnicity, etc.), they will be treated disrespectfully, and they will get inadequate medical care

You can address the barrier by ...

- empowering clients to feel comfortable with whatever the issue is that is holding them back (see “Advocating for our clients” on page 64 for how to teach clients to be self-advocates)
- giving clients alternatives to keep in mind should they see a doctor they feel uncomfortable with
- providing clients with escort services or an advocate

Perception of low risk

It's a barrier because ...

- clients do not feel they are at risk, or that they put others at risk, so they don't seek medical care. Examples are:
 - people who are in denial that they could be HIV positive
 - people who engage in risky sexual acts without protection because they do not consider those acts as “sex”
 - HIV+ people who have unsafe sex with other HIV+ people thinking that this is completely safe

You can address the barrier by ...

- providing clients with health education

Client **ADVOCACY**

Although client advocacy may be important both for initiating medical care for a client and maintaining a client in care, it is discussed here because these skills may be more crucial in the early stages of establishing a client in medical care.

What is an advocate?

Advocate used as a verb is to defend; used as a noun it is a “defender.” In a social services sense it means to speak up for and protect the rights of the client, and to help obtain for them benefits and services they need and are eligible for.

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Advocating for our clients

In our role as problem-solvers, we often have to advocate for our clients in order to resolve barriers to treatment. This means interacting with public and community-based organizations, nurses and doctors within our own hospital system or outside, possibly with family members, and so on.

REMEMBER: while we advocate for clients when they cannot advocate for themselves, our task is to mobilize clients whenever possible to begin advocating for themselves. This does not mean we will not continue to advocate, or won't step in when the client is having trouble making headway. It does mean that we must avoid the temptation to take on too much of the job ourselves. Emotional needs to be liked, admired, respected, looked-up to, can result in us trying to be all things to our clients and not acting in the clients' best interest in terms of encouraging clients develop their own skills and independence. This is called counter-transference. We may find it more reinforcing to our own self-esteem to be the Protector than the Teacher of Skills for Self-Protection. This is not actually a service to your client. The greater the degree of independence and self-advocacy your clients can learn, the better-prepared they will be for the many aspects of life where you will not be around to take care of them.

Teaching clients to be self-advocates and how to form a good relationship with a primary care provider involves some main components.

The first is **honesty**. This is the key to quality healthcare. Many clients are tempted not to be honest about certain things such as substance use in order to escape the stigma. However, they need to know that it is impossible for providers to address their problems if they don't give them a full picture of their lifestyle.

The second component of establishing a relationship with providers is **communication and advocating for one's self**. Here are a few steps to help you help your client learn to self-advocate.

- In discussion with the client, identify what the barriers are for this person in self-advocacy. Some problems may be (but are not limited to) shyness, a passive personality, unfamiliarity with the subject (e.g., medical terminology), mistrust of doctors or other health care providers, etc.
- Plan *with the client* a course of action, such as asking particular questions; having a prepared list of questions, comments or requests; talking about symptoms; etc.
- Help the client *rehearse* the encounter mentally and in role play with you or someone else. Continue the rehearsal until the client feels comfortable with it

Conducting Outreach, and Connecting Clients to Medical Care

There are three questions that your client can use to at least get started with having a successful encounter with a doctor. These questions don't take the place of developing more advanced skills, but they do provide a foundation for those skills. These questions are for use in making decisions about accepting or rejecting medication, a medical device or a procedure.

What will it do FOR me?

What will it do TO me?

What will happen if I DON'T do it?

Armed with the answer to the Three Questions, most people will have enough information to make an informed medical decision.

A third component to being a self-advocate and establishing a productive relationship with a doctor is simply knowing that there are **alternatives to this particular doctor**. Clients are often paralyzed by fears about the treatment they may get from providers if they are honest about their problems or ask questions. They need to know that they have a right to express themselves without being judged and still get adequate medical care. If they are not satisfied with their doctor for whatever reason, they can always switch doctors. If they feel they have been mistreated, "everyone has a boss." They can complain in order to try and get the problem resolved.

Maintaining Clients in Medical Care

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Once you have connected clients to medical care, the purpose of your work is now to strengthen their connection so that they go to their appointments regularly. Some of our Access-to-Care programs are done with their work after connecting clients to medical care and leave the maintenance phase to other parts of their agency or to other programs. Many of our Maintenance-in-Care programs pick up where Access-to-Care programs leave off. Maintaining clients in medical care involves a specialized form of case management that is generally more intensive than regular case management. The aspects of the type of case management our agencies provide are described in more in this section. Many of the skills required for maintaining clients in care are also applicable to the work of connecting clients to care, so providers interested primarily in outreach and initiating care may want to skim this section for useful information.

Case management involves assessing the client's situation upon enrollment, creating a plan with goals for the client's progress, providing supportive counseling to the client on issues that are important to him/her, addressing the client's needs such as housing, drug treatment, or primary care through appropriate referrals and follow-up, and reassessing the client's needs and the treatment plan as you go along.

Accurate client assessment depends upon good interviewing skills. The following is a guide on developing these skills.

Interviewing SKILLS

Active listening: hearing what is NOT said, as well as what IS

There is a difference between active and passive listening. Passive listening is rather like being a stone in a stream. Water splashes on you, flows past, some splashes onto upper surfaces and some swirls around. If there is a stick in the stream a few feet away, you'll never know it: it is outside of your range. Active listening means paying attention to all the little details, and trying to see if there is a stick somewhere in the distance. You can find out by asking yourself certain questions. What is the client's tone of voice? The facial expression? Do the person's comments match the behavior you see? Active listening is a much more attentive, purposeful kind of listening than passive listening.

At its best, active listening should involve both your thoughts and your feelings, both your intellect and your intuition. In other words, you should be consciously examining what you see and hear, thinking about its truthfulness, its correspondence to other parts of the picture, whether it seems complete or whether there are pieces missing. At the same time you should listen to the voice of your feelings. Does this supposedly "straight" (sober) person seem just a little too hyperactive to you? Do you get the feeling he/she might be telling a half-truth in order not to lose your approval? If you feel it, there's a good chance there's something causing the feeling. It is at least worth checking out, by further observation or by directly (and as tactfully as seems appropriate) questioning what seems questionable to you.

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Open-ended questions and how they work

Open-ended questions are questions that cannot be answered with a “yes” or “no” or one-word answer. They are questions that invite detail and elaboration. When you ask someone a closed-ended question, it can only be answered with a yes-or-no or single reply. You get only the limited amount of information that narrowly and specifically answers the question. Example: “Is your mother’s name Mary?” “Yes.” Now you know her name is Mary. Had you asked, “What is your mother’s name?” you might have learned: “Her name is Mary Elizabeth Herringbone-Huff; she hyphenated her married name onto her maiden name.” Now you have a more precise, complete identification of this woman, you know she was married, you know she was either modern enough in her outlook or proud enough of her maternal heritage to hyphenate her maiden name onto her married name. Let’s say your client’s name is Lisa Smith; now that you know her mother’s name you can say to her, “I see you have a different last name; how did that come about?” You may find out that your client was also married, and uses her married name, or that her father was not her mother’s husband, or was her first husband, or third. In other words, by using a string of open-ended questions you can extract a lot of information. Sometimes you may want very precise, yes-or-no answers. You may want to pin the client down. That’s the time to ask questions with a more limited range of possible responses. Questions serve as a funnel directing the flow of information. Open-ended questions are a wide-mouthed funnel through which much information can flow. Closed-ended questions are narrow funnels designed to limit the flow of information to exactly what is asked, and no more.

Open and closed-ended questions each have their value. It’s a matter of picking the right tool for the job you want to do.

The truth is in the details

People seldom know the “why” of why they do things. They usually have a number of explanations handy, which they use to justify their actions to themselves and others, but they usually are not really in touch with their own motivations. When you spend some time with someone, get to know them, hear what they say, see how they act, have some time to pick up on patterns, etc., you can usually start to develop a more accurate understanding of the “why” of things.

This is useful to you for the sake of giving you a more complete understanding of your client, and useful to the client because it can help you formulate a more targeted, individual plan of action, and because you can share your insights about the client with the client to enhance his/her understanding of him/herself.

This section started off with the statement: “The truth is in the details.” Check it out for yourself. Try listening to a couple arguing, or someone describing an experience to you. Or think back to some crisis in your life. When you explain why you did what you did, you may come up with something like, “I broke my ankle in the fall and had to take the rest of the semester off.” Thinking about it in more detail, you may say to yourself, “Well, yes, I did break my ankle, but I wasn’t so happy in that school after all. A broken ankle sure handed me a great excuse to drop out (traveling by train in a cast is no picnic!) and then start again somewhere else when I was ready.” You will see that the “broad strokes” are only a suggestion of the whole; it is in the fine points and details that the whole story can be found.

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Contradictions between what you see and what the client says

Sometimes there is a glaringly obvious contradiction between what the client does and what the client says he/she is doing. A study on communication once yielded these interesting results: 70% of all communication is non-verbal, and 70% of all verbalized communication is not truthful.

Non-verbal communication includes such things as facial expression, tone of voice (not content of speech, which is verbalization), body language and behavior. If a man looks at the menus posted in the windows of two restaurants, and then goes into one of them and orders lunch, he is communicating non-verbally his preference through the behavior of going into one restaurant and not the other. Your client claims she hasn't had a beer in three months, but each time you see her there is a smell of beer on her breath and she seems a bit tipsy. She, too, is communicating non-verbally.

In interviewing and counseling it is important to be alert to these cues about what the client actually does vs. what the client says he/she does. By noting contradictions, you develop a more complete picture of not only the client's actual activities but also how the client wants to be perceived; things the client is afraid of, or addicted to, or concerned about; how the client perceives him/herself, etc. This gives you more tools to work with in helping that person stay on track. This is also another example of how paying attention to the fine points and details in your client's presentation can give you a truer understanding of your client.

The difference between confrontation and judgment

Sometimes it makes sense to keep your observations about the client to yourself, for example, when to do otherwise would be to scare or alienate the client, or damage their self-image, etc. Sometimes it is obviously more useful to confront the client directly about their behavior or about contradictions between what they say and what you see. In that case, it becomes especially important to master the art of confrontation without judgment. The goal here is to identify the fact that you see a discrepancy, or that the client is doing something potentially harmful to oneself or others, without seeming to be judging or condemning the client, or finding the client lacking.

In this case it would, for example, be appropriate to say something such as, "It seems to me that even though you say you are not drinking, each time I see you, you seem to be intoxicated and you smell of alcohol. What's the story?" Assuming the client gives you some more details, a suitable follow-up might be, "I'm concerned that if you are drinking you may be missing medication times." This places the focus of your confrontation on possible negative effects for the client, rather than on the behavior as a "bad" or undesirable behavior in itself.

Everyone has some biases regardless of how one prides oneself on "not being prejudiced." Sweeping your biases under the rug on the assumption that if you ignore them they won't get in the way is a formula for acting out your biases inadvertently. Clients aren't fooled. If you are judging them they will feel it. The better you know your own judgment "tripwires" the less likely they are to get the better of you.

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Creating an **INDIVIDUALIZED PLAN** for the client, addressing client needs, and reassessment of the plan

Formulating a plan from the information you gather

Once you have all this comprehensive information about your client, you are ready to start formulating a plan. The plan should address all the major areas of need you have identified and should be formed with the agreement and cooperation of the client. Remember this formula: people do better when they have a sense of ownership about their choices and actions. Nine times out of ten, if you and your client don't see eye-to-eye about what the client needs, the client will do what he/she feels is appropriate. This is about perception, not about Absolute Truth. Sure it would be great for your client if he would stop shooting up, or she would leave her abusive mate, but if he or she does not see the issue the same way you do, it is his/her perception that will rule.

In designing programmatic goals, the thumb-rule is: use short-term goals as steps toward a long-term goal, and be able to measure or evaluate the result (outcome). For example, your long-term goal may be, "Mary will keep 8 out of 10 doctors' appointments within two years." Mary is scheduled for an appointment monthly; that means you are aiming for 80% adherence within 24 months/24 possible visits. Your short-term goal could be, "Mary will keep 2 out of 5 appointments (40% adherence) within the first 6 months." You could then step up by 10% or so per 6 month period to attain your target level, or better, of adherence to appointments.

Some goals are less subject to numerical evaluation. The goal might be, for example, for the client to participate actively in a support group. You can state as your plan, "Client will be referred to Agency for support group." Follow-up assessments could reflect that "Client went for intake at Agency and was enrolled in a support group for Hispanic women with children. Client states she attends most meetings and finds it helpful." If your client states that she wants to attend meetings but sometimes gets nervous about disclosing personal issues in a group setting, you can then explore whether she wants to avoid the group setting, or would prefer to increase her comfort level in the group. Then you can design a plan to support her in whichever of these choices she makes.

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What makes a plan “individualized?”

Although many of our clients will have very similar treatment plans, there will be some unique differences in each. Even so small a matter as setting the medication reminder beeper on a 6 AM-2 PM-10PM schedule instead of a 7 AM- 3 PM-11 PM schedule is a way of individualizing the plan. Other adjustments will also distinguish one plan from another. This “fine-tuning” of the plan to suit the client’s needs is the hallmark of Individualized Treatment Planning.

What are the advantages of individualized over standardized treatment plans?

Standard-size basic bookcase shelves are typically about 8” in depth, 12” in height and about 48” long, with an overall cabinet height of about 6 feet. Have a book over 12 inches tall or 8 inches wide? Better lay it on its side...or get a cabinet with off-size shelves.

Individualization allows us to take a client-centered approach, using the client’s own needs and characteristics to provide the model for the services we offer. Planning based on standardized models does not offer such a user-friendly approach. More to the point, individualizing the plan assures that it is appropriate to the client’s needs.

Structure: breaking the problem down to its parts and addressing them all

There’s an old joke: “How do you eat an elephant?” “One bite at a time.”

In designing a treatment plan, the first step is to break the problem down into its various parts. Then you describe the action to be taken. For example:

The client is living with her three children in an inadequately heated 1-bedroom apartment, fifth floor walk-up. She has some osteoarthritis of the knees, but is ambulatory on anti-inflammatory medication. She is not known to the local HIV division of the welfare office. She receives welfare but has just gotten a letter asking her to enroll in a work program. She has Medicaid. Her sister, who avoids her, is the only family member other than her 15-year-old daughter who knows about her AIDS diagnosis. She is not close with most other family members. She misses appointments, she says, because she sometimes doesn’t feel well enough to get herself and the youngest, pre-school-age child dressed, out of the house and on the bus.

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Break it down this way:

- **Client is not known to the local HIV division of the welfare office.**

Make referral to the HIV division of the welfare office.

- **Client is inadequately housed.**

Identify housing needs in your referral to the HIV division of the welfare office, and subsequently follow-up with the welfare office caseworker (in New York City, the city welfare office can often provide housing assistance to people with HIV). Identify other sources of housing assistance; refer client to other sources of appropriate housing, if available.

- **Client is unable to work; has been referred to a welfare work program.**

Provide a letter to welfare caseworker identifying incapacity to work. Refer client for Social Security (SSI or SSD) benefits. (This is generally a better income than welfare, and many welfare departments require that the application be made.)

- **Client misses appointments due to the physical difficulty of travel by bus with her arthritis.**

Explore available resources for transportation; if needed, obtain medical documentation to support the need for enhanced transportation.

- **Client has poor social supports.**

During individual counseling sessions, discuss with client family issues impacting on her support network; assist her in strategizing alternative ways to build support. If desired and appropriate, refer to organized support such as social groups or other available support.

The above is just a model; the key point here is that the problems be delineated in bite-size chunks and the plans to address each chunk are spelled out and appropriate.

Review and revision of individual plans

On a regular periodic basis (quarterly or semi-annually is recommended) the plan should be reviewed to determine its continuing appropriateness and/or effectiveness, and modified as needed. For example, in your quarterly progress review you may note that after three months (one quarter) the mom above is on a waiting list for housing; her SSI application is pending; she has been waived from the work program; her family supports remain minimal, but she is starting to talk about disclosing her HIV status to her mother; she attends no outside support programs but has been attending approximately every other group meeting at your program; she's been following through with her appointments since she started getting transportation; now that she's able to make appointments, she has begun a multi-drug regimen.

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Given her progress, you might revise the plan accordingly: focus on following-up on the housing and SSI referrals; focus on discussing her expectations if she does disclose to her mother; encourage greater involvement in support group meetings; further explore outside support programs. In this case, you may want to pay particular attention to the medication regimen. Is she able to follow it? How about side effects? Maybe there's no problem, but you have supplied a reminder beeper. You may identify the need to acclimate to the regimen as an issue to be addressed and reminder phone-calls from a peer as the means to address this need.

The treatment plan, once established, is not written in stone. It should be a flexible, appropriate tool that changes according to the client's changing needs.

Basic supportive **COUNSELING SKILLS**

Like the assessment interview, only different: defining counseling

As clients work on changing their lifestyle, developing new skills and trying new things that will help them stay in care, they may need a lot of support. Without support, it is easy to fall back on old and familiar patterns, no matter how destructive.

Supportive counseling is an important part of case management, but remember you are not the person's therapist in a case management relationship. Psychotherapy should be provided only by a licensed mental health professional.

Many of the techniques of counseling are similar to those employed in doing an initial assessment. Active listening, open-ended questions, close observation of what you see, etc., are all parts of counseling. There are some distinctions between interviewing and counseling a client, however. The goal of an assessment interview is to collect information. It is generally a short-term process, occurring in one or several sessions but usually not over an extended period of time. The purpose of assessment is to identify issues and evaluate the client's present status. The assessment interview is not intended for problem solving or for directing the client's subsequent course of action.

Counseling generally has a longer-term time frame (though single-session short-term counseling may also occur) and DOES have as its objective such things as problem solving and analysis, guidance or education that may influence behavior change, etc. Counseling does continue to involve discovery of new or additional details, especially as the relationship builds and the client becomes more trusting. Some of the conclusions of the original assessment may have to be revised as the counseling process continues.

Building a client-counselor relationship

The labels "counselor" and "client" indicate a certain kind of relationship in which one person is the designated "professional" and the other is a person in need of help or services. The initial relationship indicated will have certain characteristics, depending on what each brings to their respective role. The counselor may have a peer-like perception of the role, or a very professional, somewhat detached perception; the client may respect or resent professionals, etc.

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During the assessment interview and thereafter, each person begins forming impressions and developing opinions about the other. Studies have indicated that many people have difficulty asking for help. They may feel weak and vulnerable, or needy and dependent, or they may resent people in authority and see the “helper” as an authority figure, or any other of a number of possibilities. The counselor may see the client in a sympathetic light, or as an opportunistic user, or again, in any number of ways. Over time, if they continue to interact, a relationship is formed.

It's important to acknowledge, on the one hand, that some clients are highly resistant to forming a positive relationship and may never give the counselor a fair shot at it. Having said that, it is also important to note that in the client-counselor relationship it is the responsibility of the counselor to try to make the relationship as positive and beneficial as possible. This doesn't mean that you should allow yourself to be abused, or that you must accommodate the client's every whim. We'll get into limit-setting below. It DOES mean that rather than personalizing the client's rude or hostile behavior you should attempt to diffuse it, and leave the door open, if possible, to future communication. It DOES mean that limit-setting should be based on both real external limits (you can't, for example, promise to solve a client's problems with a utility company, since you are not in charge of the utility company), or on reasonable inter-personal limits (you can't take the client home to stay at your house until they get their check, etc.).

Applying harm reduction thinking to counseling

In counseling there are two broad approaches (and innumerable variations of technique and theory within them.) One approach is to be very directive, identifying what the client is doing “wrong,” and telling him or her what to do that is “right.” The other is to be non-directive, to help the client reach his or her own conclusions about what courses of action are right, whether he or she can live with that change, and finally, to enact the changes decided upon. In our experience, general non-directive counseling yields better results because it offers, as in harm reduction prevention planning, maximum ownership of the change by the client.

This has special applicability in treatment adherence counseling. The treatment regimen is full of “you must” and “you have to” and “do this, don't do that.” It is no wonder many people get caught up in the simple struggle to resist direction, without ever giving a fair hearing to why adherence is so critical.

In the best of all possible worlds, it would be enough to say non-directive is better, and harm-reduction is the better model. In the real world as we know it, however, things are seldom so cut-and-dry. Sometimes you will come across a client, or your usually self-directed client will come across a moment, when he or she is completely incapable of making a decision, a choice, or of taking an action. In that case it may be necessary for you as a counselor to recognize that the client is at such a point and to step into a more directive role. Then it may be necessary to be more assertive. “I'm going to have Julio meet you tomorrow morning and get you over to the clinic, you need to be seen.” “I know you're worried about your kids if you go into the hospital, but your kids won't have you around to worry about them if you DON'T go in. I'm going to arrange for a few nights of respite care, and then we'll go over to the ER together and get you admitted.”

Try to avoid being more directive than the situation calls for, and try to avoid making major decisions for the patient unless it's a life-and-death situation with no time for delay.

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Mirroring or reflection

“Mirroring,” also called “reflection,” is a technique for assuring that you and your client have the same understanding of something or for holding up the client’s own words and actions for their scrutiny. For example, if the client tells you that “I can’t stay at home, I don’t get along with my sister, if I go there I’ll get into a fight with her; I don’t have anywhere to go, but I don’t get along with my sister,” you can pull out the salient points and “reflect” them: “It sounds like you really don’t have too much choice about where to go except your sister’s house, but I also hear that you and your sister get into a lot of arguments. Is that right?” From there you can open a discussion about what options are possible. Possibly there are no good alternatives. Then you can use this reflected information to assist the client in coming to terms with the need to accept living-conditions he or she may consider less than ideal.

Here’s another example. The client says, “I only miss a dose of medication once in a while, not a lot.” So you ask, “In an average week, how many doses do think you miss?” Suppose the answer is, “one or two.” “OK,” you say, “if we figure two misses a week for the six weeks since you’ve been on these meds, that’s about 12 doses you’ve missed so far.” After the client stops being shocked about the surprisingly large number, you can start strategizing with him or her ways to reduce that number. You have taken the same information supplied by your client and reframed it so that its significance can be more easily seen.

Paraphrasing

Paraphrasing is similar to mirroring in that it involves reframing a statement in different words that mean the same thing. The paraphrase can be based on the client’s statement, to verify the accuracy of your perception of it. It can be the client’s restatement of information you have provided, to check the accuracy of the client’s understanding. It can also be a restatement of your words, in order to give a fuller sense of the meaning by stating it differently.

Perhaps you are explaining how viral resistance develops. You tell the client, “When the medication wears off, some virus is able to reproduce, especially the stuff that’s a little resistant to the meds. This means resistant virus is increasing in numbers by reproducing.” The client restates it as an accuracy check: “The virus that’s able to grow isn’t killed by the medication any more, and its offspring isn’t killed by the medication either.” That’s one paraphrased check-point. Now you say to the client, “It sounds like you’re saying that once a virus particle becomes resistant, it can pass along that resistance to future generations of virus. Is that right?” Now the paraphrase serves to check the accuracy of the client’s understanding, and the agreement of perception between counselor and client. Now you explain that this is why every dose should be taken reliably and as close to on-schedule as possible. “This way,” you say, “The virus is prevented from reproducing at all and developing resistance. In other words, you have to keep a lid on viral reproduction in order to prevent resistance from happening.” This paraphrase is a teaching tool to make your point clearer.

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Authenticity

To be authentic is to be real. Most clients cannot be fooled. If you have genuine interest and concern in your client's well-being, she or he will know. Conversely, if you look down on the client, he or she will know that, too.

This presents an interesting challenge if you are having difficulty with a client: to be authentic (genuine, real) but at the same time to be warm, welcoming, supportive, concerned...even when you really DO have negative feelings about your client.

There are a couple of responses to this. First, if you don't genuinely like people and have a compassionate attitude toward them in their daily struggles with the Human Condition, you probably won't do well in a career in human services. Secondly, it is possible to be quite real about the behavior you object to, while being equally real in your concern for the person's well-being: "You're a good guy, John, when you're sober and you take the time to think. You can be a real nasty character when you're stoned, or looking to get stoned, and you think someone's getting in your way." This kind of authenticity, based on distinguishing between what people do and who people are, can actually serve the valuable therapeutic purpose of intervening in the obnoxious behavior while continuing to affirm the individual worth of the person.

Once in a while an individual can grate on you so severely that there is no possibility for you to work successfully with that person. Although we often learn a great deal about the art of counseling from such "difficult to counsel" clients, if you feel you are really unable to build a relationship with such a person you are encouraged to bring the issue to your supervisor. That way, if you can't be helped to work with this person effectively, the case can be reassigned.

Body language and facial expressions: yours and theirs

Remember that research finding about communication: 70% of all communication is non-verbal, and 70% of verbal communication is untrue. We get far more cues and information than we realize from non-verbal sources. Other research involving early childhood development shows that infants begin recognizing the faces of familiar people (mother first, usually) within the first few months of life. They begin to discern and respond to facial expression early, too. A baby of a few months will respond with smiles to a smile and with tears to an angry face. Babies will react fearfully to threatening gestures like a raised hand coupled with an angry facial expression. As we mature we integrate an ever-more complex repertoire of non-verbal cues into our perception of others. You observe the client; the client observes you. Hopefully, as a trained, experienced and professional observer, you are learning all the time to refine the accuracy of your "reading" of non-verbal communication. The client, who may have less formal coaching in this, may nonetheless be an excellent observer, or, on the other hand, he or she may be less quick to see the meaning behind subtle body language.

There is not much you can do about deliberately altering some of your non-verbal expressions, since they are automatic physical expressions. Actors do learn to have a high degree of control over facial expression and body language. The very best actors, the ones about whom we say, "he always becomes his character," are the ones who develop the most authentic-seeming voluntary control over these expressions. Unless you are willing and able to develop advanced acting skills, you will probably be much more transparent to your clients than you realize.

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By the same token, even street-smart “performers” of the kind who are good at lying to and manipulating counselors, also are limited in their ability to completely cover-up non-verbal expressions. Hone your skills as an observer and you will improve the accuracy of your perception of your clients.

IMPORTANT: As we mentioned before, sometimes the visible affect (visible signs of the person’s emotional state, such as a sad expression or tears, or laughter and apparent good humor) and the spoken statement don’t agree. This is a red flag to you to explore further what is really going on with your client. Also look for subtle physical cues; for example, constantly crossed arms and legs express a “closed,” more private personality, while broad gestures and uncrossed legs may indicate a more open, expansive personality.

Proxemics: bodies in space

Closely related to face and body language is proxemics, the study of bodies in relation to each other and in relation to surrounding space. For example, in some cultures it is common for people to sit or stand very close when talking. This is true of many Latino and Caribbean subgroups. Other groups, like caucasian Americans, are accustomed to staying a bit further apart. In addition to obvious physical placement, there are more subtle proxemic differences between individuals and cultures. Many Caribbean people emphasize their statements by touching the person they are speaking with. Sometimes this is a touch on the arm or hand, but sometimes it is a touch on the chest or belly, areas where a white American would find it uncomfortable to be touched by a social acquaintance.

There is a verbal cousin of physical proximity which may be described as emotional space. This involves personal comments and observations that may be better tolerated by some individuals than others, or is more acceptable in some cultures than others. For example, in Caribbean and Asian culture, personal observations (about, say, weight or personal appearance) are more acceptable than in African American, Latino or White culture. Although a person’s cultural background influences his or her perception of physical and emotional space, individuals vary widely in their preferences, even within cultures. Generally a more relaxed and outgoing person will tolerate close physical proximity or personal comments better, while a nervous, introverted or anxious person will tend to withdraw.

Coaching and rehearsal

Sometimes the counselor’s role is to draw out what is going on inside the client. Sometimes the role is to teach the client new information or a new skill. At yet other times, the role may be to prepare the client to face some difficult challenge, such as a hospitalization or a medication change. Useful techniques for accomplishing these things are coaching and rehearsal.

Coaching involves offering support, encouragement, and a non-critical evaluation of what the person is doing, with pointers for how to make improvements. Think of all the supportive aspects of sports coaching, without the aggression sports coaches sometimes express. Here are some examples:

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- *The client wants to tell you something but finds it awkward and embarrassing. You say something like, “I know you’ve got something to get off your chest; whenever you’re ready we can talk about it.” This is coaching to prompt better communication. You are offering encouragement without judgment, and you are making it safe for him to speak.*
- *You know your client has a number of questions to ask the doctor, but often gets nervous while seeing the doctor and forgets to ask her questions. In a phone call with her the day before her appointment you ask her if she wrote down a list of questions to take with her. She has started, but not finished, so you discuss for a few minutes what she wants to ask, and she writes down her questions as you talk. In this case you are helping her learn a skill for getting information and feeling more in control.*
- *Your client is about to go into the hospital and she’s very nervous. Although her kids are safe with her sister, she’s worried about them, she’s worried about getting out in time to pay her bills, she’s worried about getting her check at the beginning of the month, and, oh yeah!, almost as an afterthought, she’s worried about needing a lymph-node biopsy. So you spend some time with her going over the plans for the kids, the arrangement to have her sister pick up her check from her mailbox on the 1st, the back-up plan for her to obtain a check-cashing letter from her caseworker authorizing the sister to cash the check and pay her bills, etc. In this example you are coaching her to make advance plans for foreseeable problems, again giving her a greater sense of control.*

Though we don’t always realize it, most of us rehearse our responses to various situations, or how we will solve a problem, or carry out a complex physical task. Some rehearsal is physical, like practicing your swing in stickball. Some of it is mental, like imagining that swing. In some ways it’s kind of like remembering a phone number until you can write it down. You repeat it, wear it into memory. Of course, it can be very complex things that we rehearse, both physically and mentally, like driving a car or solving equations.



Rehearsal in the counseling sense means much what it does in the theater: practice, practice, practice!

In counseling we may sometimes encourage our clients to think about a potential problem, think about how they could best respond to it, and then rehearse the response. They can rehearse in the privacy of their own minds and also in role-play with us. For example, a role play where the client asks his/her partner to use condoms during sex, can be rehearsed like this: Say “I’ll be your husband, just think of me as Jim, and you practice telling me that you want to start using condoms, even though we are both positive, to avoid re-infection and cross-infection and possible infection with other organisms.” Your client, at first a little awkward and giggling with slight embarrassment, can try, and then try again, with more authority on each try.

Maintaining Clients in Medical Care

This combined use of coaching and rehearsal is a very good teaching tool for skill-building and for planning ahead to deal with possible problems. In fact, it is such a useful tool that it is good to get your clients into the habit of mentally rehearsing things for themselves.

Setting and respecting boundaries

How close do you like people to get to you physically on short acquaintance? How much personal information will you share with a stranger? With an acquaintance? With a friend? With a relative? Are there secrets you tell no one? Is your life an “open book?”

These are boundaries, the limits we set on others and ourselves for “closeness.” A healthy, sane, reasonably stable adult will have boundaries that protect privacy while allowing relationships to grow. That person will also be able to respect another person’s boundaries, and not try to overcome them by force or ignore them, nor will he/she trivialize another person’s boundaries. That same person, blessed with good mental health and developmental maturity, will maintain his/her own boundaries comfortably, without anger or fear of invasion, because he/she has a clear sense who he/she is and does not become insecure when others are less certain in their boundaries.

Boundaries are a healthy and necessary part of human functioning. If the skin provides a barrier and containment for the rest of our bodies, psychological boundaries can be thought of as the “skin” surrounding our mental and emotional contents. A breakdown in one’s own boundaries, or the capacity to respect someone else’s, is a breakdown in mental health. Sometimes this is encountered among our clients because of underlying mental health problems they have, independent of their HIV status.

Sometimes boundaries break down as an emotional response to illness. The person feels vulnerable and childlike because of the threat to their survival, so he/she resorts to childlike defenses. Since children run to Mommy or another “safe” adult when threatened, your client may identify you with Mommy or that other safe person and practically and emotionally “run to you,” relaxing their boundaries to include you as a more intimate part of their emotional functioning than you really are. There is a flip-side to this: since the person has now opened up to you, they want you to open up to them too. Some relaxation of boundaries is natural and desirable as a therapeutic relationship grows, but it is almost never productive or beneficial to buy into a total breakdown of barriers. You lose your authority and the client loses his or her protector. It is precisely when your clients are at their most vulnerable that they need you to be strong enough to maintain the boundaries and save them from disclosing so much of themselves that all sense of safety and privacy, and hence dignity, is lost.

Conversely, when you or the client are too rigid and well-defended, communication breaks down because one or both parties are more vested in concealment than sharing. A frontal assault on your client’s defenses will not eliminate them, but patient, friendly, genuine concern over time will often slowly loosen them. You’re the counselor; it’s your job to be the patient, understanding one. If a client makes you feel very rigid and guarded, talk to your supervisor: you need help with this one.

Maintaining Clients in Medical Care

I've got you under my skin: transference and counter-transference

We all have our baggage, held over from earlier life experiences. Some of the most profound baggage we carry comes from our earliest family experiences. This is the stuff that shaped us in childhood, that we reacted against in adolescence, that influences us throughout our adult lives. Sometimes we see something in another person reminiscent of some significant person from our childhood. This can color our entire perception of that person, determine how we relate to them, even whether we like them or not. We may carry negative feelings over, and be angry or resentful toward someone who has not actually done anything wrong. We may carry positive feelings over and expect great things from someone, and possibly be deeply disappointed if the person cannot deliver as expected.

When the client does this, we call it transference. In psychotherapy an understanding of transference is critical to interpreting a person's behavior, and can be a major tool in treating the person by giving us deeper insight into how the person was formed and how he or she functions. In the kind of supportive counseling/case management relationship you will have with clients, it is valuable to understand transference and to recognize that sometimes it may be useful to say something like, "I'm not your mother, I'm not the person who did terrible things to you" While it is not your job to conduct psychotherapy and not necessary to have a psychotherapist's in-depth knowledge about transference, a basic understanding of transference can help you to work successfully with the client.

When we as counselors see in our clients a reflection of ghosts from our past, we call it counter-transference, which is basically the same as transference in that it is the result of held-over baggage from the past. The difference is in the level of understanding we bring to our role of counselor. Because we know that this counter-transference can and does happen, we can be on the lookout for it in ourselves. That doesn't mean it will never slip in and surprise us, or that a supervisor will never say, "Do you think maybe you're counter-transferring onto her a little bit because her family reminds you of your own?" But, "forewarned is forearmed," it is said. You are less likely to get caught up in counter-transference if you are aware that it could happen than if you are blissfully but counter-transferentially ignorant.

If you find yourself over-personalizing the client's plight, if you have to fight back the urge to invite him or her to move in with you "just till you get settled," if you weep each time your client gets sick, the odds are you are counter-transferring onto that person. By the same token, if you have a total intolerance to someone who always seems to rub you the wrong way; if being around that person sets your teeth on edge, you are also counter-transferring.

Every human services practitioner experiences transference and counter-transference from time to time. The best approach to dealing with it is to discuss it with your supervisor and develop with his or her help a care plan for your client (and maybe for yourself) that helps you identify and deal with transference issues. In extreme cases it may be advisable to transfer the client to another worker. This is a last resort, though, and one should try to work it through first.

Maintaining Clients in Medical Care

Making REFERRALS

Your agency will most likely not offer all that your client needs. It is therefore necessary to familiarize yourself with other agencies and programs that can help your client. You will find other programs and agencies that are useful to your client through formal means, like directories, and informal means, such as networking. Not only is it important to have referrals available to you, but to know about the actual referral beforehand, if possible. Important facts to consider are:

- *Is the referral in a location that is good for the client?*
- *Do they have services the client needs?*
- *Are you satisfied with the quality of the services?*
- *Are there long wait times and appointments?*
- *Will your client be stigmatized in any way while at the referral location?*

If it is not possible to obtain this information beforehand, follow up with the client after he or she completes the referral so that you can learn more about the referral agency for the future.

You may need to help clients get to a referral. They may need public transportation passes, money, a car service or a ride from your mobile van if you have one. Clients may also need an escort.

The importance of referrals, how to set them up, and the need to evaluate them has been discussed in “Setting up linkages with other programs” on page 31.

Maintaining Clients in Medical Care

Regular FOLLOW-UP

Regular and consistent follow-up with your client is necessary to ascertain whether he or she is meeting goals you both have set up in the client's plan. If he/she knows you will be calling regularly to find out what is happening, it can help motivate the client to meet those goals. Additionally, it can help prevent the client from losing touch with your agency, and from dropping out of medical care. Before engaging in any type of follow-up activity out of the office, however, it is important that you **get consent from the client to follow up with him/her**. He or she may not want you to call at home. The client may fear people will ask questions. Also, the client may not want you to call a referral agency or hospital. He or she may be uncomfortable if you call an emergency contact number if you lose track of him or her. Discuss this matter with the client beforehand to assess his or her comfort with this. You may also have release forms you want clients to sign, permitting you to try and find them if you lose touch with them. It is worth working out a system for finding the client as early as possible as this is a crucial aspect of keeping the client connected to medical care. There are some strategies you may come up with to address the client's fears about keeping in touch. For example, you can say that when you call, you will only use your name, and you will not disclose your agency.

The "follow-up" approach can be geared toward the type of client you are dealing with. If the client is relatively independent, you may not have to follow up with the client or the referral agency as often. Clients who need more help and attention may need more intensive follow-up. In contrast, if clients are "lost to follow-up," you may need to explore every possible avenue to find them. To follow up with clients who are more responsive:

- *Call the client regularly*
- *When making referrals, call the referral agency before and after the appointment to make sure it goes smoothly and that the client followed through*
- *Conduct a home visit with the client (again, evaluate safety when making home visits)*
For following up with clients who are "lost to follow-up:"
- *Write a letter to the client (you can send the letter by registered mail if you want to see if the client still lives there)*
- *Go to where clients "hang out"*
- *Talk to a friend or family member who may know the client's whereabouts*
- *Speak with other agencies clients may have contact with*
- *Check local hospitals*
- *Check jails or prisons (Riker's Island, a NYC jail, for example, has a central information number; the NY state prison system has a website – you can see if a client is there if you have his/her name, date of birth and Social Security number)*

You can also make it easy for clients to contact you in case of emergency.

- *Get a toll free number for your program and provide it to clients*
- *Provide a laminated photo ID for the client that says something like "If the client can't speak, please call . . . [your program contact information]"*

Maintaining Clients in Medical Care

Here are some strategies you can use to increase contact with clients and encourage them to come into the program office more regularly:

- *Provide alternatives to home storage for HIV medications and delivery*
 - *Create a system where clients can come in and take their meds on site. Provide a lockable storage unit with a refrigerated section*
- *Allow clients to use your agency address as theirs. When they come to pick up mail, you will see them*
- *Offer to hold important documents for clients in a secure folder on-site (for example, their birth certificates). When clients need the documents, they will come to your program*
- *If clients are getting several services from your program, set up appointments close together so that it is easier for them to go to all their appointments*
- *Make appointments for clients, but build in flexibility in case clients are late. This gives clients a chance to show up and be successful instead of discouraging them*
- *Connect clients with peer workers to provide support and escort to appointments*
- *Offer incentive services and goods*
- *Set up raffles, holiday parties, or other social events on site*
- *Offer skills-building programs in which clients can learn skills that may be useful to them*
- *Have an informal waiting room where clients can spend time and connect with other clients for support*
- *Connect clients to support groups, or provide them in your program*
- *Involve clients in a Community Advisory Board or other type of group that will help the community and empower them at the same time*
- *Provide a warm and welcoming environment for the client*

Some clients may be so sensitive to HIV stigma that they may avoid your program if there are references to HIV in the program title, staff titles, building names and badges. Although it's a complex issue, you may want to consider minimizing such references in your program if you find they are problematic for your clients.

CASE SCENARIOS

Throughout this manual, we have talked theoretically about how to address barriers clients may face. We would like to illustrate some of the concepts in a more real-world way through case scenarios that are based on our own experiences working with clients. The first four case scenarios describe a client's problems and how you might address them. The last three scenarios are presented without resolutions so that you can use the scenarios as exercises to think through how you would handle resolving the clients' problems yourself. For these last three scenarios, we provide the suggestions on the page following each scenario.

Maintaining Clients in Medical Care

Case Scenario #1: Francisco

Prior to being discharged from jail, a discharge counselor helped Francisco arrange an appointment with a physician at the ID clinic at your agency. He kept the initial appointment but then didn't come back. After he missed his next appointment and did not re-schedule it, he was referred to your Maintenance-in-Care program, and you were able to find him and convince him to come in to see you.

During your intake, you find out that Francisco is 36 years old and was recently released from jail after a relatively short (2-year) incarceration for drug possession. He also has prior incarcerations for drug-related and theft convictions. Francisco is living with his mother, a dialysis patient who is separated from his father. Francisco had recently been diagnosed with HIV just prior to his release, but has never been treated.

You also find that Francisco has resumed sporadic heroin use and that his use is escalating. He has not followed through with providing documents requested by the clinic social worker and is therefore uninsured despite being Medicaid-eligible. He is interested in getting his own housing, but he has no benefits yet and is living on his neighbor's SSI and food stamp benefits. Attempts to provide him with information reveal that he is illiterate.

You identify necessary steps to meet Francisco's concrete needs:

- 1) Connect client to the HIV division of the local public assistance office
- 2) Apply for public assistance and Medicaid for the client
- 3) Connect client to a methadone maintenance program
- 4) Refer client to a scatter-site housing program
- 5) Assist client in keeping medical appointments

A few weeks after Francisco has enrolled in your program, metrocards and small objects start coming up "missing" in the office. The connection to Francisco is not immediately apparent, but over time a pattern emerges; items are missing after his visit, particularly from areas where he had been unsupervised and not under a staff members' scrutiny. Finally, he is seen looking through someone else's handbag. The program director and you meet with him and confront him about the handbag incident and the missing items that seem to accompany his visits. Rules are established: he cannot be alone in any area of the office other than the rest room. If you leave the room to make copies, he has to go with you.

Ultimately Francisco achieves most of the initial goals of his treatment plan: his benefits are initiated, he obtains housing, he keeps his medical appointments and attains a low viral load and rising CD4 count. He continues to receive services from the program under direct observation, and he attains independence in remaining in care. No further thefts occur that can be attributable to Francisco.

Maintaining Clients in Medical Care

Case Scenario #2: Lydia

Lydia is encountered during street outreach and enrolls in your Access-to-Care program, which is located in a hospital. At her first case management visit with you, she tells you she is HIV+ and wants to know about the services you provide.

During your initial assessment, you find that Lydia is not connected to medical care, and has not seen a medical doctor in at least a year. You formulate a treatment plan for her, with the main goal being to connect her to medical care. Barriers to care that Lydia may have encountered until now are not yet apparent. You refer her to a doctor at your hospital and make an appointment for her. She goes to the appointment, and it goes smoothly.

Three months later, Lydia is due to come in for a follow-up interview with you to evaluate how she is doing in your program. She comes to the interview high, so you decide to re-schedule for another time. It is clear now that long-term substance use treatment is a need, but you don't refer her yet because:

- 1) Lydia says she is not interested in detox, and
- 2) you learn that she has domestic violence issues and that enrolling in drug treatment could aggravate them.

One day, Lydia goes to an emergency room half-naked and cursing. Doctors are frustrated and impatient and not willing to deal with her even though she has Medicaid. She sits in a chair, being a nuisance to everyone at the ER, until they can find an outpatient program for her. She is there from 9AM-6PM.

You try to get Lydia to continue seeing her doctor and to stabilize other areas of her life, but her connection to your program remains weak. She sees the doctor one or two more times. The next time you see Lydia, she curses and complains about your program, and she says that the program is not helping her or doing anything for her. Nothing you do or say convinces her to continue, and she drops out of the program.

One year later, you get a phone call from her. Lydia is in the hospital because of a suicide attempt. Hearing this, you feel helpless and as if you had not done anything for her.

Your supervisor brings in a trainer to talk to you and the rest of the staff about dealing with clients who have mental health issues. The training shows that Lydia's behavior may have been related to mental health issues, such as borderline personality disorder. People with this problem are amiable and even flattering when they feel they are getting what they want, and reject and criticize people when they cannot get it. You realize that it's important to be clear on "who owns the problem" – that it is the client's mental functioning, and not any failing on your part, that led to this outcome. Your supervisor tries to prevent staff from being discouraged in the future by providing regular training on mental health issues and holding regular case conferences.

Maintaining Clients in Medical Care

Case Scenario #3: Eddie

Eddie comes to your program as a “walk-in.” He found out about your program from a friend who is also a client of your program.

You find out through an initial intake that Eddie is in his forties, is an active drug user, and is also HIV+. He has documents confirming his HIV status. He is in a monogamous relationship with a man, but they do not use condoms because they believe that since they are both infected with HIV, they are not at risk for anything. Typically, they have sex after drinking and using crack cocaine.

Your goals with Eddie are to:

- 1) Connect him to health care
- 2) Provide him with health education to help him learn to reduce his and his partner’s risk of co-infection
- 3) Provide substance use counseling

The health educator at your program provides health and risk-reduction education relating to HIV, and you refer him for substance use counseling. Furthermore, you educate him on the increased potential for viral reproduction with cocaine use and give him condoms and literature to supplement the education provided. You make a referral for Eddie to get medical care at a local hospital, and you make an appointment to follow up with him. In order to facilitate his participation in your program and an incentive to keep participating, you give Eddie a pass for public transportation and movie tickets.

At Eddie’s most recent follow-up visit, you observe that he is in the “preparation stage” of change. He went to the medical appointment you set up for him, has not done drugs in one month, and is beginning to use condoms with his partner, though not all the time. You continue to provide health education and substance use counseling as Eddie’s situation becomes more stable.

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Case Scenario #4: Jerry

Jerry, a forty-four year old homeless man, is recruited into your program through street outreach. In addition to housing problems, he has mental health issues. Your initial assessment reveals that he has depression, low self-esteem and sexual identity issues. He has used drugs, although he has been clean for three months, and he does not know his HIV status. Jerry has no family to help him, although he receives a Supplemental Security Income (SSI) check.

You formulate a case plan, and you decide to:

- 1) address Jerry's barriers to medical care first, and then
- 2) help him get connected to a doctor after that, which will include an HIV test.

First, you tackle Jerry's housing problems and his mental health issues. Ideally, you take this step first to be sure he is stabilized and mentally ready should he have a positive HIV diagnosis. (For other clients you may change the order of what you do depending on your assessment of him/her, or resources readily available to you.) You make a referral for rental assistance, and then you help him find a place to live. In the meantime, you refer Jerry to a psychiatrist for depression and a counselor who can help him with his other mental health issues, and you find a day program for him where he can continue to be supported in his sobriety. You also work on budgeting issues and on maintaining housing with Jerry – this will be a challenge because of his history of chronic homelessness.

After Jerry's situation is more stable, you focus on getting him connected to medical care. You refer him to a doctor and for HIV testing. You work closely with Jerry and follow up with him to make sure that his medical and other appointments are being kept.

You continue to follow up with Jerry even after he successfully keeps his medical care appointments. Continued follow up is key to stabilizing clients who are motivated to make changes in their lives. You evaluate how he is doing in the day program, and you ask him about his sexual identity issues and depression. You also continue to work with him on life skills such as cleanliness in the home, personal hygiene, and budgeting.

Maintaining Clients in Medical Care

Case Scenario #5: Lisa

Lisa is 30 years old. She has two children, ages 5 and 6, and is pregnant with a third. She was diagnosed with HIV a month ago. You have worked closely with the HIV counseling and testing program where Lisa received her HIV test results, and the program has referred her to you. She works in a restaurant, but she has no medical insurance through her employer and is ineligible for Medicaid because she makes too much money at the restaurant. Because she is pregnant, however, she is temporarily covered by the Prenatal Care Assistance Program (PCAP) available in New York State. She has an abusive husband who is in and out of her life and is not much help. She works overtime to make ends meet, but when she does this, she is forced to leave her children alone at home. She has not told anyone about her HIV status.

How would you address Lisa's problems?

(see next page for our suggestions)

Maintaining Clients in Medical Care

Our suggestions for addressing Lisa's problems

- Provide HIV education and counseling
- Get Lisa signed up for the AIDS Drug Assistance Program (ADAP) and continue to work on getting other types of benefits for her so that she can have regular medical care
- See to it that Lisa is connected to appropriate medical care and is on an HIV medication regimen. Provide adherence support for her medication regimen
- Regarding her child care issues, help her find another working woman who has children and is free during the hours that she works, and vice versa. Perhaps they can alternate taking care of each other's children
- Refer Lisa to an agency that specializes in domestic violence to help her deal with her abusive partner
- Make sure Lisa gets appropriate OB/GYN care from someone specializing in HIV pregnancies so that she does not pass on HIV to her unborn child

Maintaining Clients in Medical Care

Case Scenario #6: Milagros

Milagros, who is HIV+, is referred to your program from another department within your health center. She is referred to you because she does not come to her medical appointments consistently, and she does not adhere to her medication regimen. Meanwhile, she has a high viral load and a low CD4 count. She is also an active substance user.

How would you address Milagros' problems?

(see next page for our suggestions)

Maintaining Clients in Medical Care

Our suggestions for addressing Milagros' problems

- Provide Milagros with health education and counseling regarding her viral load and CD4 count
- Ask her if she is interested in substance use treatment services and, if she is, connect her to these services
- Assist Milagros with keeping appointments
 - Ask her what she feels keeps her from coming to her appointments. Don't assume that drug use is the barrier. Perhaps the problem is that she sleeps late in the morning, so she misses morning appointments, but she can make it to afternoon ones. See if you can work around her barriers or address them somehow
 - Counsel Milagros on the importance of medical care and going to her appointments regularly
 - Call her to remind her of her appointments
 - Provide escort services to accompany to her appointments if she needs this kind of support
- Refer Milagros to a treatment adherence nurse for help with taking her HIV medications on time

Maintaining Clients in Medical Care

Case Scenario #7: Margaret

Your program's outreach workers meet Margaret during street outreach and enroll her in your program. She is 35 years old and has not been tested for HIV. While doing the initial intake, you ask her about her HIV risk factors. She states that she has not had sex in over 5 years, and that therefore her risk is low. When you ask her how she supports herself, she says that she is a prostitute, which surprises you given her description of not having had sex in several years. She says she also does sex work in exchange for drugs. She is not connected to medical care.

How would you address this client's problems?

(see next page for our suggestions)

Maintaining Clients in Medical Care

Our suggestions for addressing Margaret's problems

- Understand Margaret's language. For her, sex means being with a lover, and sex for money is just a job and not really sex
- Provide health education with a focus on STDs and how they are transmitted
- Encourage Margaret to get tested for HIV and for other STDs because of her drug use and because of her job
- See if she has benefits that would enable her to get medical care. If not, help her obtain benefits
- Connect her with medical care

Maintaining Clients in Medical Care

Case CLOSURE

Programs differ in their case closure policies. As with many other aspects of service provision, check your agency's policy and any requirements from your funder about closing cases. Some programs rarely close a case. Other programs aim to help clients with very specific needs and close the case once those needs are met.

Closing a case can be an easy or a difficult process depending on your client's needs and your program's needs. Your program's agreement with your funder may specify how many clients you must enroll per month, the type of services you will provide, and the duration of service, and this agreement will determine your case closure policy. Or, you will have clients who are clearly ready to move beyond your program, and it will be clear that the case should be closed.

But often the situation will be more ambiguous, and you may be faced with questions such as: Is the client ready to leave the program? What if the client backslides once he/she is out of the program? Am I giving up too early on this client who has never responded to any of the help I've given in the last 6 months? Is my time better spent with clients who might respond more positively to the kind of help I can give?

Here is a set of guidelines that can help you to decide when it is appropriate to close a case and when it would be better not to.

When Should You Close a Case?

- When, after a full reassessment of the client, you see that the client has met his/her goals and is stable
- When you believe a client could do better in another program
- When a client resists care and does not want it, despite extensive efforts to reach him/her
- When a client is lost to follow-up for more than 6 months
- When a program's policy requires that a client who is a danger to others in the program be discharged
- When a client moves outside of your service area
- When a client is incarcerated for a long period of time (you can then re-open it when he/she is released)

When Should You Keep a Case Open?

- When clients continue to engage in high risk behavior, such as substance abuse and unsafe sex
- When other barriers to medical care have not been resolved, for example:
 - Client is unstably housed
 - Client does not have benefits
 - Client does not have a source of income
 - Client has un-addressed mental health issues
 - Client has domestic violence issues
- When other case management plan goals have not been met

Maintaining Clients in Medical Care

A good **discharge** or **TRANSITION POLICY** is crucial for preventing problems that may occur with case closure. When handling the case of a client who is ready to move on, we suggest the following steps to prevent a client from backsliding or from feeling abandoned by your program.

Step 1

Ask the client if he/she is ready to handle the transition. Talk about his/her feelings and concerns. Ask the client how he/she pictures life after the transition. Address any problems or concerns the client raises.

Step 2

Talk about the transition with the client ahead of time. If the client is moving to a new program, educate him/her about the new program. If he/she is moving toward living independently without the help of a support program, help the client adjust to the idea of a more independent life. You have no doubt gone over independent living skills before, but discuss things you may not have covered or go over things that are especially useful again. Talk about any worries or concerns the client may have.

Step 3

If the client is moving to another program, introduce the client to his/her new case manager. Work with both of them together and see how comfortable the client is with this new person. If the client is not comfortable, talk about alternatives. Bring the case manager up to date on the work you've done together and what still needs to be addressed.

Step 4

If applicable, assure the client that your program is still available to him/her after he/she leaves in case the client runs into difficulties. Give the client your contact information at the office.

Step 5

Check up on how the client is doing periodically to see if the client is OK or if there has been any backsliding. See if any additional support is needed.

Program dependence

Sometimes a client is ready to transition but has become dependent on your program and is very resistant to leaving. If you are faced with this situation, we suggest that you first assess the reasons for the client's dependence on the program. If the client is not likely to ever be able to be on his or her own, perhaps your organization can transition the client to a program designed for lifetime support after the client's more urgent problems are addressed. In other situations that are less extreme, we have had success by working with the client and setting clear goals for a more independent lifestyle. For some clients, we try to get them alternative sources of support, while for others we encourage them to depend more on themselves. If a client is dependent on a particular staff person, we may get another staff person to sit in on their visits, or we may get them to see different service providers even if it's for the same services so that they are weaned off a particular person and re-focused on working toward independence.

Working With Special Populations

Working With Special Populations

When we talk about “Special Populations,” we are really talking about the qualities that distinguish one group of people from other groups. These qualities can include ethnic, cultural and language elements, belief systems, behaviors, lifestyle choices, health and mental health status and more. Any one person may be a member of more than one “special population.” For example, one person may be a woman, an African American, heterosexual, and chemically dependent all at once. Another may be a gay, homeless, caucasian man with depression. Each of these people fits into more than one category of “special populations” and may have health and social service needs that reflect the person’s own mix of identities.

We can see in the general population that there are basic human needs that all people share: the need for food, shelter, economic support, healthcare, dignity, etc. When we regard individuals as representatives of a group, we can see qualities that are unique to that group, the qualities that link them and define them as a group. When we regard people as individuals, we look at their commonalities with all people and their uniqueness as persons.

A balanced recognition that people have both uniqueness and commonalities with others from the groups they belong to is key to a counselor’s or case manager’s ability to deliver appropriate, relevant services to individual clients.

Working With Special Populations

Some Special Populations **UP CLOSE**

Let's take a look at some specific groups that present special needs and face special challenges in preventing HIV infection and getting HIV treatment. This is not an all-inclusive list but identifies some of the chief population-related needs most Maintenance-in-Care and Access-to-Care programs in the United States are likely to encounter. This list is presented in alphabetical order to avoid placing undue emphasis on any single group.

Adolescents and children

For the most part, adolescents infected with HIV have either become infected through sexual contact or were infected at birth through perinatal (mother-to-infant) transmission. We can assume that there are some young people regularly using or experimenting with injection drugs who became infected that way, but this seems to be an infrequent route of exposure for children and younger adolescents. The potential for injection use to be a risk factor increases with the age of the adolescent, especially in (but not limited to!) impoverished and underserved urban areas where injection drug use is more prevalent.

Although children are more likely to have become infected through perinatal transmission, it is important not to dismiss the possibility that a pre-teen or teenage child may have been infected in the context of sexual abuse. Do not jump to this conclusion without some cause or investigation, but don't disregard the possibility, especially if there is something questionable about the information available to you. What might be questionable? Some examples are an infected child whose natural (birth) mother is uninfected, or a child who was shown to be HIV-negative soon after birth and who tests positive some time later. Also keep in mind that a child who seems improbably young to be sexually active might actually be having sex consensually.

Most localities have reporting requirements and child welfare authorities to help you address known or suspected instances of child abuse, including sexual abuse.

Bear in mind that the medical definition of adolescence includes young adults up to 24 years of age. This means that some people who may be referred to you as adolescent clients may, from a behavioral and lifestyle standpoint, be, in fact, young adults. This means that they may be caring for children, may live apart from their parents or guardians, and may be generally self-sufficient.

Recent discoveries in the fields of psychiatry and developmental neurology tell us that the adolescent brain really is different from the adult brain. The adolescent brain is less time-binding; it is less likely to consider the long-term consequences of immediate actions, or to relate cause and effect. The adolescent brain is less attentive; it is more easily distracted. Adolescent judgment is often poorer than adult judgment, and the adolescent brain is less likely to take all possible factors into account in evaluating risks and making judgments. Additionally, adolescents are more apt than adults to simply disbelieve that something bad can happen to them.

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When something bad does happen to an adolescent, these biological factors can influence how the adolescent deals with the problem. Denial and avoidance are common defenses for teens when confronted with a life-altering event, and it may be very difficult to engage them in even discussing the problem, much less exercising the day-in, day-out self-discipline it takes to adhere to HIV treatment.

Adolescents are particularly responsive to their peers. In making choices and decisions, adolescents take a look around them to see what their peers are doing. Teens want to fit in and be accepted. They look at adult behavior and choices, too, but tend to validate adult guidance in consultation with their friends. Whether your goal is to encourage adolescents to accept HIV testing, or to help maintain an HIV-positive teenager in medical care, it is helpful to have your outreach and support efforts targeted specifically to that age group, rather than trying to fit adolescents into adult services.

A word about parents: unless it is the policy of your agency or of the child welfare laws in your locality to involve parents when you deliver HIV-related services to adolescents, it is advisable to conduct a thorough assessment of your client and his/her family environment before involving the parent(s). A primary task of adolescence is separation and differentiation from the parents. If you ignore this, your teenage client may become more trenchantly resistant to your message the more you push for parental involvement. Additionally, although we would like to believe that parents represent a safe-haven for children, and that parents are looking out for their child's wellbeing, this is not always the case. A poorly considered decision to involve some parents can actually increase the potential for harm for your teenage client.

Families

Sometimes HIV is a family affair. One or more parents and children may be infected, and even if there is only one infected person, everyone in the family is affected in some way. In addition to immediate family (parents, children, siblings), members of the extended family can be affected, including grandparents, siblings, aunts/uncles and cousins, and persons not biologically related who nonetheless are regarded as members of the family.

Family members can be a great resource for each other in addressing HIV, but they can also present barriers to effectively maintaining treatment. People often invest a great deal of effort in "protecting" family members from the burden of knowing about the infected person's HIV status. Sometimes, though, it is him/herself that the client is protecting, from confronting the issue squarely, from addressing how he/she became infected, and so on.

The identification of one person's HIV+ status can imply the possibility that other family members may be infected. The infected person may be very fearful of finding that he or she has infected a sexual partner or child. If a person has been infected through sexual contact with someone other than a legal spouse or steady partner, he or she may fear disclosure of extra-relational sexual activities. All of these factors can influence how effectively a family can deal with HIV infection.

Some things to watch for in families include "conspiracies of silence," the tendency of family members to isolate and not discuss the presence and impact of HIV in their lives, even though individual family members may all be aware that the issue exists; placing blame, the process of trying to identify who is at fault (first infected) when multiple family members are HIV+; and reinforcement of avoidance, the capacity of families to support each other in denying a problem and avoiding addressing it.

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On the other hand, the power of family ties to support the wellbeing of the entire family, once it is harnessed, can be a great asset in helping people address their HIV-related needs.

Formerly incarcerated

Also referred to as the “reentry population,” people returning to the community after incarceration face many challenges. Depending on the length of stay, many things may have changed since the person was last at liberty. Often prison returnees have difficulty finding and providing for the necessities of life, let alone the demands of managing HIV illness.

If the person was uninfected when entering the prison population and comes out HIV+, he or she may well have become infected via sexual contact with same-sex partners during incarceration. This can include persons who do not engage in same-sex relations when they are in the community but engaged in same-sex relations in jail because they lacked other options. For some people, this can be very difficult to acknowledge. Because, in theory, inmates are supposed to refrain from sexual activity, many prisons do not allow condom distribution. As we have already stated, though, most human beings are sexual by nature, and inevitably some inmates will be sexually active.

Despite efforts to control inmate access to drugs and paraphernalia, some people continue injection drug use in prison. This too is an avenue of exposure.

Many people are HIV+ (whether diagnosed or undiagnosed) at the time of prison entry, and the disease process unfolds during their period of incarceration. The ability of prisons to manage HIV illness varies with the policies of different jurisdictions, and often from institution to institution within a single jurisdiction, depending upon the priorities of the managers of individual prisons.

It is interesting to note that in prisons where medical management of HIV is competent, the inmates, who are literally a captive population whose use of medication is closely monitored, have near perfect adherence. If direct observation of medication use is not part of the procedures in a given prison, adherence will be poorer. Upon release, prison returnees often do not have arrangements in place for housing, food, income, and accessing and paying for medical care and medication, and will need immediate assistance with this to avoid interrupting the continuity of treatment.

When working with formerly incarcerated clients, especially those who have been in prison for a number of years, it is important to remember that this is a person whose daily life has been structured and regimented by others for an extended period. People who work with reentry populations will tell you that it is extremely difficult for returnees to structure their lives independently. Add to this the need for maintaining a stringent schedule of medications and regular medical care, and you can see that a major need of the reentry population is support in replacing internally, for oneself, the direction that has previously come from an external source.

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Homeless

To be homeless is to lack even the most minimal foundation from which to address one's HIV status and the management of HIV infection. Co-factors in homelessness often include alcoholism or other chemical dependency, mental illness, lack of marketable work skills, a history of criminal activity and/or incarceration, and other disruptions to what we regard as a more "routine" way of life. The homeless are marginalized and often cannot find a point of entry into the services that might actually help them find their way out of homelessness, because of how highly stigmatized they often are socially.

Incentives that help to meet basic needs, such as transportation reimbursement, food, access to sanitary facilities, assistance in accessing shelter, etc., can all help to engage homeless persons for HIV testing. Helping an HIV+ person to attain stable housing is one of the keys to helping that person remain engaged in medical care and adherent to medication.

Immigrants

Language, cultural and economic barriers can complicate both Access-to-Care and Maintenance-in-Care for immigrants. Depending on how HIV is regarded in the country of origin and in the immigrant's new community in the US, there is a potential for significant stigma to be associated with HIV infection. Both documented and undocumented immigrants may have limited financial resources for addressing health care, and it can be difficult to find a health care provider who is both conversant with HIV treatment and speaks one's language. Immigrants living in concentrations of population from the same homeland often cluster together and insulate themselves, to greater or lesser degrees, from the surrounding culture. Because HIV infection is associated with behaviors (sexual and substance-related) that are often culturally stigmatized, there may be a reluctance to explore the possibility of HIV infection or even resentment if HIV testing is suggested.

It is important not to confuse immigrant status and language barriers with lack of knowledge. Many people who are not fluent in English are quite well-educated and sophisticated in their understanding in their own language. On the other hand, some immigrants to the USA come from countries where the standard of education is poor, or higher education is available only to a privileged few, and the foundation of knowledge needed to understand HIV can be lacking. A careful evaluation of your client is important in order to determine what learning needs your client may have, and what information he or she may need.

It is not always possible to staff a program in such a way as to include representatives of all the cultures and languages in a community. If at all possible, staff who can speak the prevailing languages of your catchment should be selected. In planning your resources for delivering services to immigrants, it is vital to know what capabilities you have in your organization and what is available in your community. If culturally accepted, group-level activities involving members of the same ethnic group, and bilingual/bicultural peer volunteers and educators can help to bridge some of the cultural and linguistic gaps. Be sure you know what local sources of economic and health care support are available to both documented and undocumented immigrants in your area. For more information on cultural competence, see "Cultural competence, client-centeredness and a non-judgmental approach" on page 50. See "Undocumented immigrants" on page 23 for our experience with legal issues related to serving this population.

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Lesbian, Gay, Bisexual and Transgendered Persons (LGBT)

This “group” is actually several groups, linked not so much by their specific characteristics as groups, as by the fact that their distinction from other groups lies in the area of sexual orientation and gender identity. LGBT persons may also be members of other “special populations,” such as persons of color, or members of specific ethnic groups, or substance users, etc.

Because American society has not fully embraced the presence of sexual diversity, there are many commonplace misconceptions about the sexual behavior and HIV risks of the LGBT population. For the same reason, many members of the LGBT population struggle with the same social misconceptions. For example, many people including many lesbians do not believe that lesbians are at risk for HIV. This is not true; for one thing, many women who are primarily sexually active with women are also, or have also been, sexually active with men. Additionally, woman-to-woman sexual practices can include lots of opportunities for fluid exchange even without penetration, and the use of penetrative toys can also increase risk.

Although there has been a trend toward openness about sexuality over the last two decades, many lesbians and gay men still remain covert about their sexuality, and one of the challenges of promoting Access-to-Care for members of the LGBT population can be simply engaging them for counseling and testing in the first place. While sensitivity and respect are crucial to delivering all HIV-related services, in urban centers with large LGBT populations it is somewhat easier to reach people for counseling, testing, and follow-up care. In areas with a less defined LGBT community it behooves the intelligent and savvy counselor to be especially sensitive to LGBT issues and to recognize the challenges LGBT clients face.

Transgenderism refers to a psychological and biological condition in which a person feels that he or she is, or should be, of the opposite gender from the one he or she was born as. A broader definition includes anyone who identifies or behaves in a way that goes against societal gender norms. Some transgendered people may feel they were “born in the wrong body.” Hormonal and surgical modifications are sometimes made to bring the external reality into agreement with the gender the person feels he or she is. This is not the same as sexual orientation, and some transgendered persons, with or without modification, may still be sexually oriented toward partners of the opposite sex. Others may be homosexual as well as transgendered, and may be oriented toward partners of their own sex.

Bisexual persons of either gender are attracted to and/or engage in sexual activity with partners of both sexes. Some bisexual people have a preference regarding the gender of their partners but can engage sexually with both genders. Others are more balanced in their preferences.

A social phenomenon often linked to bisexuality or to covert same-sex preferences in men who engage in heterosexual sex as a cover-up is the practice described as “the down low” or “DL.” This term is often applied to young African American men who engage in same-gender sexual interactions but do not identify as gay or bisexual and do not want to be identified as such. The term, “down low,” itself, is a source of controversy, because it suggests there is something different about this form of concealment compared to the many other cover-ups people engage in regarding their sexual behavior and preferences, and because of the term’s association with the African American community when in fact the behavior takes place in all communities. The secretiveness surrounding sexual behavior “on the DL” can increase the risk to sexual partners of the men involved by fostering the illusion of low risk.

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The bottom line: human beings are sexual. Regardless of whom they choose as partners, all sexually active people are at risk for HIV and need to take responsibility for protecting themselves.

Men and Women of Color

African immigrants and people of African ancestry, including Caribbean Islanders; Native Americans, Eskimos, and Aleutian Islanders; Asians and Pacific Islanders, and Hispanics or Latinos are often categorized as being “people of color.” It is a mistake to think of all people of color as being members of one monolithic class of persons. For example, a person from Mali is culturally different from someone whose forbears came from Africa but have lived in Atlanta for the last few generations. Moreover, within each group, people may come from a variety of different national, cultural and linguistic backgrounds. Hispanics living in the USA, for example, include representatives of all 29 countries in the world in which Spanish is the primary language.

People of color are disproportionately affected by HIV, largely because of economic, racial and other social inequalities, which exacerbate HIV risk and also create barriers to diagnosing and treating HIV. The Access-to-Care and Maintenance-in-Care programs that we are discussing here offer strategies for reducing disparities in access to and utilization of services, thereby improving health outcomes for people of color living with HIV.

People with Mental Illness

The most frequently reported mental health problem for HIV+ people is anxiety, followed by depression. Sometimes these are reactive conditions related to the challenges of living with HIV. Sometimes they are pre-existing conditions the person experienced prior to HIV diagnosis.

Because of the potential for severe and persistent mental illness (SPMI) to impair judgment and limit an individual’s self-care capacity, mentally ill people who are HIV-negative may be at increased risk for HIV infection. Some examples of SPMI that can increase risk are schizophrenia, paranoia, severe depression, and chronic anxiety disorder. Mental illness also increases the risk for cofactors such as homelessness and substance abuse. Many people impaired by mental illness have difficulty accessing medical and mental health services. Mental illness can also limit a person’s ability to understand HIV, its treatment, and the ramifications of adherence.

In evaluating a client, counselors should consider the possibility of mental illness as a barrier to accessing and remaining in care and adhering to medication. If the counselor is not a mental health practitioner, appropriate referrals should be made and follow-through on referrals should be monitored to increase the likelihood that the client will receive appropriate care.

Older Adults

Once thought to be the province of younger adults, HIV increasingly affects older people. As standards of treatment have improved, people are living longer and healthier with HIV/AIDS, and are aging into middle and old age. Older adults are also sexually active but often are not seen in this way and thus may not be regarded by others or even by themselves as being at risk for HIV. Because of this, older adults are not always attuned to the need to use barrier protection such as condoms during intercourse. In addition, medical care providers may not be as quick to recommend HIV

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testing for their older patients. For example, an older adult presenting with diabetes and thrush, a fungal infection common to both uncontrolled diabetes and uncontrolled HIV infection, may be assumed to have thrush solely as a consequence of diabetes. The provider may not think of underlying HIV infection as a possible cause until the thrush persists even after the diabetes is controlled. This can delay diagnosis and appropriate HIV treatment. The failure to perceive older adults as potentially at risk may be partly to blame for an increase in the reported number of adults over 50 who have been recently infected with HIV infection.

Older adulthood is also the time of life when people may be seeking new sexual and life-partners, because of divorce or the death of a spouse. Again, failure to recognize the risk can increase the potential for new infection. While aging is a normal process, the older person living with HIV faces additional challenges. All of the issues of aging come into play, including concerns about being acceptable and attractive to new partners. Self-image and self-esteem can be diminished by HIV infection, causing the older person to fear isolation if he or she lets others know he or she is HIV+. Peer support and mental health support can be useful in engaging older persons in care and supporting their adherence to treatment for HIV as part of the global medical care older adults often require.

Physically and Developmentally Disabled Populations

Physical disability and developmental disability present a number of potential barriers to accessing and remaining in care. For one thing, medical assessment of the needs of disabled persons often focuses on their disability, which can obscure the possibility that a person is HIV+ until he or she becomes symptomatic. Assumptions about the behavior and potential for exposure of disabled persons can also result in overlooking HIV.

Some developmental delays and disabilities reduce the intellectual and learning capabilities of individuals. Patients may be unaware of or unable to learn about or identify risks, yet may be sexually active or otherwise at risk. Such limitations will also determine whether a person is capable of making and keeping appointments, setting up and taking medications reliably, and carrying out other aspects of health maintenance. Some people will only need patient education. Others may require lifetime support to accomplish these things.

Physical accessibility is something to consider carefully. If you expect some of your clientele to be wheelchair users, for example, you need to have offices and corridors they can negotiate, and ramps and elevators as needed to access your facilities. Otherwise, you may wish to structure your services so that you can go to the home or other adaptive, accessible meeting place to work with clients who can't navigate your usual service site.

People with disabilities face some degree of stigma at least occasionally in life and do not want it from their advisors and service providers. Beware of unwarranted assumptions about such things as the sexual, substance use, educational background and professional or occupational activities of your client.

Consider both the *nature* and the *degree* of disability in evaluating your client. For example, your client, a cerebral-palsied woman, may have limited mobility and speech but may be intellectually intact and simply need patience and adaptive planning to physically manage her medications successfully on her own. Another, similarly affected woman with some intellectual deficits may need someone to pre-pour medication and monitor her use of it permanently. Adaptation is the key. Assess your client's abilities as well as any disabilities, and you will maximize personalization in your approach to your client's needs.

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Recently Diagnosed

Learning that you have tested positive for HIV sometimes follows on the heels of being recently ill or hospitalized, but can result from a physician's recommendation that you be tested as part of routine care, a testing outreach initiative, or your own choice to get tested. Although the expectations one has when approaching the test have a bearing on how one will receive the results, it is always something of a shock and cause for alarm when the test is positive. As with all of human experience, people process the diagnosis in widely differing ways, ranging from prompt acceptance to profound denial, and with a range of emotional color from anger to despair to determination, and more.

No matter how well an individual copes with a new diagnosis of HIV, newly diagnosed people can be assumed to be somewhat fragile. This is another area, as in meeting the needs of disabled persons, where identifying and drawing on strengths is as important as recognizing limits. At the same time, limits as well as strengths make up a person's coping skills, and both should be sought and respected. For example, a skillful counselor will recognize that people who pride themselves on their strengths may in reality feel very threatened by an HIV diagnosis but may have a need to avoid displaying their fears in order to maintain the appearance of strength. Probe gently to determine if clients want you to give them permission, by your accepting attitude, to express their fears, or if the path of tact is to provide lots of information that may let this person find answers without actually having to ask revealing questions.

At the other end of the spectrum of response is the person who is in denial about the reality and significance of the diagnosis. This reflects a personality style that probably runs through other aspects of the person's life, a strategy of avoidance of challenges that seem too threatening to this individual. This person may avoid testing for a long time, especially if he or she has any reason to think he or she might truly be at risk. Once diagnosed, this is the person who may be extremely difficult to engage in care, and attaining medication adherence may require long, persistent coaching, assistance and monitoring. This is a person who may have confounded the efforts of many people throughout life who have tried to help and who eventually gave up in frustration. Chemical dependence is frequently a cofactor of denial and avoidance. Testing of relationships is frequent and trust is hard to maintain with this kind of client. Underlying mental health needs should be explored and addressed. Persistence, patience, and constant reengagement can help promote increments of change.

While a recent HIV diagnosis is a life crisis, it is also, as many life-altering events are, an opportunity for change and an opportunity to make a good start at lifelong management of a chronic HIV infection. Unfortunately many newly diagnosed persons squander their first treatment regimen on the learning process. Clinically, the first-line regimen is the most potentially durable regimen for a new, treatment-naïve patient. Every subsequent treatment failure due to medication resistance formation will create some limitation on future treatment options for that patient. This is an important point to impress on the person starting a first regimen. Be tolerant of the fact, though, that not all people will be able to take the logic of your teaching and apply it directly to their own adherence from the start of therapy.

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Sex Workers

“Sex worker” is a term for people engaging in a wide spectrum of sexual behavior for monetary or other gain. For the purpose of this discussion we will include sex for drugs or drug money, sex for cash or items of cash-equivalency values, but exclude marital and other domestic partnerships that may include both sexual and financial support elements. “Sex workers” include both street workers and workers in more elaborately established sex-based businesses.

Outreach, education and prevention efforts targeting sex workers have sometimes been quite successful. Many sex workers are concerned about their health and will cooperate readily in advocacy efforts to make condom use a community standard. Frequently a marginalized population, sex workers are often pleased to have their needs and rights as persons, and their ability to contribute to the public good through their own behavioral choices, addressed respectfully.

Some things to keep in mind if you plan to provide Access-to-Care and Maintenance-in-Care services to sex workers:

- There are sex workers of both genders, transgender sex workers, and widely varied sexual orientations among sex workers
- Sexual behavior practiced as part of sex work may not be reflective of the person’s behaviors and preferences in other sexual relationships. Both personal and professional activities should be assessed as part of evaluating risks, harm reduction strategies and coping and adherence capabilities
- If a sex worker seeks help in making life-changing choices to stop sex work, by all means offer referrals and assistance within the scope and policies of your agency. However, unless it is specifically a policy of your agency to actively promote cessation of sex work, you will probably have more success reaching your audience if you avoid promoting a specific agenda. If it is your agency’s mission to employ efforts to curb sex work, that will be part of your outreach focus. If it is not, remember that you are asking the sex worker client to address risks associated with his or her livelihood. A focus on making choices to promote health maintenance, risk reduction, and better health outcomes may be more appropriate than trying to get the person to stop engaging in sex work

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Summing Up

In planning and running your program, it is useful to identify the number and types of special populations in your catchment area and to make some policy decisions regarding if and how you will address the needs of subsets of your populations that may present special needs. If your agency will deliver services to specific special populations, you must ensure that your staff is equipped with training, information, and resource knowledge needed to serve that population. If specialized personnel are needed to serve a population, you must be sure you are able to provide appropriate staffing. If you are unable to meet particular needs, it is important to know what resources exist for that need in your area and to have a plan for referring your clients for those services.

Policies about ways to meet the needs of special populations vary with the overall mission and sources of support for a particular agency. For example, if your agency has an abstinence-based philosophy regarding drugs or sexual behavior, funding streams that mandate harm reduction services would not be appropriate for that program. Clients who might not be appropriate to enroll in such a program might be sex workers who are not interested in stopping sex work or substance users not willing to quit using drugs.

Evaluating and Updating Your Program

Why We Do This Work

About Us

Evaluating and Updating Your Program

EVALUATING and Updating Your Program

In order for your program to be effective and stay effective, it is important to evaluate your program and update it in response to the evaluation findings. For the kinds of programs we are describing here, the most relevant forms of evaluation are **process evaluation** and **outcome evaluation**. Process Evaluation generally refers to evaluation activities that help you to understand whether you delivered the services as you intended to. For example, process evaluation might involve counting the number of clients you served and the number and types of services provided, and then comparing these numbers to whatever numerical goals you set for your program. Process evaluation tells you how much work you did and what kind of work you did. If your program relies on previously studied and proven methods of serving clients, and you have a good quality assurance program in place to monitor the quality of your services on an ongoing basis, a well-structured process evaluation can be quite sufficient to keep your program on track.

Client satisfaction surveys are sometimes considered to be a form of process evaluation and can be an important tool in understanding how well your program is working. An example of a client satisfaction survey developed for HIV ambulatory care programs can be found at: <http://www.hivguidelines.org/Public/Content.aspx?PageID=65>

Outcome Evaluation goes to the next level, asking whether the clients experienced any beneficial changes while participating in your program. An outcome evaluation starts with defining certain desired “outcomes,” such as becoming stably housed, initiating anti-retroviral therapy, or having a reduction in viral load. An outcome like initiating anti-retroviral therapy is often seen as an “intermediate outcome” because it happens on the way to a “final outcome” like reduction in viral load. If the main goal is to reduce viral load, whatever it takes to achieve that is considered an intermediate outcome.

The 23 MAI programs described in this manual are involved in an extensive outcome evaluation required by the federal funding source. This evaluation involves collecting a wide range of information on program participants at the very beginning of their participation, and every three months thereafter. By conducting such an evaluation, we are able to monitor changes in participants’ housing status, substance use activity, and connection to medical care. One of our most important outcomes is health-related quality of life, which captures the way participants feel physically and mentally. The measure of health-related quality of life that we use is based on the participants’ self-report, meaning that it is based on what clients say about how they feel at the moment. Overall, that data we collect consistently shows that participants’ health-related quality of life improves after entering our programs.

It is not possible for an outcome evaluation to show definitively that your program caused a positive change without a more rigorous, scientific approach. Such an approach is called a randomized clinical trial, in which participants are randomly assigned to the program or to a comparison group. Conducting a randomized clinical trial is usually beyond the capacity of most community-based organizations.

In evaluating your programs, the value of qualitative information should not be under-estimated. Qualitative information includes information that comes from in-depth un-structured interviews and focus groups, for example. The information is in the form of people’s words rather than numbers. Interviews and focus groups with staff, community members and clients can reveal a great deal about how well your program is doing and how it might be improved.

Why We Do This Work

WHY We Do This Work

To wrap up, we wanted to put all of what we said in context by going back to why we do this work. Reflecting on why we do this work keeps us motivated when things get tough and also gives us focus when things get confusing. To give a variety of perspectives, below we offer the direct words of several staff members of the Access-to-Care and Maintenance-in-Care programs featured in this manual.

What brought me into HIV and high risk behavior is that I had a niece who was raped when she was seventeen, and she became HIV+ because of it. She didn't have any information on the medical aspect. So, she let herself go. She walked in the rain, and just didn't want to live. Before she died, she wrote on a paper bag that she had HIV. She died of the complications of it. Also, a lot of my friends were dying. AZT gave them a lot of side effects that were hard to take. I felt like there had to be a better way.

The better way was that I needed to help people. I was a nurse's assistant, and I knew how people should care for themselves. So, I focused on people with HIV and how to keep them from being sick from anything else. Substance use was another piece. I'm a recovering addict myself. I was affected by HIV and drugs were part of my history. I could help people with my personal and professional experience. Putting both of them together, I had a better outlook.

I especially wanted to help people of color. White people know of funding, resources and who can help. But I noticed for people of color, it wasn't happening for them. I went out to different shelters and HIV hotels. I saw that people were allowed to die in HIV hotels. This was in 2001. A lot, I caught in time. I put them in rehab centers. They weren't receiving the proper care. HASA [the city public assistance office] was paying for their rent, but no one was going door to door. That's what I started to do.

Now I'm a supervisor. I send people out like soldiers. It feels good to see people change. I get them to take care of themselves and they appreciate it. I educate people and they are open to getting the information. It's beautiful.

I never feel burned out because I work better under pressure. It motivates me. When I come up against something different, I just know that it's time to do more research and footwork. I need to pick up on it. I learn new things. You learn more and more.

What I love about this job is that you can be more useful than the doctor sometimes. Doctors help clients with the medical aspect, but they don't have all the information CBOs have, and many are behind the times.

To prevent burnout, my biggest suggestion is to stay open minded. You can't come into this field thinking you know everything. Structure is good. But you have to get to know the population, and they have to want you. It's not what you want, but it's what the client wants. You have to sell this program and show them that it will save them. And listen to the client. A client will teach you things that will help you help 100 others.

Darlene Jenkins, Project Coordinator, New York Harm Reduction Educators, ATC Program

Why We Do This Work

I have been working with the HIV population for eight years. The main reason I became involved in this field is personal. I have several members in my family who are HIV+, and others who have died as a result of the virus. Other reasons are because I want to address substance abuse, lack of education about HIV, the stigma that comes from being infected with HIV, and because I want to help those who are less fortunate and need support and guidance through difficult times in their lives

I enjoy working in the field of case management and utilizing my expertise in substance abuse because I am able to assist and enable clients to stay on the right track. I want to show them that there is hope, and that there are people in the world who don't look at them differently because they are sick.

Working for St. John's Hospital's Hope Center has not only been rewarding but has been a place where I have grown in many ways. The staff here have been a great source of strength and have encouraged me to become the person that I am today. Through ongoing education and working together with of all my co-workers at the Hope Center I will continue striving to assist my clients in their growth, stability, and well being; encourage them to make healthy choices; and assure them that there are people who really do care.

Carmen Vasquez Brown, Assistant Clinical Supervisor, St. John's Riverside Hospital, MIC Program

I've been infected with HIV for over 20 years. Two of my brothers died of this in '81. Also I was a volunteer at Montefiore Hospital and I worked with families who were infected and affected. When I moved to Westchester and Yonkers, I saw there was a real need. HIV+ people didn't have activists and advocates like they have in New York City. I felt compelled to do something about it.

The staff at St. John's is great. They don't see me differently. There is still a lot of stigma out there, but I feel great here. I will do this work 'till it's my time.

I want to help people. Many people are not educated. Many people wait until they get sick before they get treatment. That's what I did. My brothers both died, but I still waited to get treatment. And when I got sick and went to the hospital, I had no T-cells left, and I almost died. I don't want others to do the same thing.

I truly feel blessed to work with such great people – from management, to my peers, to the clients I serve. This work has helped me grow tremendously in spirit and in health. My viral load has been undetectable for over three years, and my CD4 is 890.

Melvin Littles, Case Manager and Outreach Worker, St. John's Riverside Hospital, ATC Program

Why We Do This Work

I have ten years of experience working with this population. I do it because I like helping others. What keeps me going is when I see that the work I do is worth it, when clients accomplish things, or when they are getting better, or getting their needs satisfied.

When someone comes back or follows up, or does what they need to do, that is rewarding. When they have an apartment now, or benefits, or if their child is born HIV- because they took their meds, that makes me feel good. Thank you is enough.

The key is not giving up. Just because one case is not successful, it doesn't mean that others won't be. Don't give up.

Solangel Mata, Case Manager, St. John's Riverside Hospital, MIC Program

I'm in this because of the clients. You learn a lot about human behavior. For example, before this, I never imagined there could be people who want to be HIV+ just to get benefits. Also, as a Harlem minister, this job helps me learn about my congregation. All the people I meet doing outreach are at my [church] door.

I have seen a behavioral change in some. Knowing you are making some sort of a difference is inspirational. In others, you may have planted the seed, and they may make a change with someone else's help.

Duane Ronan, Outreach Worker, Project Street Beat, Planned Parenthood, ATC Program

My first experience in the health and human services field was in the early 70's. My transition into HIV/AIDS-specific services began in the early 90's when it became a personal issue. I realized that although there were many dedicated people providing services, there was a large group of people being ignored. I wanted to give them the knowledge and the skills to access the services they needed. One of my strengths was that I had literally walked in their shoes. That experience along with the skills I gained in my past years of service have proved to be useful assets in this field.

Jose Hernandez, Supervising Case Manager, William F. Ryan Center, MIC Program

When I applied for my first HIV-related social work position in 1989 I was asked at the interview, "Why do you want to come to the South Bronx to work with drug addicts with AIDS?" My answer then, as now, is that HIV is a frontier of social medicine, a unique intersection of fundamentally human behaviors and a disease entity specific to our times. We cannot address HIV/AIDS without addressing the centrality of sexuality in human life, the human predisposition to alter our own moods and mental status, and the socioeconomic inequalities of the human condition. What keeps me going now, almost two decades later, is the stunning demonstration of human strength and resilience that people display over and over again in the face of the most extreme adversity. Nothing brings home to me more the truth that we are all in this world together, or more clearly illustrates our common humanity, than the multi-national, multi-cultural effort, and the commitment of people within their own communities, to address the challenge of AIDS.

Susan Wayne, Program Director, Bronx Lebanon Hospital MIC Program

We wish you the best of luck with your program!

About Us

About US

This manual is based on the experiences of 23 Access-to-Care and Maintenance-in-Care programs based in the New York City metropolitan area and Westchester that are funded through the Congressional Minority AIDS Initiative. Contributor and program contact information are provided below.

Bronx Lebanon Hospital Center, MIC Program

Contributors: Susan Wayne, Director

Agency Description: Bronx-Lebanon Hospital Center offers comprehensive medical and social services for persons infected with HIV/AIDS, and for affected families and individuals.

Address: 1645 Grand Concourse, Suite 1G, Bronx, New York, 10457

Phone: 718-960-1456

Website: www.BronxLeb.org

The Bridge, Inc., ATC Program

Contributors: David de la Rosa, Director; Luis Fagundes, Case Manager

Agency Description: The Bridge, Inc. provides assistance with access to needed services.

Address: 551 W. 125th St., STOREFRONT, New York, NY 10027

Phone: 212-666-2060

Website:

African Services Committee, ATC Program

Contributors: Martha Kahirimbanyi, Program Coordinator

Agency Description: The African Services Access-to-Care Program facilitates access to appropriate HIV care for clients by testing them to find out their HIV subtypes and doing the appropriate education with their health care providers. We also target high risk individuals and get them tested and referred to care if they are HIV positive.

Address: 429 W. 127th St., 2nd Floor, New York, NY 10027

Phone: 212-222-3882

Website: www.africanservices.org

About Us

Interfaith Medical Center, MIC Program

Contributors: Iveline Valerus, Retention Coordinator

Agency Description: The Interfaith Maintenance-in-Care program is primarily a retention program. We help clients strengthen their connection to medical care, adhere to their medication regimen, and keep their appointments.

Address: Primary Care Clinic, 1545 Atlantic Ave., Brooklyn, NY 11213

Phone: 718-613-6678

Website: www.InterfaithMedical.com

St. Vincent's Hospital and Medical Center, MIC Program

Contributors: Daisy Soto-Coppola, Case Manager

Agency Description: Saint Vincent's Medical Center Maintenance-in-Care Program is an outreach program that seeks to identify and locate clients of color who are lost to follow up or potentially lost to follow up, and, in collaboration with the client's abilities, engage them into medical care with intensive clinical case management.

Address: 36 Seventh Ave., Suite 415, New York, NY 10011

Phone: 212-604-7625

Website:

New York Presbyterian Hospital, MIC Program

Contributors: Elsa Gonzalez, Case Manager; Kathy Gomez, MIC Special Needs Clinic Coordinator

Agency Description: The Maintenance-in-Care Program at the Women and Children Care Center of New York Presbyterian Hospital seeks to maintain HIV-infected pregnant

and post-partum women in specialized medical services for obstetrics, gynecology and infectious disease follow-up.

Address: 633 W. 168th St., 4th Floor, VC 419, New York, NY 10032

Phone: 212-305-7222

Website: www.nyp.org

New York Harm Reduction Educators, Inc., ATC Program

Contributors: Darlene Jenkins, Project Coordinator; Edith Springer, Director

Agency Description: The New York Harm Reduction Educators is "The Cadillac of Harm Reduction."

Address: 1991A Lexington Ave., New York, NY 10035

Phone: 212-828-8464

Website: www.nyhre.org

About Us

Health People, ATC program

Contributors: Andre Williams, Case Manager

Agency Description: The Health People Access-to-Care program targets people of color who have many barriers to care, and who are HIV+ or at risk for HIV, and connects them to medical care.

Address: 552 Southern Blvd., Bronx, NY 10454

Phone: 718-585-8585

Website:

SUNY Downstate Medical Center, ATC Program

Contributors: Carolyn Ferdinand, Project Coordinator; Pamela Neely, Case Manager

Agency Description: Educating People At Risk (EPAR) is the outreach component of the STAR Program at SUNY Downstate Medical Center. Our primary function is to provide outreach intervention, HIV testing, referrals and follow up for participants at risk for HIV infection or clients living with the virus. Our target populations are substance users and commercial sex workers. We reach our clients through one-on-one street intervention and institutional outreach. Our staff consist of a Project Coordinator and two Community Liaison Workers.

Address: 450 Clarkson Ave., Box 1240, Brooklyn, NY 11203

Phone: 718-270-3897

Website: www.downstate.edu

St. John's Riverside Hospital, Park Care Pavilion, MIC Program

Contributors: Carmen Vazquez, Assistant Clinical Supervisor; Melvin Littles, Case Manager/Outreach Worker; Solangel Mata, Case Manager

Agency Description: St. John's Riverside Hospital is a Designated AIDS Center, providing quality inpatient and outpatient care to those infected with and affected by HIV. Services offered through The HOPE Center for those infected with HIV include: HIV-specific medical care, on-site dental clinic, case management services, mental health assessments, psychiatric care, support groups, medical transportation, street outreach, and HIV-related education.

Address: 2 Park Avenue, Yonkers, NY 10703

Phone: 914-964-7742

Website:

About Us

Project Street Beat, Planned Parenthood of New York City, ATC Program

Contributors: Duane Ronan, Outreach Worker; Ronald McBurney, Outreach Worker; Ina Cope, Outreach Worker

Agency Description: Project Street Beat tries to identify people who are HIV+ or at risk for HIV, and connects them to medical care and other social services they may need, using primarily a harm reduction approach.

Address: 349 East 149th St., 3rd Floor, Bronx, NY 10451

Phone: 718-783-7100

Website: www.ppnyc.org

The Institute for Urban Family Health, MIC Program

Contributors: Virna Little, Director

Agency Description: The Maintenance-in-Care Title I program provides case management services such as entitlements, advocacy, referrals, psychosocial assessment, treatment adherence, and escort services. Walk-in services are available from 9-4PM.

Address: 5098 E. 168th St., Bronx NY 10452

Phone: 718-583-3060

Website: www.Institute2000.org

Health Center at Tremont, North Bronx Healthcare Network, ATC Program

Contributors: Melissa Chiodi, Supervisor

Agency Description: The North Bronx Health Care Network Access to Care Program is affiliated with Jacobi Hospital and North Bronx Hospital. The Access-to-Care Program addresses the needs among HIV infected and/or at risk individuals living in the Bronx by providing comprehensive biopsychosocial care regardless of their ability to pay.

Address: 1826 Arthur Avenue, 2nd Floor, Bronx, NY 10457

Phone: 718-918-8717

Website:

About Us

Partnership Homeless Services Corp., ATC Program

Contributors: Fiamma Eason, Program Coordinator

Agency Description: The Positive Step Program has within it two other programs, a housing case management program and a housing case management technical assistance program. The housing program provides assistance to HIV+ individuals who are currently homeless to find appropriate stable housing. The Housing Technical Assistance Program offers free capacity building support to help service providers to secure entitlements, emergency accommodations and long term housing for homeless individuals and families living with HIV/AIDS. The Partnership runs a number of other programs including Peter's Place, a drop-in center for individuals 55 and older, and Furnish a Future, a furniture program for families leaving the tier II shelter system. For more information about these and other programs please see our website.

Address: 305 Seventh Ave., 13th Floor

Phone: 212-645-3444

Website: www.partnershipforthehomeless.org

St. John's Riverside Hospital, Park Care Pavilion, ATC Program

Contributors: Christina Hernandez, Case Manager

Agency Description: St. John's Riverside Hospital is a Designated AIDS Center, providing quality inpatient and outpatient care to those infected with and affected by HIV. Services offered through The HOPE Center for those infected with HIV include: HIV-specific medical care, on-site dental clinic, case management services, mental health assessments, psychiatric care, support groups, medical transportation, street outreach, and HIV-related education.

Address: HOPE Center, 2 Park Ave., Yonkers, NY 10703

Phone: 914-964-7833

Website:

William F. Ryan Center, MIC Program

Contributors: Jose Hernandez, Supervising Case Manager

Agency Description: The Ryan Center Maintenance-in-Care program works with minorities, primarily Black/African American and Hispanic/Latino, at risk of falling out of primary medical care, and assists them with maintaining their connection to care. The program helps them with adverse circumstances affecting their participation in care, such as loss of benefits, homelessness or imminent homelessness, or co-morbidities such as acute mental health episodes or severe mental illness, or active drug use. We also work with people recently released from hospitals or jails, and people with an unstable CD4 (<200). Service elements include outreach, assessments and service plan development, quarterly assessment and service plan update, escort and/or home visits, crisis intervention, and health education (both individual and group).

Address: 110 West 97th St., New York, NY 10025

Phone: 212-316-8357

Website: www.ryancenter.org

About Us

HHC Cumberland Diagnostic and Treatment Center, MIC Program

Contributors: Ernesto Myrie, Senior Addiction Counselor; Leonard Montfleury, Case Manager

Agency Description: The Cumberland Maintenance-in-Care program assists HIV+ clients maintain their health and a healthy lifestyle by helping them to keep medical and other health related appointments, and addressing barriers to care.

Address: 100 North Portland Ave., Brooklyn, NY 11205

Phone: 718-260-4819

Website:

Mount Vernon Hospital, ATC program

Contributors: Sophia Abreu, Case Manager

Agency Description: The Mount Vernon Hospital's HIV/AIDS Treatment Care Center's Outreach Program seeks to identify persons who are HIV positive and in need of primary care. As part of this activity, we also assist persons in the identification and elimination of personal barriers to the testing essential to proper diagnosis and treatment.

Address: 12 North Seventh Ave., Mount Vernon, NY 10550

Phone: 914-664-8000 ext. 2624

Website:

Settlement Health, ATC Program

Contributors: Hector Quinones, Assistant Director; Angelica Ramirez, Program Coordinator

Agency Description: The Settlement Health Access-to-Care program links HIV+ or high risk people of color to medical care and to other services they need.

Address: 212 East 106th St., New York, NY 10029

Phone: 212-360-2684

Website: <http://www.settlementhealth.org>

Bellevue Hospital Center, ATC Program

Contributors: Angel Suarez, Senior Community Liaison Worker; Javier Torrez, Senior Community Liaison Worker

Agency Description: Bellevue Hospital Center's Access-to-Care team works with people who are newly diagnosed as well as known positives who have been lost to follow-up. We link them to primary care, mental health services, H.A.S.A., social work, treatment adherence, dental services. We also assist them with their housing, legal, educational and social needs. We ensure that they keep their medical appointments by escorting them to their appointments when necessary. We continue to follow up with the clients until we feel that they are ready to take care of themselves without further assistance.

Address: NYC HHC, HIV Services, 462 1st Ave., 12 East 12 (12th Floor), New York, NY 10016

Phone: 212-562-2628

Website:

About Us

Harlem Hospital Center, MIC Program

Contributors: Erick Wilson, Program Administrator; Ray Garcia, Senior Public Health Educator

Agency Description: Maintenance-in-Care (MIC) provides consistent case management services to clients that see their medical providers infrequently nor at all. In addition to case management, we also provide advocacy and linkage to other services, individual supportive counseling, education, and support groups.

Address: 506 Lenox Ave., Ronald H. Brown Pavilion, Suite 4103, New York, NY 10037

Phone: 212-939-2932

Website:

Betances Health Center, MIC Program

Contributors: Jenny Almache, Case Manager Technician, Edith Quinonez, Supervisor

Agency Description: The Betances Health Center Maintenance-in-Care program was created to optimize treatment adherence and continuity of care for HIV patients. Targeting Hispanic and Black/African American adults, Betances supplements medical care with peer support and psychotherapeutic interventions to help patients overcome barriers to care that are rooted in stigma and social marginalization.

Address: 280 Henry Street, New York, NY 10002

Phone: 212-227-8401

Website:

Greyston Health Services, ATC Program

Contributors: Michael Cubria, Supervisor

Agency Description: The Greyston Access-to-Care program identifies and provides an assessment of PLWHA'S in Westchester County. We refer clients to appropriate agencies and or services, and we provide 3 to 6 months of monitoring/follow-up, focused on linking clients to community based primary care, permanent housing and other essential services. When we reach our goals with the client, we work collaboratively with him/her to develop a discharge plan.

Address: 21 Park Avenue, Yonkers, NY 10701

Phone: 914-376-3903 ext., 229

Website: www.greyston.org

About Us

New York Academy of Medicine, Division of Health Policy

Contributors: Elana Behar, Project Coordinator; John Chin, Principal Investigator

Agency Description: The Division of Health Policy (DHP) is focused on the improvement of health among society's most vulnerable populations including immigrants, people of color, children, the elderly, people living in poverty, people with HIV/AIDS, and drug users. Among other projects, the Division of Health Policy leads an ongoing evaluation of HIV programs at hospitals, community-based health centers, and social service organizations that are designed to help African Americans, Latinos and other people of color with HIV to access the care system and stay more consistently connected to it. These programs, which are located in New York City and Westchester County, are funded through the Congressional Minority AIDS Initiative (MAI), which was created to address the disparities in access to health care and health outcomes experienced by people of color with HIV. The evaluation study relies on an assessment of functional health status and other health-related measures before and following program participation to define barriers and to identify characteristics of programs successful in linking people to care. These analyses are being used to inform the planning process of the New York Title I HIV Planning Council.

Address: Division of Health Policy, 1216 5th Ave., New York, NY 10029

Phone: 212-822-7374

Website: www.nyam.org

Appendix A

Appendix A

Harm Reduction Versus Zero Tolerance

While many harm reduction principles are used in our programs, the programs embrace the philosophy to varying degrees. Because some readers may be interested in learning more about harm reduction techniques, we offer a more in-depth discussion here, authored by Edith Springer from one of our agencies, New York Harm Reduction Educators, Inc. – an agency that firmly believes in the harm reduction approach. For more information about the harm reduction approach, please contact the agency directly (their contact information is located in the section “About Us” on page 114).

I. What is Zero Tolerance?

Zero Tolerance is a strategy that has as its goal the complete elimination of illicit drug use in the United States (or whatever geographic or political entity that uses the strategy). It is predicated on the belief that all illicit drug use is bad for people; that using drugs hurts the citizens of the country. It is also predicated on the belief that it is possible to rid the country of drugs and get people to stop using them.

- A. Interdiction.** Interdiction is one of the main strategies of this policy—keeping drugs out of the country. This is extremely difficult because it is impossible to protect the borders to the extent that all drugs can be kept out. Unless you build an “iron curtain,” contraband will always be able to enter the country.
- B. Prohibition.** The second part of this policy is Prohibition. Laws are passed that prohibit the possession, use and sale of certain drugs the government deems harmful. One of the inconsistencies of this policy is that there are many prescribed medications that have similar effects as illicit drugs. For example, sedatives and psychotropic drugs are mood altering substances, just as most illicit drugs are.
- C. Classifying Potentially Useful Drugs as Illicit Drugs** Some of drugs are classified as having no medical utility, such as marijuana and heroin. This is not true in all cases, however, and there is a movement underway to have marijuana reclassified so it can be prescribed for certain illnesses (e.g., cancer, glaucoma, multiple sclerosis, migraine headaches, etc.). Pharmaceutical heroin (diamorphine hydrochloride) is used in Europe as pain medication (it is very similar to the morphine that is used for pain medication here in the U.S.). Cocaine also has medical uses. It has been used to numb the eye for ocular surgery. Ecstasy has been used in psychotherapy in the U.S. before it was classified as having no medical uses, and it is used in therapy in Europe.
- D. The Profit Motive and Organized Crime.** As we learned in the United States from alcohol prohibition (or at least we say we learned it) when you forbid the people of a country something they want, you cause more harm than good because the forbidden item is manufactured anyway and sold on the black market for excessively high prices by criminals, and organized crime grows and is strengthened. The profit motive is so strong that people take great risks in order to make big money. In addition, there is no quality control and the drugs produced, as during alcohol prohibition, may greatly harm or kill the population you are trying to protect. Thus the goals of prohibition are never met and both the citizens and the country are harmed, sometimes irreparably by prohibition.
- E. Criminal Justice System Involvement.** The result of prohibition is that ordinary citizens become criminals. Why criminalize people just because they want to get high? Families are broken up and made poor, people lose their jobs, children are taken away, partners are left alone—all because someone enjoyed changing his/her mood or using drugs to reduce pain or change intolerable emotions. Had that same person gotten a prescription from a doctor, none of this would happen. It is senseless!

Appendix A

- F. Racial Profiling.** Because of the racism inherent in everything done in the United States, more people from communities of color are arrested, convicted, and incarcerated for longer periods of time than are white people. It's a fact of life in a country which has institutionalized racism. Go to prison. See the incredible imbalance. Studies show that the typical drug user in America is caucasian, yet the typical drug user in jail is African American or Latino. Thus, the communities that can least afford to have their young members taken away at the prime of their lives, suffer more poverty and family disruption, and more parentless children are raised because of Zero Tolerance.
- G. Conclusion:** Zero Tolerance is an ill-conceived policy. Its goal—the elimination of illicit drugs—is an impossibility. Its strategies clearly have not worked. We've tried interdiction and prohibition for many years and we still have a major drug problem according to the prohibitionists. People have always used drugs to get high, and they always will. Even in the bible, alcoholic consumption is discussed, and alcohol is, of course, a drug. To separate it and say “drugs and alcohol” is just a ploy to keep alcohol socially acceptable and legal. Actually, alcohol is one of the more harmful drugs. It is far more harmful to the cells and tissues of the body than either heroin or marijuana, two illegal drugs. There is no rationality to the drug laws. A policy that causes increased harm to the country and at a great price—both financial and human, should be changed.

II. What is Harm Reduction?

Harm Reduction is a model for policy, service delivery and behavior change. It is based on reality—what IS, rather than what we wish things would be. People use drugs. They always have and they always will. When something with potential harm is desired by the populace, the rational way to deal with it is to reduce the potential for harm or the actual harmful consequences.

- A.** Examples of harm reduction in other areas: Motor vehicles -- cars, buses, trucks -- are all potentially harmful and actually harmful. They can maim and kill people when accidents occur. They pollute the environment with their toxic emissions. People can also die of carbon monoxide poisoning. So if we followed our drug policy, we'd ban motor vehicles totally—no more cars! Just say no to buses and trucks! However, we don't. Instead we have the following ways to reduce the harm from motor vehicles:
1. Traffic laws, right of way, traffic lights, stop signs, etc.
 2. Driver's ed, learner's permits, licensing
 3. Minimum age when you can drive
 4. Seat belts, air bags
 5. Alarms to prevent theft
 6. Insurance (to pay in case of personal injury or property damage)
 7. Designated driver, breathalyzer, police checks/roadblocks
 8. Child safety seats
 9. No cell phone in hand while driving
 10. Emission control devices
 11. New types of fuel
 12. Electric cars
 13. And so on.

Appendix A

- B.** Policy: Harm Reduction as a policy looks to find ways to reduce the potential for harm of a behavior, practice, or piece of equipment, and to reduce actual harmful consequences. Syringe exchange is an example. If sharing injection equipment causes HIV transmission/infection, than instead of banning drugs, give people sterile injection equipment, educate them and support them in not sharing. Teach people how to use drugs safely and moderately. Moderation Management, an alternative to Twelve Steps, is a self-help group system that teaches people who had a drinking problem how to drink moderately like a non-alcoholic.
- C.** Service Delivery: Make it user-friendly, nonjudgmental and attract people into your program by giving them what they want and being welcoming, warm and compassionate. Have a positive service delivery environment where their needs are met the way they feel comfortable having them met—e.g., walk-in services. Meet people where they are, both physically—streetside service delivery model, and psychically--don't push things on them they don't want or aren't ready for (like saying, "you need to get off drugs"). Let them choose what services they want.
- D.** Behavior Change/ Slow and incremental. One step forward and two steps back. Change is difficult. We are informed by the Stages of Change Model: Assess where the person is on the change continuum and deliver the right service for where they are.
 - (1)** Precontemplation: no desire to change. Create contact with clients using outreach, incentives, giving what they want (food, clothing, syringes, shelter, kindness, use of bathroom, drink of water, coffee). Treat them with respect and dignity. Focus first on survival needs and safety issues (HIV prevention—condoms, bleach kits, syringes, information, support). Start to talk about the issues that confront them (HIV, hepatitis C, getting med care, getting tested, etc.) slowly and without pushing. When they start thinking about those issues, they move into next stage
 - (2)** Contemplation: not at all ready to change. Ambivalent. Yes, I want to give up drugs, but not right now. Yes, but....Help the person explore all sides of the ambivalence. What do you like about drug use? Why do you do it? What would you miss if you gave it up? Then, what is less good about it? What concerns you about your drug use? What would you gain if you gave it up? If they decide to change it in some way (and it doesn't have to be all the way to abstinence, it could be just to use clean syringes or to cut down a bit, or modify their use in some way) they move to the next stage
 - (3)** Preparation. Preparing to change. Assess barriers to change. Set goals for change. Figure out how you're going to do it (referrals to treatment, housing, services, etc.) Make a plan. Remove as many barriers as possible. Work on commitment to change. Then build confidence in ability to change. When ready, move to next stage,
 - (4)** Action. Do it. That's where you do the plan you made that should help you reach your goals. He/she may make it, or may not make it. In harm reduction the worker is nonjudgmental. It doesn't matter if the client was successful or not, we still feel the same way about the client. We help them avoid feeling guilty or ashamed. We validate the process and the intention. We help them lick their wounds and feel good about themselves for the attempt. If they do make it, the next stage is . . .

Appendix A

- (5) Maintenance. Change must be reinforced or it can be lost. Some people become volunteers or get a job or go to school as their maintenance plan. Some go to support groups. Some take on another change, like nutrition or exercise.
- (6) Most clients go back and forth through these stages. If drawing it, draw a circle to show the cyclical nature of change.

Whether clients change or they don't change, harm reduction sees each person as valuable, unique and autonomous. Each one of us should be able to determine our own lifestyle. Drug use is seen as a coping mechanism to deal with things that are intolerable or feelings that are uncomfortable. People should have the legal right to use drugs if they wish. After all, as noted above, what's the difference between the drugs doctors prescribe and illicit drugs? The difference really is who is making the money off their sale—the establishment or the criminal element.

People use/misuse legal drugs, prescribed drugs and illegal drugs. Harm Reduction acknowledges this fact and knows people cannot be controlled by laws or other people. So it seeks to reduce the harm and allow people to be as happy, healthy and contented with their lives as possible.