

# Integrating Peers into Multidisciplinary Teams:

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## A Toolkit for Peer Advocates



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Each person and agency mentioned on this page is deeply committed to bettering the lives of other people. It is my sincere hope that "Integrating Peers into Multi-Disciplinary Teams: A Toolkit For Peer Advocates" assists people as they work towards this goal of improving lives.

Sincerely,  
Cornell Wrisby, MSW  
Project Director and Director of Community Education Projects  
Cicatelli Associates, Inc.

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# Introduction

Not all people share common experiences in life. Nurses, physicians, social workers and other medical staff can relate to a person living with HIV, whether or not they live with the virus themselves. But a Peer Advocate is someone who shares certain qualities with consumers, in a way that makes the peer more of an equal to the client than any other staff in the clinic.

This “sameness” could be based on living with HIV, on racial or ethnic culture, sexual orientation, drug use, gender, age, national origin, language, class or some combinations of these life experiences. These commonalities can make a helping relationship easier and more effective for someone living with HIV.

A Peer Advocate in a multidisciplinary team can share personal experiences and insight with the team while providing support for the consumer that can ease the process of dealing with HIV. Peers also facilitate communication between the client and medical providers, educate the client about prevention, infection and disease progression, and serve as a role model.

As a member of a multidisciplinary team, the Peer Advocate:

- conducts enhanced outreach and navigation;
- provides patient education;
- supports client treatment adherence; and
- advocates for clients within the multidisciplinary team.

This tool kit will provide tools for the Peer Advocate to use in each of these tasks.

# Section I: The Enhanced Outreach Model

Enhanced Outreach refers to an outreach model that is very interactive and intensive. Other outreach models might involve meeting a client at a particular venue and distributing clinic information or other brochures and handouts. Enhanced outreach involves developing an ongoing relationship with the client, making referrals, providing education, navigating the client to services, and supporting the client in a variety of ways including helping the client with adherence. Through the work of enhanced outreach, the Peer Advocate also represents the client's interest to the multidisciplinary team, and advocates for the client.

The Relational Outreach and Engagement Model (ROEM) provides the framework for the Peer Advocate's work in Enhanced Outreach. Following the principles of this model will allow the Peer Advocate to develop and strengthen relationships with clients. This section covers the following topics:

1. The Relational Outreach and Engagement Model
2. Preparing for Outreach
3. Conducting Outreach

# 1. THE RELATIONAL OUTREACH AND ENGAGEMENT MODEL

The foundation for the enhanced outreach is the Relational Outreach and Engagement Model<sup>1</sup> (ROEM). **ROEM:**

- provides a theoretical framework for outreach and engagement;
- offers specific practices appropriate to each stage of the work;
- suggests benchmarks by which movement along the outreach and engagement continuum of care can be assessed; and
- describes *HOW* the outreach relationship will develop and take shape from moment to moment over time.

**ROEM** includes the four phases described below.

## **Phase 1: Approach**

- Honor the tentativeness of the relationship
- Outreach worker needs to be present and try to establish a connection
- Should not attempt to rush
- Meetings are random, spontaneous, loosely planned
- Visits are brief with little or no agenda
- Role of the worker is varied – *neighbor, caring observer, passerby, etc.*
- Specific activities are minimal - *a smile, a nod, offer to assist, etc.*

### ***How to do it:***

- Greet the person
- Introduce yourself
- Initiate casual conversation
- Identify yourself in your specific role

## **Phase 2: Companionship**

- Peer Advocate offers and is permitted to share the client's journey
- Peer Advocate is recognized, greeted, welcomed
- Peer Advocate seen as increasingly trustworthy

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<sup>1</sup> The ROEM model is adapted from unpublished papers by Craig Rennebohm, Mental Health Chaplaincy as seen in CAPC Enhanced Outreach Institute, March 2003.

- Peer Advocate provides a reliable presence – *listens to client’s story, offers empathy, acts with knowledge and proper timing*
- Peer Advocate is attuned to client’s current situation – *perception of self, world around them, ability to meet their needs for care*
- A series and accumulation of events together suggest shift from approach to companionship

***How to do it:***

- Hear client’s story
- Do activity together
- Identify client’s perceived needs
- Provide material assistance
- Accompany client to services
- Provide information
- Respond to emergencies
- Client initiates contact
- Meet in public venue

**Phase 3: Partnership**

- Capacity of worker and client to open their relationship of trust to a significant third party – *social worker, case manager, nurse, doctor or counselor*
- Individual’s acceptance of growing circle of care
- Worker’s companionship role continues to be critical
- Client still needs the trustworthy presence of the worker

***How to do it:***

- Identify mutual longer-term goals
- Enhance motivation to positive change
- Plan for meeting these goals
- Provide education
- Connect w/other longer-term services

#### **Phase 4: Mutuality**

- Completes the outreach and engagement process
- The growing, common human bonds shared between client and worker allows for this
- Will lead eventually to an appropriate termination
- Worker celebrates accomplishments with client
- Worker prepares for separation and transition

#### ***How to do it:***

- Adjust your helping role
- Advocate within new support systems
- Meet together to review client's work
- Monitor client's progress
- Terminate formal provider-client relationship

#### **Refer to:**

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# 1. The Relational Outreach and Engagement Model TOOLS

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**An Overview of ROEM**  
Relational Outreach and Engagement Model

| Phase                | Predominant Quality   | Characteristic Activities   | Role/Relational Stance of Worker  |
|----------------------|---|---|---|
| <b>Approach</b>      | Spontaneous, unplanned meetings<br><br>Random<br><br>Brief  | Minimal specific activities<br><br>Examples: A smile, a nod, an inquiry, a brief offer to help  | Like a neighbor, a caring observer<br><br>Like a passerby willing to stop and listen                      |
| <b>Companionship</b> | Providing a reliable presence   | Having an agreed upon, regular meeting place<br><br>Small shared tasks<br><br>Examples: Sharing a cup of coffee or a meal; Walking or riding together | Worker is recognized, greeted, welcomed and experienced as a reliable presence<br><br>Empathetic listener |
| <b>Partnership</b>   | Increasing trust in relationship to the worker<br><br>Willingness and capacity to open a trusting relationship with a third party | Extended from companionship phase<br><br>Trusting relationship now includes primary care or another provider  | Trustworthy presence<br><br>Providing information and encouragement                                       |
| <b>Mutuality</b>     | Fruition of relationship<br><br>Participant has a healthy sense of self and place   | Celebrating milestones and accomplishments together<br><br>Multiplicity of relationships  | Supportive other<br><br>Worker prepares for appropriate termination of relationship                       |

**ROEM WORKSHEET**

*Use this worksheet to help you develop an outreach plan for the population you will be working with. Describe what you would do or say for each of the phases in ROEM, ask other Peer Advocates for feedback, and then share your work with your supervisor.*

|               | Street-based sex workers who can't be seen with outreach workers | People injecting substances in a "shooting gallery" | Recent immigrants staying with family | Street based youth who never visit the clinic | Other: | Other: |
|---------------|--|---|---------------------------------------|---|--------|--------|
| Approach      |  |   |                                       |   |        |        |
| Companionship |  |   |                                       |   |        |        |
| Partnership   |  |   |                                       |   |        |        |
| Mutuality     |  |   |                                       |   |        |        |

## 2. PREPARING FOR OUTREACH

The Peer Advocate needs to prepare before going out into the community to conduct outreach.

The more you know about your population, the better prepared you will be. You can gather information such as:

- description of your target population
- where the target population can be found
- what their interests and concerns are
- their behaviors
- their special needs
- the gatekeepers who can help you access the population.

You can gather this information from:

- other Peer Advocates or outreach workers in your agency
- your supervisor
- your direct observations

**Refer to:**

Tool # 3: “What I need to know about my Target Population”

**PAGE**

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In preparing for outreach, it is also important to think about your safety.

**Refer to:**

Tool #4: “Outreach Safety Planning”

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## 2. Preparing for Outreach TOOLS

| <b>TOOLS:</b>   | <b>PAGE</b> |
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| Tool #3: “What I need to know about my Target Population” | 12          |
| Tool #4: “Outreach Safety Planning”                       | 13          |

**What I Need to Know about My Target Population**

*Directions: Write in your target population(s) and complete the worksheet for each population. Ask other Peer Advocates or your supervisor for help in identifying all the information.*

| <b>Outreach Population &amp; Situation</b>                   | <b>Where do they gather?</b> | <b>What are their interests and concerns?</b> | <b>What are their behaviors?</b> | <b>What are their special needs?</b> | <b>Who are the gatekeepers?</b> |
|--|------------------------------|---|----------------------------------|--------------------------------------|---------------------------------|
| Example: People injecting substances in a “shooting gallery” |                              |   |                                  |                                      |                                 |
|  |                              |   |                                  |                                      |                                 |
|  |                              |   |                                  |                                      |                                 |
|  |                              |   |                                  |                                      |                                 |

# Outreach Safety Planning

Some things to consider in safety planning include:

**Know the history of your area.** Are there racial or ethnic tensions? Has the population changed? Is there a history of gangs? Are there colors you shouldn't wear? What do you know about from newspapers or television news? Are there trouble spots? What do the people of the area say about it?

**Be familiar with the streets.** Know where you're going. Learn your way around and note the landmarks. Don't look confused or lost.

**Work in pairs, when possible, and communicate with the office.** If you're going someplace new, go in pairs or groups. Let your office or supervisor know where you're going and when to expect your return. Develop signals with your fellow outreach workers, to let one another know when you're in danger.

**Dress and carry yourself appropriately.** The way you dress, act and talk will affect how people interact with you. What behaviors, dress and activities might offend this community or population? Wear a visible ID badge. Don't wear expensive jewelry. Carry your outreach materials in clear plastic bags. Behave in a non-threatening way.

**Get to know store owners, safe houses and pay phones.** Develop a relationship with store owners; they may be able to help you if you're in danger. Carry change for a pay phone.

**Get to know the police who work in the area.** Let them know who you are, where you work and what you're doing.

**Trust your "gut"** If it doesn't feel safe, it probably isn't.

### Outreach Safety Planning

*Use this worksheet to help you plan for a safe outreach experience. Be sure to discuss your safety plan with your supervisor.*

**1. Know the history of your area.**

What do people say about the area?

Are there racial or ethnic tensions?  
What are they?

Are there trouble spots?  
Where?

How has the area changed in the past few years, if at all?

**2. Be familiar with the streets.**

What are the major landmarks?

Where will you do most of your outreach?

| <b>3. Work in pairs and communicate with the office.</b>            |  |
|---|--|
| Who's your contact at the office?                                   |  |
| Who is your outreach partner?                                       |  |
| How will you signal your partner if you are in danger or need help? |  |
| <b>4. Dress and carry yourself appropriately.</b>                   |  |
| What kinds of clothes are inappropriate?                            |  |
| What kinds of clothes are inappropriate?                            |  |
| Where will you carry your ID badge?                                 |  |
| What words or phrases would be offensive?                           |  |

| <b>5. Get to know store owners, safe houses and pay phones.</b> |                      |                    |                        |
|---|----------------------|--------------------|------------------------|
| Store owners  | Store name           | Owner/Manager name | Address/Intersection/# |
|   | 1.                   |                    |                        |
|   | 2.                   |                    |                        |
| Safe houses   | Safe house name      | Contact            | Address/Intersection/# |
|   | 1.                   |                    |                        |
|   | 2.                   |                    |                        |
| Pay phones  | Address/Intersection | Near what business | Phone number           |
|   | 1.                   |                    |                        |
|   | 2.                   |                    |                        |
| <b>6. Get to know the police who work in the area.</b>          |                      |                    |                        |
| Police  | Name                 | Badge #            | Precinct/Phone Number  |
|   | 1.                   |                    |                        |
|   | 2.                   |                    |                        |

### 3. CONDUCTING OUTREACH

When conducting outreach, it is important to plan how you will meet your clients, and how you will introduce yourself.

The first step when meeting with a potential client is your introduction.

The introduction sets the tone for your relationship with the client, so it's helpful to consider what to say and how to say it. Check with your supervisor or other peers for help in identifying ways to introduce yourself to clients you meet through outreach.

**Refer to:**

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| Tool #5: Three Easy Ways to Introduce Yourself | 19          |

The more you understand the clients you will be working with, the better able you will be to work effectively with them.

**Refer to:**

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| Tool #6: Tips on Outreach | 20          |

There will always be some situations that are difficult to know how to respond to. Try to think of questions or situations that you might be difficult for you. Practice what you could say in those situations with other Peer Advocates.

**Refer to:**

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| Tool #7: How to Respond in Difficult Outreach Situations | 24          |

*It is very important to know how to respond appropriately in situations where a person talks about hurting themselves or someone else.* Consult with your supervisor about how to respond in those situations, and be sure you are able to contact your supervisor when such a situation occurs.

### 3. Conducting Outreach TOOLS

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| Tool #6: Tips on Outreach                                | 20          |
| Tool #7: How to Respond in Difficult Outreach Situations | 24          |

| <b>Three Easy Ways to Introduce Yourself</b>   |  |
|--|--|
| Here are three examples of ways to introduce yourself. In the blanks on the right, write down three introductions of your own. Ask coworkers and your supervisor for suggestions and feedback. |  |
| 1. “Hi, I’m Juan. I came by because...”  |  |
| 2. “Hi. I work with ABCD clinic. I’d like to share some information with HIV/AIDS with you. . . “  |  |
| 3. “Hi. My name is Rose and I’m a Peer Advocate at XYZ clinic. Do you have a few minutes to talk? I’d like to share some information with you about the services that you might benefit from”  |  |

**Tips on Outreach with People Using Alcohol and Other Substances**

| <b>Recognize:</b>   | <b>And in response...</b>  |
|---|--|
| <p><b>Potential for guilt and shame.</b><br/>                     People who struggle with their use may feel that they should stop using, and ashamed that they cannot stop.</p>   | <p>Avoid “should” and questions that point in the direction of abstinence, unless that is the client’s goal. Focus on the client’s sense of well-being, instead of an end-goal.</p>  |
| <p><b>Fear of “tests” and authority.</b><br/>                     Sometimes people feel that no news is better than bad news, or may feel paranoid about what will happen to their results. Some people may want to avoid tests that might confirm their fears.</p> | <p>Be clear about who sees test results and why they are important. Explain confidentiality and patient rights. Explore what test results would mean for the client.</p>   |
| <p><b>Denial.</b><br/>                     Everyone experiences difficulty facing the harm and, sometimes, the pleasure of their behavior. Drug use also carries a stigma, so some clients may want to hide their concerns by denying their real experiences.</p>   | <p>Be safe, neutral and open. Avoid the words “good” or “bad”, so clients can share the gray areas that concern them. Instead of “consequences” talk about “what happens when...” and how to help clients get what they want while reducing negative outcomes.</p> |
| <p><b>Money.</b><br/>                     If a client needs a certain amount of money to support a habit, costs of services and time or money spent getting to services may be a barrier to health care.</p>  | <p>Know the financial options for care, and provide an easy, accessible way to get there.</p>  |
| <p><b>Questions.</b><br/>                     Some people who have been through the “system” get tired of answering questions about their history, especially when it’s unclear how it will be used and who will see it.</p>  | <p>Build a relationship with the rest of your team, so you can confidently describe how doctors or other medical providers will treat your clients. Validate your clients concerns and their right not to answer questions; build rapport first.</p>               |

**Tips on Outreach with Adolescents**

| <b>Recognize:</b>   | <b>And in response...</b>  |
|---|--|
| <p><b>They will test you.</b><br/>Adolescents will want to determine how to trust you. To figure you out, they'll likely try to "push your buttons".</p>  | <p>The more calm and unruffled you can be, the more likely adolescents will learn to trust what they can and cannot expect of you. Be consistently positive, supportive, repetitive and reassuring.</p>  |
| <p><b>Lack of trust is self-protection.</b><br/>When people feel alone, isolated and afraid, they protect themselves.</p>   | <p>Be respectful of your clients' feelings. Build trust at the client's pace, and follow through on what you say you'll do for the client.</p>   |
| <p><b>Adolescents are developing into adults.</b><br/>At some point during growth from childhood to adulthood, adolescents begin to learn the outcomes of their actions.</p>  | <p>Don't get angry with clients when they don't see outcomes. Try to let them see the connections themselves, with you as a consultant to their process of discovery.</p>  |
| <p><b>Confidentiality is key.</b><br/>Young people are extremely conscious of other people "knowing their business".</p>  | <p>Build familiarity with people and the process of HIV care by explaining confidentiality and patient rights.</p>   |
| <p><b>Experimentation is part of learning.</b><br/>Taking risks and learning about oneself and others in the process is key to developing into an adult. Even harmful behavior is a learning experience, despite how we might feel about the possible outcomes.</p> | <p>Frame risk-taking in terms of what your clients are learning about themselves. Most adolescents are given a slap on the hand for their sex lives and drug use. Being neutral about their behavior lets them share more of their lives, and opens the door for you to talk about real harms, instead of imagined ones.</p> |

| <b>Tips on Outreach with Marginally Housed or Homeless Populations</b>   |  |
|--|--|
| <b>Recognize:</b>  | <b>And in response...</b>  |
| <p><b>Financial and time concerns.</b><br/>Even if services are free or low-cost, street-based clients may prefer to spend their time making money.</p>  | <p>Know the financial options for care. Be very clear about what the fees will be, and the benefits of the services offered.</p>   |
| <p><b>People get asked a lot of questions.</b><br/>Homeless clients who have been in the system already may be tired of being asked about their personal history.</p>  | <p>Acknowledge that they have been approached by others before; Identify what is unique about what you are offering.</p>   |
| <p><b>Filling out forms may be scary.</b><br/>Most medical settings require a permanent address for their records. This can be intimidating and embarrassing for someone who can't fill a form out completely, either because no address is permanent or because the client can't read or write.</p> | <p>Offer a permanent address that clients can use on forms. Offer to read or fill out forms for your clients, rather than assume they can fill forms out on their own.</p>                                     |
| <p><b>Immediate concerns can outweigh long-term concerns.</b><br/>People meet their needs in the order that is the most important to them. Basic human needs like food, shelter, and social contact may be more important than making appointments.</p>  | <p>Identify what you can and can't do for them to meet their immediate needs. Help them find sources to get immediate needs met.</p>   |
| <p><b>Concern over judgments.</b><br/>Homelessness can be a humbling experience. It can also be a source of pride for some people, to have survived on the streets. Some people respond by being defensive and rejecting help.</p>   | <p>Roll with the client's resistance and at the client's pace. Remember to praise the client's strengths and resilience. Reframe 'failure' in terms of how the client had survived despite being homeless.</p> |
| <p><b>People move.</b><br/>Homeless people may be on the move, and may not be able to access the same services at the same site.</p>   | <p>Provide options for care locations, since a client's personal location may change.</p>  |

**Tips on Outreach with Immigrants**

| <b>Recognize:</b>   | <b>And in response...</b>  |
|---|--|
| <p><b>Language may be a barrier.</b><br/>Immigrants are sometimes treated as though they are not capable of understanding, when the real issue is the difference between English and their native tongue.</p>                               | <p>Either know the language or find a suitable interpreter, possibly through a local immigrant organization. Never make fun of or underestimate your client’s ability to understand what you are trying to communicate.</p>  |
| <p><b>Responses to authority and immigration.</b><br/>Some immigrants may be suspicious of the authority you represent. Others might respond by agreeing with you and saying “yes” to everything, and then not taking any action.</p>       | <p>Let clients know you are not with immigration and you will not report information on them to legal authorities. Describe what your role is, and how you can be of service.</p>  |
| <p><b>Culture.</b><br/>Cultures approach health and wellness differently. What might seem perfectly reasonable in one culture may be the opposite in another.</p>   | <p>Explore the medical approaches to health of your clients’ cultures. Do not assume every client from the same country has the same perspective. Offer services that will enhance the medical experience of HIV care, rather than pit one approach against another.</p> |
| <p><b>Gender.</b><br/>Some cultures strictly define women’s roles and one must approach women through their male partners, who make major decisions in the household.</p>   | <p>Respect the gender roles of different cultures, even if you do not agree with them. You might have to talk to the man first, in order to reach a woman consumer.</p>  |
| <p><b>Lack of materials and resources.</b><br/>Brochures and referrals are usually limited to only a few languages. While translation is always possible, not seeing one’s own language may cause a client to feel isolated and unseen.</p> | <p>Make attempts to find brochures and pamphlets in the common languages in your outreach area.</p>  |
| <p><b>Fear of the unknown.</b><br/>Social and medical services may not be offered the same way as they are—if they are at all—in someone’s home country. Services may seem scary or intimidating at first.</p>                              | <p>Be ready to explain in detail what the services are and why they’re offered. Walk your clients through the process, and leave the door open for questions. Explain things more than once to assure understanding.</p>   |

**How to Respond in Difficult Outreach Situations**

*Directions: Think of how to respond in each of the situations described below. Write your response in the space provided. Ask coworkers for suggestions. Share your worksheet with your supervisor for feedback.*

| <i>When a client says...</i>                                    | <i>You can say or do...</i> |
|---|-----------------------------|
| "I don't want to talk to you."                                  |                             |
| "Why should I trust you? I don't even know you!"                |                             |
| "I think you sold me bad dope two years ago!"                   |                             |
| "I don't understand why you're here. What do you want from me?" |                             |
| "I don't trust you."  |                             |
| "Please don't tell this to anyone else, but I..."               |                             |
| Other:  |                             |

# Section II: Referral and Navigation

Navigation corresponds to the partnership phase of the ROEM. During navigation, the Peer Advocate not only connects the client with services and agencies, but accompanies the client to the service provider in order to:

- assure that client can access the service;
- help with keeping appointments;
- assist client with keeping appointments and adherence to treatment;
- help explain educational points and answer questions; and
- provide support whenever possible.

To navigate clients, you need to have referral sources for services at your agency and at other agencies, and know how to access those services.

Before helping clients get the services they need, the Peer Advocate needs to know what services the client might need and what service providers meet those needs.

- List out all possible needs your clients might have.
- Check with other Peer Advocates or your supervisors for referral agencies you can use if your agency doesn't provide the service.
- Develop a list of referral agencies you can use for clients.

Also, ask clients for service agencies they know of and have used in the past. Check with your supervisor to see if you can add these agencies to your referral list.

## Refer to:

Tool #8: Referral Agencies

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Talk with your supervisor about how to find referrals for services if you don't already have the referral available. Find out everything you can about the referral service including:

- hours of operation
- specific services offered
- languages spoken
- if childcare is available
- what documentation or papers clients will need to have
- financial or payment information
- how to get to the service
- the target population of the service
- typical 'waiting time'
- whether they accept walk-ins or appointments
- how long it takes to get an appointment.

Try to find the ‘best’ referral source for a client, based on what he or she needs and what the referral agency has to offer. Once you have referred or navigated a client to a service, ask clients for feedback on agencies they have used, and share that feedback with your supervisor, so you can decide how to proceed.

**Refer to:**

Tool #9: Tips on How to Make a Good Referral

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Many clients will need help in accessing services. In this case, your job is to navigate the client to the service agency. For instance, a client at your agency may have missed an appointment for follow-up care. You may want to meet with the client, discuss the need for care, and then accompany the client to your agency so they can receive important medical care and other services. Depending on the particular client’s needs, you may be more or less intensively involved in navigating a client to services.

**Refer to:**

Tool #10: Navigating Clients to Services

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# Section II: Referral and Navigation TOOLS

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| Tool #10: Navigating Clients to Services     | 30          |

**Referral Agencies**

Talk with your supervisor about any referrals you do not have a source for, or any referral sources clients have not been satisfied with. Be sure your supervisor has approved all referral sources you are using.

|   | <b>Agency or agencies you can use as a referral</b> | <b>What kind of feedback have clients given you about this referral?</b> |
|---|---|--|
| <b>Medical services</b>                         |   |  |
| <b>Health education</b>                         |   |  |
| <b>Case management</b>                          |   |  |
| <b>Nutrition</b>                                |   |  |
| <b>Immunizations</b>                            |   |  |
| <b>Vision</b>                                   |   |  |
| <b>Dental and oral health</b>                   |   |  |
| <b>Reproductive health</b>                      |   |  |
| <b>Mental health</b>                            |   |  |
| <b>Physical therapy</b>                         |   |  |
| <b>Complementary therapy (like acupuncture)</b> |   |  |
| <b>Chemical dependency</b>                      |   |  |
| <b>Spiritual care</b>                           |   |  |
| <b>Family-related care, childcare</b>           |   |  |
| <b>Legal</b>                                    |   |  |
| <b>Housing</b>                                  |   |  |
| <b>Formal education &amp; training</b>          |   |  |
| <b>Job training</b>                             |   |  |
| <b>Clothing</b>                                 |   |  |
| <b>Food</b>                                     |   |  |
| <b>Needle exchange</b>                          |   |  |
| <b>Other:</b>                                   |   |  |
| <b>Other:</b>                                   |   |  |
| <b>Other:</b>                                   |   |  |

## Tips on How to Make a Good Referral<sup>2</sup>

### 1. Make sure the client wants a referral.

Referrals don't solve problems unless a client has an interest in working on a problem in the first place, and sees how a referral will help. Be sure you find out what the client thinks, feels, and wants out of a referral— before you offer one.

### 2. Ask questions to find out the client's past experience.

People drop referrals all the time, sometimes because they don't know what to expect and other times because they've had bad experiences in the past. Ask, "Have you seen a social worker before? What did you think about the experience? Would it help if I described how it all works?"

### 3. Give a contact name.

Offering a name personalizes the referral. For example, "I know a really cool nutritionist named Luna. She's very open-minded, and a lot of my clients like her."

### 4. Make sure the referral is culturally relevant.

Find referrals that match the client's interest in terms of language, gender, sexual identity, relationship to drug use, ethnic background, racial identity, or whatever other cultural identities your client would want reflected in a referral.

### 5. Referrals should be easily accessible and affordable.

Make sure you offer a referral that your client can get to and can afford.

### 6. Explore obstacles and allow room for resistance.

Sometimes clients nod and say "Yes" to a referral, just because they think that's what you want. Find out how realistic this referral is for the client by asking, "Sounds like you want help with your meds, so we've talked about seeing a nurse I know named Oliver. Really, though, how does that sound to you?"

### 7. Invite feedback, and don't force the referral.

Clients are the best source for knowing how well a referral has met their needs. Be curious and ask directly, "I'm wondering how you felt about that referral. If you were able to go, what was it like? Would you recommend I send other people there?"

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<sup>2</sup> Adapted from the University of California San Francisco AIDS Health Project, *Ensuring Quality HIV Prevention Counseling* (training manual), September 2006.

**Note: Clients may need more or less help in accessing services. Personalize this plan to meet the needs of the particular client with whom you are working and go over the plan with your supervisor.**

| <b>Navigating Clients to Services</b>      |   |
|--|---|
| <b>Step One: Initial contact</b>           | <p>Make contact with the client (in person or on the phone) and explain your role as a Peer Advocate, why you're calling (e.g., to schedule an appointment or to discuss the importance of follow up care.)</p> <p>Gather basic information during the encounter, such as whether or not the client lives alone, if the client would like to have others with him or her (family or friends) at the time of the meeting, and basic demographic information if such information is not already known.</p>  |
| <b>Step Two: Meet with the client</b>      | <p>Discuss the importance of follow-up care and explore why the client has not yet returned for follow-up care:</p> <ul style="list-style-type: none"> <li>• “What has prevented you from seeking follow-up care?”</li> <li>• “If you schedule an appointment now, what might stop you from keeping the appointment later?”</li> </ul> <p>If client has missed a previous appointment for care, explore why the client did not follow through on her appointment. “I’m concerned that you didn’t keep your scheduled appointment, and I’d like to talk with you about this. Last time I was here, you said you wanted to go for follow-up care, so I want to understand what made it difficult for you to do that.”</p> |
| <b>Step Three: Offer basic information</b> | <p>Provide basic information on the provider and visit, such as what the appointment is for, where to go, what the client can expect at the appointment, how long the appointment should take, when test results will be available, etc.</p>  |
| <b>Step Four: Assess needs</b>             | <p>In a non-judgmental and respectful manner, conduct a comprehensive needs assessment. Explore with the client her barriers to follow-up care. Barriers could include:</p> <ul style="list-style-type: none"> <li>• A need for child care</li> <li>• Lack of English proficiency</li> <li>• Fear</li> <li>• Low level of literacy</li> <li>• Family obligations</li> <li>• Lack of carfare or transportation</li> <li>• Current drug use</li> <li>• Eligibility requirements</li> <li>• Restrictive agency regulations and policies</li> <li>• Cost</li> </ul>   |

|  |   |
|--|---|
|  | <ul style="list-style-type: none"> <li>• Lack of culturally competent service provision</li> <li>• Other or conflicting priorities</li> <li>• Disbelief in the importance of follow-up care</li> <li>• Mental illness, including depression and anxiety</li> </ul>  |
| <p><b>Step Five: Anticipate and problem solve barriers</b></p> | <p>Help the client anticipate any problems that might interfere with keeping her appointment, and help the client strategize around these problems:</p> <ul style="list-style-type: none"> <li>• “Who will take care of your children?”</li> <li>• “Who could you ask to come with you to the appointment?”</li> <li>• “How will you get there?”</li> <li>• “Will you go from work, or from home?”</li> <li>• “Are you asking for time off from work?”</li> <li>• “Who provides emotional support for you?”</li> <li>• “If you get anxious about this appointment, is there someone you can call to talk to?”</li> </ul> <p>Depending on the barrier, interventions will vary. For instance, the tasks might include:</p> <ul style="list-style-type: none"> <li>• Listening empathetically to the client’s fears and concerns</li> <li>• Talking with family members with the client to explain the service and the importance of follow-up care</li> <li>• Helping the client develop coping strategies to manage anxiety</li> <li>• Making referrals for other services, such as mental health care; food stamps; legal services</li> <li>• Explaining eligibility and cost requirement</li> <li>• Listening to the client’s health beliefs, and helping the client see follow-up care as an additional service, rather than a competing service</li> </ul> <p><u>Walking into the provider’s office with the client, just so the client can see what it is, who is there, what will happen, etc</u></p> |
| <p><b>Step Six: Help client with appointment</b></p>           | <p>You can help the client call for an appointment, or, if it is a ‘walk-in’ determine time when client would like to go. Help client with issues such as getting to the service agency:</p> <ul style="list-style-type: none"> <li>• Help the client call the provider</li> <li>• Write questions for the client to ask the provider</li> <li>• Indicate that you will remind the client of the upcoming appointment</li> <li>• Let the client know that you will maintain contact between now and the appointment with phone calls or in-person visits</li> <li>• Offer to meet the client at the provider’s office</li> <li>• Offer to accompany the client to the provider’s office from the client’s home</li> </ul>   |

|   |  |
|---|--|
| <p><b>Step Seven: Follow-up</b></p>                       | <p>Get permission to call the client back or return to visit the client in a week or sooner to see if the client was able to schedule the appointment, or needs any assistance in doing so.<br/>Continue with follow-up phone calls or in-person visits until the date of the appointment.<br/>During this time, explore ongoing services needed, as well as barriers and fears of the client, and address them, as may be appropriate.<br/>Other tasks might include:</p> <ul style="list-style-type: none"> <li>• Helping the client figure out transportation issues (e.g., how to use public transportation, parking issues, etc.)</li> <li>• Agreeing to meet the client at the provider’s office for the appointment</li> <li>• Helping the client problem-solve concerns regarding child care, or offering to meet the client at the provider’s office and watching the children during the client’s appointment with the provider</li> <li>• Helping the client explore possible coping strategies and naming possible people for support who can help the client if she becomes anxious about her upcoming appointment</li> </ul> |
| <p><b>Step Eight: Accompany client to appointment</b></p> | <p>Accompany the client to the provider’s office, unless the client has said she does not want you to go with her. In that case, call the client after the time of the appointment, to inquire as to whether the client kept the scheduled appointment.</p>  |
| <p><b>Step Nine: Keep in touch</b></p>                    | <p>If the client kept the appointment, keep in touch as necessary. For instance, you might call back when the client gets his/her test results; or ask if the client wants you to accompany him/her to the provider for the test results.<br/>If the client did not keep the scheduled appointment, then the barriers addressed were not the barriers keeping the client from follow-up care. In this case, continue to meet with the client and attempt to uncover the barriers keeping the client from attending follow-up care.</p>   |
| <p><b>Step Ten: Next steps</b></p>                        | <p>Work with your supervisor to problem-solve and determine strategies for next steps.</p>   |

# Section III: Patient Education

An essential part of the Peer Advocate’s job is patient education. To be effective as an educator, the Peer Advocate needs to have good communication skills, and to be knowledgeable about the information they want to share with others.

**Refer to:**

|   | <b>PAGE</b> |
|---|-------------|
| Tool #11: Frequently Asked Questions about HIV and AIDS     | 35          |
| Tool #12: Frequently Asked Questions about HIV Transmission | 37          |
| Tool #13: What is Hepatitis C?                              | 39          |
| Tool #14: Syringe Disinfection for Injection Drug Users     | 40          |

It is also important to be clear about what you know and don’t know, and to be comfortable saying “I don’t know, but I’ll find out for you” when appropriate. Another key skill is knowing how to respond to questions that ask for your opinion, rather than factual information.

**Refer to:**

|                                   | <b>PAGE</b> |
|-----------------------------------|-------------|
| Tool #15: Responding to Questions | 47          |

Some questions or topics may be easier for you to respond to, and some more difficult. Identify what topics you are less comfortable talking about, and check with your supervisor and other peer advocates about how to increase your comfort level in discussing those topics.

**Refer to:**

|   | <b>PAGE</b> |
|---|-------------|
| Tool # 16: Assessing Your Comfort Level | 48          |

## Section III: Patient Education TOOLS

| <b>TOOLS:</b>   | <b>PAGE</b> |
|---|-------------|
| Tool #11: Frequently Asked Questions about HIV and AIDS     | 35          |
| Tool #12: Frequently Asked Questions about HIV Transmission | 37          |
| Tool #13: What is Hepatitis C?                              | 39          |
| Tool #14: Syringe Disinfection for Injection Drug Users     | 40          |
| Tool #15: Responding to Questions                           | 47          |
| Tool # 16: Assessing Your Comfort Level                     | 48          |

**Frequently Asked Questions about HIV and AIDS**

*Below are some frequently asked questions. What other questions might you clients ask? Write the questions in the boxes provided, and ask your supervisor for help in determining how to answer them.*

|  |   |
|--|---|
| <p><b>1. What is HIV?</b></p>                                  | <p><b>Human Immunodeficiency Virus.</b> It is the virus that causes AIDS. There are two main types of the virus, HIV-1 and HIV-2</p>  |
| <p><b>2. What's the difference between HIV-1 and HIV-2</b></p> | <p>HIV-1 is the most common type of HIV in the U.S.</p> <p>HIV-2 is primarily found in West Africa</p> <p>HIV-1 and HIV-2 are transmitted the same way; both cause immune system damage</p> <p>Very few cases of HIV-2 in the U.S.</p> <p>Most of the cases of HIV-2 in the U.S. are associated with people who are from West Africa, or have sexual or injection partners from West Africa</p> |
| <p><b>3. What is AIDS?</b></p>                                 | <p><b>Acquired Immuno-deficiency Syndrome</b></p> <p>AIDS = HIV and a T-cell count below 200 or at least one opportunistic infection(s)</p> <p>Opportunistic infections are listed in the current CDC case definition</p>   |
| <p><b>4. What is the immune system?</b></p>                    | <p>The body's method of protecting itself from germs</p> <p>Immune system develops antibodies in response to germs</p> <p>Antibodies attempt to eliminate germs</p>   |
| <p><b>5. What are T-cells?</b></p>                             | <p>Also called CD4 cells, these are part of the immune system</p> <p>Recognize germs and tells the immune system to fight them</p> <p>HIV destroys T-cells as HIV reproduces</p> <p>Without T-cells, the immune system no longer recognizes germs, and therefore does not fight them off</p>  |

|   |   |
|---|---|
| <p><b>6. HIV is a retrovirus. What is a retrovirus?</b></p>   | <p>Retroviruses cannot reproduce on their own; instead they invade T-cells and then use T-cells to produce more virus</p> <p>As new HIV breaks out of the T-cell, the T-cell is destroyed; new HIV particles find more T-cells, make more HIV, and destroy more T-cells</p>   |
| <p><b>7. How does HIV make people sick?</b></p>   | <p>HIV weakens the immune system by destroying T-cells (CD4 cells)</p> <p>As the immune system is weakened, it cannot protect the person from other germs it comes in contact with</p> <p>Germs that normally would not harm a person can have a major impact because the immune system is impaired</p>                                 |
| <p><b>8. What are the major characteristics of HIV?</b></p>   | <p>Lifelong infection; once infected, always infected</p> <p>HIV mutates as it reproduces, making it difficult to develop medications that work over long periods of time</p> <p>Damages the immune system</p> <p>Easily destroyed when outside of the body; HIV is no longer infectious after contact with air for several seconds</p> |
| <p><b>Question:</b></p>   | <p><b>Response:</b></p>   |
| <p><b>Question:</b></p>   | <p><b>Response:</b></p>   |
| <p>For more information, please visit one of the following:<br/>         NYSDOH: <a href="http://www.health.state.ny.us/diseases/aids/facts/index.htm">http://www.health.state.ny.us/diseases/aids/facts/index.htm</a><br/>         NYCDOH: <a href="http://www.nyc.gov/html/doh/html/ah/ah.shtml">http://www.nyc.gov/html/doh/html/ah/ah.shtml</a><br/>         CDC: <a href="http://www.cdc.gov/hiv/">http://www.cdc.gov/hiv/</a></p> |   |

**Frequently Asked Questions about HIV Transmission**

*Below are some frequently asked questions. What other questions might your clients ask? Write the questions in the boxes provided, and ask your supervisor for help in determining how to answer them.*

|  |  |
|--|--|
| <p><b>1. How is HIV transmitted from person to person?</b></p> | <p>Body fluids from a person living with HIV must enter the blood stream or contact a mucous membrane of an uninfected person. This is called “exposure”</p> <p>Infection happens once HIV enters a cell and starts to reproduce</p> <p>Not every exposure to HIV leads to infection, which is why some people may not contract HIV even after unprotected sex or sharing injection equipment</p>  |
| <p><b>2. What body fluids transmit HIV?</b></p>                | <p>Blood, semen (and possibly precum), vaginal and cervical secretions, and breast milk contain enough virus to be able to transmit HIV from person to person</p> <p>Internal body fluids, found in the lungs, heart, joints, brain and spinal cord, are also infectious; people rarely come in contact with these fluids</p> <p>HIV is also present in saliva, tears, perspiration, urine, and feces, but in the amount of HIV present is not enough to transmit the virus through casual contact</p>   |
| <p><b>3. How can sex transmit HIV?</b></p>                     | <p>Sexual transmission can happen when body fluids carrying HIV come in contact with a mucous membrane or torn skin</p> <ul style="list-style-type: none"> <li>• Anal intercourse (penis to rectum)</li> <li>• Vaginal intercourse (penis to vagina)</li> <li>• Oral sex (mouth to penis or vagina)—this is considered low to very low risk for HIV</li> <li>• Blood, semen, vaginal secretions directly on broken skin or mucous membrane</li> </ul>  |
| <p><b>4. What does “the hierarchy of risk” mean?</b></p>       | <p>Some forms of sex transmit HIV more easily than other. For example:</p> <ul style="list-style-type: none"> <li>▪ The rectum has one layer of very absorbent skin and very little natural lubrication</li> <li>▪ The vagina has two layers of skin and can produce natural lubrication</li> <li>▪ The mouth has three layers of skin and saliva (which may offer some protection against HIV)</li> </ul> <p>HIV is more easily transmitted through unprotected anal sex than vaginal sex, and oral sex is considered low to very low risk for HIV.</p> |

|   |   |
|---|---|
| <p><b>5. How can injection drug use transmit HIV?</b></p>   | <p>HIV is found in blood and blood can be passed from person to person through shared injection equipment.</p> <ul style="list-style-type: none"> <li>• Blood caught in the needle point or syringe barrel</li> <li>• Blood can also collect near the plunger</li> <li>• Tourniquets used to “tie off” may also carry blood</li> <li>• Cookers used to prepare drugs</li> <li>• Filters (also called “cotton”)</li> </ul> <p>Hepatitis C Virus (HCV) lives outside the body longer than HIV and so is an even greater risk when injection equipment is shared</p> |
| <p><b>6. How is HIV transmitted from mother-to-child?</b></p>   | <p>HIV transmission can happen from a pregnant mother living with HIV to her child before birth, during delivery, and after birth while breastfeeding (mostly through chapped, cracked nipples that leak blood)</p> <p>With medical care and medications, an HIV+ woman has less than a 1% chance of passing the virus on to her child; that number rises to 25% without medical treatment</p>  |
| <p><b>7. What other ways is HIV transmitted?</b></p>  | <p>Donor products: blood products, semen, donated body organs or tissues</p> <p>Tattooing, piercing, injecting steroids</p> <p>Occupational injury: needlesticks, recapping needles, blood splashes, risk of transmission is low</p>  |
| <p><b>8. What is reinfection?</b></p>   | <p>This is commonly used to refer to when people who are already infected with HIV come in contact with HIV again. For example, someone who is HIV positive may have unprotected sex with another person who is HIV positive.</p>   |
| <p><b>Question</b></p>  | <p>Response:</p>  |
| <p><b>Question</b></p>  | <p>Response:</p>  |
| <p>For more information, please visit one of the following:<br/>         NYSDOH: <a href="http://www.health.state.ny.us/diseases/aids/facts/index.htm">http://www.health.state.ny.us/diseases/aids/facts/index.htm</a><br/>         NYCDOH: <a href="http://www.nyc.gov/html/doh/html/ah/ah.shtml">http://www.nyc.gov/html/doh/html/ah/ah.shtml</a><br/>         CDC: <a href="http://www.cdc.gov/hiv/">http://www.cdc.gov/hiv/</a></p> |   |

| <b>What is Hepatitis C?<sup>3</sup></b>   |  |
|---|--|
| <p>“Hepatitis” is a general term that means inflammation of the liver. Hepatitis A, B and C are all viruses that can cause this inflammation. Each one is very different in the ways they are transmitted and the ways your body deals with them. None of the viruses is spread through casual contact (holding hands, hugging, sneezing, sharing food, etc.)</p> |  |
| <b>Transmission</b>   | <p>Hepatitis C (HCV) is a blood-borne virus that is largely transmitted through sharing injection equipment (including cookers, cotton, water and syringes), or needles for piercing or tattooing. Sexual transmission ranges from 5-15% and mother-to-child transmission during birth from (5%). There is also a small risk from occupational exposure for health care workers.</p>   |
| <b>Symptoms</b>   | <p>Jaundice (yellowing of the skin and whites of the eyes), fever, loss of appetite, diarrhea, vomiting, exhaustion. 75% of people infected with HCV report no symptoms and symptoms, when they do appear, may not be felt for as long as 30 years.</p>  |
| <b>What’s the connection with HIV?</b>  | <p>In the United States, about 1 in 3 people living with HIV are also co-infected with HCV. The rate varies from 50-90% based on the area. Risk of mother-to-child transmission of HCV is higher if the mother is HIV-positive (from 6% to 25%).</p>   |
| <b>Treatment</b>  | <p>There is no vaccine for Hepatitis C but treatment can help slow the virus and, for some people, clear the virus from the body. Side effects can be very challenging and may interfere with HIV medications. Early diagnosis and treatment by a specialist is important.</p>   |
| <b>Prevention</b>   | <p>HCV can live outside the body for several days. It is suggested not to share toothbrushes, razors or any item that could have blood on it, even if you can’t see blood with your eyes. For drug injectors, HCV can be prevented by not sharing needles, tourniquets, cotton, cookers or anything that could come in contact with blood. Sharing straws for snorting or pipes for smoking drugs (because of cracked or bleeding lips) is best avoided.</p> |

<sup>3</sup> Information gathered from ACRIA (AIDS Community Research Initiative of America), as cited in *Peer Training Institute Adult Curriculum*, Cicatelli Associates, Inc.

## Syringe Disinfection for Injection Drug Users

**NOTE: This document is from: <http://www.cdc.gov/idu/>**

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For 20 years, syringe disinfection has been a part of HIV prevention efforts for injection drug users (IDUs). Questions about it persist, however, because of limited scientific studies, varying recommendations on the right way to disinfect, and evidence suggesting that IDUs do not use this approach very much. This fact sheet presents basic information on disinfection, especially bleach disinfection. The central message is that disinfection is a back-up prevention strategy if the user cannot stop injecting; does not have a new, sterile syringe; and is about to inject with a syringe that has been used before.

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### How Did Disinfection Become a Widely-used HIV Prevention Strategy?

The strategy of disinfecting syringes to prevent HIV emerged in California in the 1980s. East Coast epidemics among IDUs (especially in New York) made public health officials fear that HIV would be a major threat to California IDUs.

California IDUs, like those in other parts of the country, shared and reused syringes, in part because it was hard for them to get new, sterile ones. This greatly increased their [risk of HIV transmission](#). State law made it illegal for drug users to buy syringes from pharmacies and a crime to possess them. Restricted access to sterile syringes, combined with limited capacity of substance abuse treatment programs, forced prevention programs to focus on reducing injection-related risks among IDUs who would not or could not stop injecting. Field research in California showed that IDUs would act to reduce their risks if acceptable measures were available to them. One such measure was syringe disinfection with household bleach. (Disinfection means using something to kill viruses and bacteria that cause infection.) Laboratory tests had shown that bleach killed HIV. Bleach also was cheap, quick, and available everywhere.

Substance abuse treatment and access to sterile syringes through pharmacies, physician prescription, and syringe exchange programs are essential components of HIV prevention efforts among injection drug users. See “To Learn More About This Topic” at the end of this fact sheet for information on how to get fact sheets on these topics as well as other materials on HIV prevention among IDUs.

This led community programs to train outreach workers to teach IDUs how they could reduce the risk of infection by disinfecting their syringes and needles.

Distribution of bleach kits — small (usually 1-oz. size) bottles of full strength household bleach with instructions on how to disinfect syringes — quickly became a standard component of IDU prevention in San Francisco. Other U.S. cities then rapidly adopted this strategy.

### How Disinfection Can Reduce Transmission Risk: It Reduces the Number of Viruses and It Kills Them

Current disinfection recommendations are based on the following steps:

- Flush out blood, drugs, and other organic matter from the syringe. These can contain viruses and do interfere with the disinfection process.
- Disinfect the syringe.
- Rinse out the disinfectant.

The idea behind these steps is to reduce the risk of HIV transmission in two ways. First, flushing removes blood and drugs from the syringe, which reduces the number of viral particles. Second, using a disinfectant can kill remaining viruses so they can't infect anyone else. Instructions for disinfecting syringes usually include ways to make sure that viruses are removed and killed:

- Fill the syringe with clean water (such as water right from a tap or a new bottle of water).
- Shake or tap the syringe containing water or disinfectant (this dislodges particles and thoroughly mixes the water or disinfectant with material in the syringe); then squirt out and throw away the water; repeat until no more blood can be seen.
- Leave the water or disinfectant, especially the disinfectant, in the syringe for a while (in principle, the longer the better; for example, 30 seconds is better than 15 seconds); then squirt out the disinfectant.
- Rinse out the syringe with clean water (fill syringe, shake or tap, squirt out and throw away water); rinsing is done to get rid of disinfectant and any viruses left in the syringe.

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### **Does Disinfection Work Against Viral Hepatitis?**

Hepatitis B virus (HBV) and hepatitis C virus (HCV) cause serious illness among millions of people. They also are closely connected with HIV, injection drug use, and high-risk sexual behaviors. Many people think that disinfection doesn't work against HBV or HCV, but laboratory studies on HBV show that disinfection works against this bloodborne virus in the same ways that it does against HIV.

An important thing to remember about HBV and HCV is that the numbers of viruses in blood are much higher for HBV and HCV than they are for HIV. As a result, getting rid of as much blood as possible by flushing out and rinsing is especially important in reducing the risk of becoming infected with viral hepatitis.

### The Link Between Preparing Injection Drugs and the Risk of Transmission

The drugs used by IDUs (heroin, cocaine, amphetamines) usually are sold as a powder that must be dissolved in water before they can be injected. Some injection drugs, such as black-tar heroin, which is a gummy solid not a powder, must be heated in a spoon or bottle cap (a “cooker”) to speed up the dissolving. Once dissolved, the drug is drawn into a syringe through a filter (a “cotton”) that prevents small particles in the solution from clogging the needle. The drug is then injected into a vein. Sometimes, two or more IDUs will draw up drugs from the same cooker.

Before injecting, a user must be sure that the needle is in a vein. He or she does this by pulling back on the plunger after pushing the needle through the skin in a likely spot. Blood entering the syringe (“registering”) shows that the needle is in a vein. Once the drug has been injected, the IDU may pull back the plunger, drawing blood back into the syringe, and then re-inject it into the vein (“booting” or “jacking”). After injecting, the user rinses out the syringe with water to prevent any remaining blood from clogging the needle. Users often dissolve drug powder and rinse their syringes with water from the same container.

HIV, hepatitis B virus (HBV), and hepatitis C virus (HCV) can be transmitted when IDUs share the same syringe. These viruses also can be transmitted when users divide drug solution among several syringes, share rinse water or a cotton or cooker, or mix the drug solution with a used syringe. Transmission can occur when any element — syringe, water, cotton, cooker, drug solution — becomes contaminated with blood that is infected with HIV, HBV, or HCV because that element can contaminate any other element it touches. Even if an IDU is careful to always use a new, sterile syringe to inject drugs, the process of sharing contaminated equipment, drug solution, or water can increase his or her risk of acquiring or transmitting HIV, HBV, or HCV. (For more information about drug preparation and viral transmission, see Koester, 1998.)

### Disinfection Seems to Make Sense. What’s the Problem?

#### *A Disinfected Syringe is NOT a Sterile Syringe*

If it is done carefully and thoroughly, disinfection can reduce the amount of live HIV, HBV, and HCV in a syringe. However, even the best disinfection procedure cannot guarantee that all viruses have been killed. The plastic syringes usually used by IDUs are designed for one-time use. They are not designed to be cleaned and used again.

Disinfected syringes do NOT meet the standards that are applied in all other settings in which people use syringes (such as hospitals, other health care settings, and insulin injections by people with diabetes). In these settings, people must use a new, sterile syringe for every injection.

For these reasons, a disinfected syringe is NOT as safe as a new, sterile syringe. Recommendations about disinfecting syringes with bleach or other agents apply ONLY to situations in which IDUs do not have sterile syringes.

#### *Scientists Have Limited Laboratory Evidence that Disinfection Works Against HIV in Syringes and Other Injection Equipment*

Scientists have published a small number of laboratory studies on the ability of bleach and other agents to kill HIV. These experiments try to mimic conditions faced by IDUs and usually test the impact of disinfection on blood to which HIV grown in a test tube has been added.

However, these conditions are not the same as those faced by IDUs, and findings are not definitive. In laboratory studies, fresh undiluted household bleach (5.25% sodium hypochlorite) appears to kill HIV pretty well. Scientists

also have tested whether other liquids can disinfect syringes. These liquids, which are sometimes used by IDUs, include dish detergent, rubbing alcohol, hydrogen peroxide, and fortified wine. Results of these few studies are limited.

Some research has found that even several vigorous rinses with clean water may be as effective as undiluted household bleach because they do a good job of reducing the number of infectious viruses.

Results of these studies depend on many things, including the strength of the agent, whether the HIV is in whole blood or by itself, and the steps used. Because few laboratory studies have been published, we have only limited data on disinfection as it is done by IDUs. As a result, we don't have clear answers to questions about which agents work best, the best disinfection procedures, or the time necessary for adequate disinfection.

Laboratory studies of the effect of disinfection on HBV and HCV are difficult because these viruses cannot be grown in a test tube. Studies with animals have shown that disinfection can prevent HBV transmission. Because HBV and HCV are similar, these findings may also be true for HCV. However, it's important to note that conditions in animal studies are not the same as those faced by IDUs.

#### *Studies of IDUs Do Not Prove That Bleach Disinfection Protects them Against HIV or Viral Hepatitis*

Studies have looked for differences in the number of new infections between injectors who say they always disinfect and injectors who say they do not disinfect. They have found no significant difference in new infections among IDUs in the two groups. Several factors may help explain these findings.

- Studies don't measure risk behaviors completely. Studies don't always collect detailed risk information and may focus only on an IDU's risky drug practices. As a result, a study focusing on disinfection may not show anything if the infection is due to something else, such as having unprotected sex with infected partners.
- Some studies have technical limitations. For example, sometimes it is hard for a scientist to know whether a person is really a "disinfector" or a "non-disinfector." IDUs in the study may not remember correctly whether or how many times they used bleach during a certain period in the past. Or, they may think that saying they used bleach is the answer the scientists want to hear. As a result, IDUs who say they disinfect may seem to be at the same risk of infection as those who say they don't disinfect.

#### *Barriers Make it Hard for IDUs to Disinfect Correctly and Can Prevent Them from Doing It At All*

IDUs may agree that disinfection is a good idea if they cannot get new, sterile syringes. However, some investigators have found that few IDUs actually use bleach to disinfect syringes or they don't go through all the recommended steps if they do use it. Many factors make it hard for IDUs to disinfect:

- Current instructions involve a lot of steps and IDUs may think it is impossible to do correctly.
- IDUs may not be able to get clean water.
- They may not want to carry bleach or other disinfectants because it marks them as drug users.
- Withdrawal symptoms (being "drug sick") and the overpowering need to inject as soon as possible also may drive an IDU to inject without disinfecting.
- Some IDUs need help to inject and other people give them the injection. The person doing the injecting may not disinfect thoroughly.

- Drug users may not have time to disinfect carefully because they must prepare the drug solution and inject quickly (for example, police are nearby).
- Once the IDU has injected, the effects of the drug may prevent him or her from disinfecting carefully before the next injection (this may be especially true with cocaine, which is commonly injected multiple times in a drug use session).

### **Bleach has Advantages and Disadvantages as a Disinfectant**

#### **Advantages:**

- It can reduce the amount of infectious HIV, HBV, and HCV in a used syringe.
- It is readily available.
- It is inexpensive.

#### **Disadvantages:**

- IDUs, outreach workers, and policymakers may mistakenly believe that disinfecting with bleach is as safe as using a new, sterile syringe.
- It does not sterilize the syringe, so the syringe may still carry infectious organisms after disinfection.
- Studies have not shown that bleach disinfection prevents HIV or HCV transmission among IDUs.
- If a person carries small bottles of bleach, police may assume he or she is a drug user.
- Sunlight, warm temperatures, and exposure to air gradually weaken bleach so that it doesn't work anymore; IDUs have to be sure to use fresh, full-strength bleach.
- It damages the syringe.

### **What are the Take-Home Messages?**

- The way that an IDU prepares and injects drugs is important in determining the risk of that person getting or transmitting HIV, HBV, and HCV:
  - Any item — syringe, water, drug solution, cooker, cotton — that is contaminated with blood containing these viruses can contaminate all the other items.
  - Even if an IDU uses a sterile syringe each time, he or she can become infected if the drug solution or preparation equipment is shared with others who are infected.
- Disinfection will not make injecting drugs “safe.” It may make injecting “less risky” because it can reduce the number of and kill some of the HIV, HBV, or HCV in a syringe. As a result, disinfection can be a useful back-up strategy for IDUs.
- We don't have clear, consistent laboratory evidence about the best disinfection procedure and we don't know how effective this strategy is. So, we suggest steps that seem logical.
- Disinfection should be used only when an IDU has no safe options for preventing transmission.
  - Disinfection is not as good as stopping injecting, getting into substance abuse treatment, using a new sterile syringe, and not sharing drug solution and equipment.
  - Bleach and other disinfectants do NOT sterilize the syringe.

**Keeping Everything Clean is an Important Part of Reducing HIV and Viral Hepatitis Risk**

More and more, health workers are realizing that cleanliness and good hygiene can help reduce an IDU’s risk of getting or transmitting HIV or viral hepatitis. Good hygiene can also help prevent sores and bacterial infections in the skin where IDUs inject. The following tips are an important part of the prevention message to IDUs who cannot or will not stop injecting:

- Wash your hands and arms before preparing to inject.
- Use a clean surface to prepare drugs for injection, or spread out a piece of clean paper.
- Use an alcohol pad to clean the skin where you’re going to inject.
- After injecting, use a gauze pad to stop the bleeding.
- Put a bandage on the place where you injected.
- Throw away the used alcohol pad and gauze and all the other drug preparation equipment.
- Clean anything else blood might have touched (such as the tourniquet, your injecting space, or your clothes).
- Safely dispose of the syringe.
- Wash your hands again to clean off dirt, blood, and viruses.

Sources: Marcia Bisgyer of SafetyWorks, Inc., Mamaroneck NY, and Allen [Clear of Harm Reduction Coalition](#), New York, NY

**What Should We Tell IDUs?**

Education and outreach workers should stress the following messages when they talk to IDUs:

Disinfection should be used ONLY when an IDU has no safe options for preventing transmission.

- The best way for you to prevent HIV, HBV, and HCV transmission is to NOT inject drugs.
- Entering substance abuse treatment can help you reduce or stop injecting. This will lower your chances of infection.
- Get vaccinated against hepatitis A and hepatitis B. You can prevent these kinds of viral hepatitis if you get vaccinated.
- If you cannot or will not stop injecting, you should:
  - Use a new, sterile syringe obtained from a reliable source to prepare and divide drugs for each injection.
  - Never reuse or share syringes, water, cookers, or cottons.
  - Use sterile water to prepare drugs each time, or at least clean water from a reliable source.
  - [Keep everything as clean as possible](#) when injecting .

If you can’t use a new, sterile syringe and clean equipment each time, then disinfecting with bleach may be better than doing nothing at all:

- Fill the syringe with clean water and shake or tap.
- Squirt out the water and throw it away. Repeat until you don’t see any blood in the syringe.
- Completely fill the syringe with fresh, full-strength household bleach.
- Keep it in the syringe for 30 seconds or more.
- Squirt it out and throw the bleach away.
- Fill the syringe with clean water and shake or tap.
- Squirt out the water and throw it away.
- If you don’t have any bleach, use clean water to vigorously flush out the syringe:
  - Fill the syringe with water and shake or tap it.
  - Squirt out the water and throw it away.
  - Do this several times.

## To Learn More about This Topic

Visit websites of the [Centers for Disease Control and Prevention](#) and the [Academy for Educational Development](#) ■ for these and related materials:

- Preventing Blood-borne Infections Among Injection Drug Users: A Comprehensive Approach, which provides extensive background information on HIV and viral hepatitis infection in IDUs and the legal, social, and policy environment, and describes strategies and principles of a comprehensive approach to addressing these issues.
- Interventions to Increase IDUs' Access to Sterile Syringes, a series of six fact sheets.
- Drug Use, HIV, and the Criminal Justice System, a series of eight fact sheets.
- Substance Abuse Treatment and Injection Drug Users, a series of six fact sheets.
- Viral Hepatitis and Injection Drug Users, a series of five fact sheets.
- Small numbers of these publications can be ordered at no charge from [www.cdc.gov/idu](http://www.cdc.gov/idu).

**See the July 1994 issue of the *Journal of Acquired Immune Deficiency Syndromes*.** This issue of the Journal includes seven papers from a workshop on the use of bleach to disinfect drug injection equipment. The papers provide an historical perspective on the use of bleach in HIV/AIDS prevention activities, review results of laboratory studies on the effectiveness of various agents in inactivating HIV, and describe the results of field studies on the disinfection practices of IDUs. (*Journal of Acquired Immune Deficiency Syndromes* 1994;7(7):741-776.)

**See the April 1993 CDC/CSAT/NIDA HIV/AIDS Prevention Bulletin.** This publication reviews the topic of disinfection and concludes that stopping injection or using new, sterile syringes is superior to disinfection. (Curran JC, Scheckel LW, Millstein RA. HIV/AIDS prevention bulletin. Centers for Disease Control, Center for Substance Abuse Treatment, and National Institute on Drug Abuse, April 19, 1993.) [www.cdc.gov/idu/pubs/bleach\\_letter.htm](http://www.cdc.gov/idu/pubs/bleach_letter.htm)

### Check out these sources of information:

Abdala N, Crowe M, Tolstov Y, Heimer R. Survival of human immunodeficiency virus type 1 after rinsing injection syringes with different cleaning solutions. *Substance Use & Misuse* 2004;39(4):581-600.

Abdala N, Gleghorn AA, Carney JM, Heimer R. Can HIV-1-contaminated syringes be disinfected? Implications for transmission among injection drug users. *Journal of Acquired Immune Deficiency Syndromes* 2001;28(5):487-494.

Bourgois P. Anthropology and epidemiology on drugs: the challenges of crossmethodological and theoretical dialogue. *The International Journal of Drug Policy* 2002;13(4):259-269.

Centers for Disease Control and Prevention. [Recommendations for prevention and control of hepatitis C virus \(HCV\) infection and HCV-related chronic disease](#). *Morbidity and Mortality Weekly Report* 1998;47(RR 19):1-39.

Ciccarone D, Bourgois P. Explaining the geographical variation of HIV among injection drug users in the United States. *Substance Use & Misuse* 2003;38(14):2049-2063.

Clatts MC, Heimer R, Abdala N, et al. HIV-1 transmission in injection paraphernalia: heating drug solutions may inactivate HIV-1. *Journal of Acquired Immune Deficiency Syndromes* 1999;22(2):194-199.

Hagan H, Thiede H. Does bleach disinfection of syringes help prevent hepatitis C virus transmission? [letter] *Epidemiology* 2003;14(5):628-629.

Hagan H, Thiede H, Weiss NS, et al. Sharing of drug preparation equipment as a risk factor for hepatitis C. *American Journal of Public Health* 2001;91(1):42-46.

Hughes RA. Drug injectors and the cleaning of needles and syringes. *European Addiction Research* 2000;6(1):20-30.

Kapadia F, Vlahov D, Des Jarlais DC, et al. Does bleach disinfection of syringes protect against hepatitis C infection among young adult injection drug users? *Epidemiology* 2002;13(6):738-741.

Koester SK. Following the blood: syringe reuse leads to blood borne virus transmission among injection drug users. [letter] *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1998;18(Suppl 1):S139-S140.

Normand J, Vlahov D, Moses LE, eds. [Preventing HIV transmission: the role of sterile needles and bleach](#). ■ Washington, DC: National Academy Press, 1995. Chapter 6, The effectiveness of bleach as a disinfectant of injection drug equipment.

Sattar SA, Tetro J, Springthorpe VS, Giulivi A. Preventing the spread of hepatitis B and C viruses: Where are germicides relevant? *American Journal of Infection Control* 2001;29(3):187-197.

Thorpe LE, Ouellet LJ, Hershow R, et al. Risk of hepatitis C virus infection among young adult injection drug users who share injection equipment. *American Journal of Epidemiology* 2002;155(7):645- 653.

United States Public Health Service (USPHS). [HIV prevention bulletin: medical advice for persons who inject illicit drugs](#). Atlanta (GA) and Rockville (MD): USPHS, May 9, 1997.

| <b>Responding to Questions</b>  |  |
|---|--|
| <b>Type of Question</b>   | <b>Tips on how to respond</b>  |
| Personal (information about the Peer Advocate):   | You should decide what information about yourself you are willing to share, and what you are not willing to share. As a Peer Advocate, you may want to share some information about yourself with the client. However, you should share information only if it in some way is helpful to the client or your professional relationship with the client.   |
| Challenging (challenging the authority or right of the Peer Advocate to be presenting information): | Don't get in arguments with clients; acknowledge the client and his or her concerns. Recognize that not all people will agree with you, or want the information you have to share. Be sure to identify where your information comes from.  |
| Don't Know (fact-based questions that Peer Advocate doesn't know answer to)                         | Never make up an answer to a question. It is always better not to know than to guess. It is okay to say "I don't know." Tell the person you will find out the information, and get back to them with it.   |
| Opinion questions (questions that don't have a specific, fact-based answer)                         | Opinion questions can often be turned back to the client: for example, if someone asks, "What's the best way to do that?" the Peer Advocate can respond by asking, "What has worked best for you?" or "What have you tried?" Emphasize that there are many different ideas about that issue and each person must choose what is best for him or herself. |



# Section IV: Adherence Support

Another important task of the Peer Advocate is to help clients with adherence to medical treatments and other issues, such as attending appointments. It is important to realize that improving adherence to a new behavior is a behavior change process. Your clients may need different types of support from you depending on where they are in this process.

When a client is trying to adjust to a medical regimen, they will need to address numerous issues before they can adhere consistently. The “Nine Steps to Adherence” indicates tasks the Peer Advocate can do that can help the client adjust to their medical regimen and adhere to treatment.

**Refer to:**

|                       | <b>PAGE</b> |
|-----------------------|-------------|
| Tool # 17: Nine Steps | 52          |

Taking HIV medications is difficult, and to be successful, the client must have significant knowledge and skills to aid them in this venture. The Peer Advocate can use the Assessment Readiness Checklist to identify in which areas the client may need additional support in order to successfully manage HIV medications.

**Refer to:**

|   | <b>PAGE</b> |
|---|-------------|
| Tool #18: Assessing Readiness for Treatment | 53          |

After assessing client readiness, the Peer Advocate can share this assessment with the clinic team to determine how each member of the team will proceed to improve the client’s readiness for treatment.

**Refer to:**

|   | <b>PAGE</b> |
|---|-------------|
| Tool #19: Readiness for Treatment Adherence | 55          |

When client is ready to begin treatment, Peer Advocates can complete the “Adherence Counselor’s Checklist” to assure that they have prepared the client for taking medications. This tool can also be used to indicate what additional supports the client might need, and can be shared with the team.

**Refer to:**

|   | <b>PAGE</b> |
|---|-------------|
| Tool #20: Adherence Counselor’s Checklist | 56          |

Many different issues can impact on a client’s ability to adhere to medical treatments. These include: the complexity of the treatment regimen, the duration of the treatment, the costs

associated with treatment, the need for behavioral or lifestyle changes in order to manage the medication, and side effects of the medication.

Peer Advocates can play an important role in assisting their HIV positive clients with side effects. Peer Advocates can advise clients of possible side effects, can serve as an important "bridge" between the patient and the physician, and, most importantly encouraging the patient to discuss any side effects with the physician.

**Refer to:**

Tool #21: Managing Side Effects

**PAGE**  
57

Taking medications involves significant behavioral changes on the part of the client. Behavior change can be difficult, and the Peer Advocate can help motivate the client by remaining supportive, and affirming the client's work. Affirmations can help keep the client motivated.

**Refer to:**

Tool # 22: Affirmations

**PAGE**  
60

# Section IV: Adherence Support TOOLS

| <b>TOOLS:</b>                                | <b>PAGE</b> |
|--|-------------|
| Tool # 17: Nine Steps                        | 52          |
| Tool # 18: Assessing Readiness for Treatment | 53          |
| Tool #19: Readiness for Treatment Adherence  | 55          |
| Tool #20: Adherence Counselor's Checklist    | 56          |
| Tool #21: Managing Side Effects              | 57          |
| Tool #22: Affirmations                       | 60          |

**Nine Steps Toward Adherence**

*Each of the Nine Steps listed below indicate tasks the Peer Advocate can accomplish to help clients with adherence. Think of what you can do at each of the Nine Steps and write it in the space indicated. Ask other Peer Advocates for suggestions, and share your work with your supervisor. NOTE: The first step is completed as an example.*

| Step                                | You can ...  |
|-------------------------------------|--|
| Establish Trust                     | Communicate clearly, build rapport, develop an open relationship, assure confidentiality, maintain a safe relationship |
| Identify & Respect Beliefs          |  |
| Assess Current Situation            |  |
| Provide Treatment Education         |  |
| Facilitate Motivation and Readiness |  |
| Identify & Enhance Self-Efficacy    |  |
| Facilitate Decision Making          |  |
| Establish an Action Plan            |  |
| Support & Maintenance               |  |

| <b>Assessing Readiness for Treatment</b>  |            |           |                  |                 |
|---|------------|-----------|------------------|-----------------|
| <i>Is the client aware of . . . ?</i>   | <i>Yes</i> | <i>No</i> | <i>Some what</i> | <i>Not Sure</i> |
| <p><b>1. Treatment for HIV/AIDS infection</b></p> <ul style="list-style-type: none"> <li> <i>Understand the illness itself</i></li> <li> <i>Understand the goals of treatment</i></li> <li> <i>Recommended T-Cell Count</i></li> <li> <i>Recommended Viral Load Count</i></li> <li> <i>Drugs that are available for treatment</i></li> </ul>   |            |           |                  |                 |
| <p><b>2. Adherence to treatment for HIV/AIDS</b></p> <ul style="list-style-type: none"> <li> <i>Definition “What is adherence?”</i></li> <li> <i>How strict adherence is important to treatment success</i></li> <li> <i>Range of Non-adherent behaviors</i> <ul style="list-style-type: none"> <li><i>a. Failure to take medications</i></li> <li><i>b. Delay in seeking care</i></li> <li><i>c. Failure to accept treatment</i></li> <li><i>d. Missing appointments</i></li> <li><i>e. Premature termination of treatment</i></li> <li><i>f. Failure to take recommended preventive measures</i></li> <li><i>g. Substituting own treatment programs</i></li> <li><i>h. Other. . .</i></li> </ul> </li> <li> <b>Common Causes of Non-Adherence</b> <ul style="list-style-type: none"> <li><i>a. Not believing treatment will work</i></li> <li><i>b. Not wanting to get better</i></li> <li><i>c. Secondary gains from illness</i></li> <li><i>d. Lack of feelings of self-efficacy</i></li> <li><i>e. Denial of medical situation</i></li> <li><i>f. Shame and concealment of illness</i></li> <li><i>g. Need to not feel different from others</i></li> <li><i>h. Not feeling ill or feeling better</i></li> <li><i>i. Unskilled or required technique</i></li> <li><i>j. Misunderstanding directions</i></li> <li><i>k. Unpleasant side effects</i></li> <li><i>l. Forgetting</i></li> <li><i>m. Substance use</i></li> <li><i>n. Medication procedure is a trigger for SA</i></li> </ul> </li> </ul> |            |           |                  |                 |

|   |  |  |  |  |
|---|--|--|--|--|
| <p>O. <i>Cultural values</i><br/>                 p. <i>Mental illness</i><br/>                 q. <i>Financial problems</i><br/>                 r. <i>Other. .</i></p>  |  |  |  |  |
| <b>3. Aware of what behavior change(s) will be needed?</b>  |  |  |  |  |
| <b>4. Willing or able to change specific behaviors?</b>   |  |  |  |  |
| <b>5. Aware of the relationship of side effects to adherence?</b>   |  |  |  |  |
| <p><b>6. Does the client. . .</b><br/>                 ⓧ <i>Live alone</i><br/>                 ⓧ <i>Have supportive family</i><br/>                 ⓧ <i>Have supportive friends</i><br/>                 ⓧ <i>Have supportive providers</i><br/>                 ⓧ <i>Have a mental illness</i></p> |  |  |  |  |
| <b>7. Knowledgeable of his/her history of adherent behavior</b>   |  |  |  |  |
| <b>8. Has the client been on a treatment regimen before?</b>  |  |  |  |  |
| <b>9. Able to afford the medications needed for treatment?</b>  |  |  |  |  |
| <p><b>10. Able to fit treatment in to present lifestyle?</b><br/>                 ⓧ <i>Major adjustments needed</i><br/>                 ⓧ <i>Minor adjustments needed</i><br/>                 ⓧ <i>No adjustments needed</i></p>  |  |  |  |  |
|   |  |  |  |  |

| <b>Readiness for Treatment Adherence</b>                   |  |  |
|--|--|--|
| <i>Readiness Category</i>                                  | <i>Sources of nonadherence (risk factors)</i>  | <i>Selected Strategies</i>   |
| <b>Low Readiness<br/>Low Motivation to use Medications</b> | <ul style="list-style-type: none"> <li><input type="checkbox"/> Misperceptions, misunderstandings, and/or uncertainties about the significance of the presenting problem</li> <li><input type="checkbox"/> Fears about unintended consequences of change</li> <li><input type="checkbox"/> Doubts about whether change is possible or within reach</li> </ul>  | <ul style="list-style-type: none"> <li><input type="checkbox"/> Ask open questions to encourage client to talk about their concerns</li> <li><input type="checkbox"/> Be empathetic</li> <li><input type="checkbox"/> Provide feedback</li> <li><input type="checkbox"/> Correct misconceptions of inaccurate information</li> <li><input type="checkbox"/> Normalize anxiety about change</li> <li><input type="checkbox"/> Encourage client to talk about their fears</li> <li><input type="checkbox"/> Reviewing past successes</li> <li><input type="checkbox"/> Affirming small steps</li> </ul>  |
| <b>Some Readiness<br/>Motivated, but still ambivalent</b>  | <ul style="list-style-type: none"> <li><input type="checkbox"/> Uncertainty or ambivalence about change</li> <li><input type="checkbox"/> Concerns about the suitability of the treatment modality offered</li> <li><input type="checkbox"/> Misperceptions about treatment</li> <li><input type="checkbox"/> Previous negative treatment experiences</li> <li><input type="checkbox"/> Negative therapist or treatment outcome expectancies</li> <li><input type="checkbox"/> Negative general relationship expectancies</li> <li><input type="checkbox"/> Culture-specific differences</li> <li><input type="checkbox"/> Stigma</li> <li><input type="checkbox"/> Mandated treatment; coercion</li> <li><input type="checkbox"/> High barriers to care (financial problems, family hardships)</li> <li><input type="checkbox"/> Low self-efficacy in handling treatment demands</li> </ul> | <ul style="list-style-type: none"> <li><input type="checkbox"/> Assure for rapport and open communication</li> <li><input type="checkbox"/> Be empathetic</li> <li><input type="checkbox"/> Explore understandings of how treatment works</li> <li><input type="checkbox"/> Provide information about how treatment works</li> <li><input type="checkbox"/> Elicit perceptions of treatment</li> <li><input type="checkbox"/> Providing information of treatment</li> <li><input type="checkbox"/> Explore pros and cons of taking medication with client</li> <li><input type="checkbox"/> Discuss benefits of treatment</li> <li><input type="checkbox"/> Reviewing past treatment experiences</li> <li><input type="checkbox"/> Negotiating short term goals</li> <li><input type="checkbox"/> Acknowledge the difficulties of adherence</li> <li><input type="checkbox"/> Identifying positive experiences of receiving help</li> <li><input type="checkbox"/> Identify barriers to adherence and work with client to develop strategies to address these barriers</li> <li><input type="checkbox"/> Display optimism about treatment effectiveness</li> <li><input type="checkbox"/> Identify skills needed for adherence and help client develop these skills</li> </ul> |
| <b>Ready and Willing to adopt new behaviors</b>            | <ul style="list-style-type: none"> <li><input type="checkbox"/> May already be doing new behavior</li> <li><input type="checkbox"/> Specific problems or situations may arise that make maintaining the new behavior difficult</li> </ul>  | <ul style="list-style-type: none"> <li><input type="checkbox"/> Identify possible problems and provide specific problem solving strategies, and contingency planning</li> <li><input type="checkbox"/> Provide support, reassurance</li> </ul>   |

*Motivational Interviewing: Preparing People for Change, Miller & Rollnick, 2002*

| <b>Adherence Counselor's Checklist</b>  |            |           |                |
|---|------------|-----------|----------------|
| <i>Issue</i>  | <i>Yes</i> | <i>No</i> | <i>Comment</i> |
| 1. Have I identified any adherence barriers and made a plan on how to overcome them in collaboration with the client? |            |           |                |
| 2. Have I linked the client to identified concrete and/or other social services?                                      |            |           |                |
| 3. Have I reviewed with the client his/her daily routines and dosing schedule(s)?                                     |            |           |                |
| 4. Have I provided adherence and treatment education?   |            |           |                |
| 5. Have I provided the client with tools to help with taking the medications?   |            |           |                |
| 6. Did I have the client repeat dosing times and instructions?  |            |           |                |
| 7. Did I provide the client with written and/or visual instructions?  |            |           |                |
| 8. Does the client know how to contact me with questions or problems?   |            |           |                |
| 9. Has a follow up appointment been scheduled and does the client know when it is?                                    |            |           |                |

## Managing Side Effects

*The following is a list of side effects that HIV positive clients on medication might experience. Many side effects can be managed with other medications or adjustments to the treatment regimen. The information below is provided only to help familiarize non-physicians with side effects and possible treatments that physicians may prescribe.*

|                              |   |
|------------------------------|---|
| <b>Nausea &amp; Vomiting</b> | <ul style="list-style-type: none"> <li>ⓧ Can be managed with a variety of antiemetics (e.g. Compazine, Phenergan)</li> <li>ⓧ If severe (e.g. patient cannot eat or drink) holding or changing the medication may be in order</li> <li>ⓧ Diet can help with symptoms- B.R.A.T. (bananas, rice, applesauce, toast); peppermint, chamomile or ginger tea, cold carbonated drinks.</li> <li>ⓧ Avoid hot, spicy, strong- smelling and greasy foods.</li> </ul> |
| <b>Diarrhea</b>              | <ul style="list-style-type: none"> <li>ⓧ Very common with Nelfinavir (Viracept) .</li> <li>ⓧ Usually can be controlled with Imodium</li> <li>ⓧ Calcium has also been found to be helpful</li> <li>ⓧ Diet Management- drink lots of fluids to prevent dehydration, avoid foods that are greasy, high fiber or sweet; Avoid milk products</li> <li>ⓧ May persist &amp; medication change may be necessary</li> </ul>  |
| <b>Decreased Appetitive</b>  | <ul style="list-style-type: none"> <li>ⓧ Common with many ARVs</li> <li>ⓧ Some patients respond to appetite stimulants (e.g. Magace, Marinol)</li> <li>ⓧ Nutritional support is helpful ( e.g. Ensure, Boost, Nutrivir)</li> <li>ⓧ If persistent, may require medication change</li> </ul>  |
| <b>Rash</b>                  | <ul style="list-style-type: none"> <li>ⓧ Occurs most commonly with Nevirapine, Sustiva, Abacavir</li> <li>ⓧ Can be managed with Benadryl or Atarax</li> <li>ⓧ Provider MUST be made aware these symptoms because they can become life-threatening</li> <li>ⓧ Avoid hot showers or baths</li> <li>ⓧ Use mild soap or oatmeal soap</li> <li>ⓧ Protect skin from sun exposure</li> </ul>   |

|  |  |
|--|--|
| <p><b>Insomnia &amp; Dizziness</b></p>                 | <ul style="list-style-type: none"> <li>ⓧ Common with Sustiva</li> <li>ⓧ Can be managed with sleep aids (e.g. Benadryl, Ambien)</li> <li>ⓧ Timing of dosing can be changed</li> </ul>   |
| <p><b>Hepatitis or Pancreatitis</b></p>                | <ul style="list-style-type: none"> <li>ⓧ Usually manifest as abdominal pain</li> <li>ⓧ Provider <b>MUST</b> be made aware</li> <li>ⓧ Evaluation with blood tests and imaging studies may be necessary</li> </ul>   |
| <p><b>Fatigue, Muscle Aches, Headache, Malaise</b></p> | <ul style="list-style-type: none"> <li>ⓧ Non-specific complaints</li> <li>ⓧ May indicate a developing underlying process (e.g. anemia, neutropenia, thrombocytopenia, myopathy)</li> <li>ⓧ Regular follow up should uncover any serious problems</li> </ul>  |
| <p><b>Neuropathy</b></p>                               | <ul style="list-style-type: none"> <li>ⓧ Commonly seen with 001 (Videx), OOC (Hivid), 04T (Zerit)</li> <li>ⓧ Usually managed with combination of analgesia (NSAIOs, narcotics), Elavil, Neurontin</li> <li>ⓧ Any symptoms of tingling, numbness and pain in the hands or feet <b>MUST</b> be reported to provider</li> <li>ⓧ Wear loose fitting shoes</li> <li>ⓧ Keep feet uncovered in bed</li> <li>ⓧ Medication change usually needed</li> </ul>   |
| <p><b>Kidney Stones</b></p>                            | <ul style="list-style-type: none"> <li>ⓧ Seen with Indinavir (Crixivan)</li> <li>ⓧ Due to lack of proper hydration</li> <li>ⓧ Abdominal pain is the common manifestation</li> <li>ⓧ Blood in urine and pain with urination can be present</li> </ul>   |
| <p><b>Lipid/fat Abnormalities</b></p>                  | <ul style="list-style-type: none"> <li>ⓧ Seen with long term use of antiretroviral (esp. NRTI's and PI's)</li> <li>ⓧ Manifests as fat redistribution such as: thinning of arms and legs with accumulation of central fat</li> <li>ⓧ Increases in cholesterol and triglycerides</li> <li>ⓧ Switching of medications might be helpful</li> <li>ⓧ It is important to follow up with provider for regular cholesterol/TG checks</li> <li>ⓧ If levels are high enough fat lowering drugs may be required</li> </ul> |

|                                     |  |
|-------------------------------------|--|
| <p><b>Glucose Abnormalities</b></p> | <ul style="list-style-type: none"> <li>⌘ Seen with long term use of antiretrovirals (NRTI's and PI's )</li> <li>⌘ Levels of glucose increase as in diabetes</li> <li>⌘ Switch to NNRTI's can be helpful</li> <li>⌘ Ultimately may require treatment for diabetes</li> </ul>  |
| <p><b>Bone Abnormalities</b></p>    | <ul style="list-style-type: none"> <li>⌘ Some correlation between use of ARV ( esp. PI's) and osteopenia (thin bones)</li> <li>⌘ Similar connection with development of avascular necrosis (hip joint destruction)</li> <li>⌘ Calcium supplementation recommended</li> <li>⌘ Development of hip pain requires thorough evaluation</li> </ul>   |
| <p><b>Drug Interactions</b></p>     | <ul style="list-style-type: none"> <li>⌘ Some HIV medications can lead to increases and decreases in the levels of other drugs that are taken concurrently (e.g. methadone)</li> <li>⌘ Some of these interactions can be life threatening or may lead to inadequate therapy</li> <li>⌘ Clients should tell their doctor all the medications they are taking, including over-the-counter medications</li> </ul> |

**AFFIRMATIONS**

*Affirmations are statements of recognition of the client’s strengths. They help build the client’s confidence their ability to manage the changes. To be effective, affirmations must be genuine. When clients can’t see their own strengths or progress, the Peer Advocate’s affirmations can show the client positive aspects of their behaviors.*

*Read the situations below, and the sample affirmations that are provided. Then, in the space provided, add sample affirmations of your own.*

*Ask other Peer Advocates about other situations that you might encounter. Write those in the spaces provide and include and the affirmations you might use in those circumstances.*

| <i>Situation</i>   | <i>Sample Affirmation</i>   | <i>Your Affirmation</i> |
|--|---|-------------------------|
| Client decided to begin medications, but has been having trouble keeping to the regimen  | “I appreciate how hard it must have been for you to decide to take medications” |                         |
| The client has been having trouble with side effects, and says he has “tried everything” and doesn’t know what else to do except quit taking medications.                        | “I think it is great that you want to do something about this problem.”         |                         |
| Client complains that taking medications is hard, and doesn’t know how anyone can do it.   | "I must say, if I were in your position, I would find it difficult too."        |                         |
| Client states that she can’t seem to manage taking care of children, trying to pay the bills and taking care of her own health. Sometimes it’s easier to just not take her meds. | ”You certainly have to cope with a lot of problems right now.”                  |                         |
| Other:   |   |                         |
| Other:   |   |                         |

# Section V: Advocating for Clients

The Peer Advocate is in a unique position to speak for the client within the multidisciplinary team. As a client advocate, you:

1. Represent your client whose needs you are seeking to meet.
2. Assess issues and information that affect clients and the services they need.
3. Bring the client's interests to your team and other decision makers.
4. Bring the client information from your team and other decision makers.
5. Represent your team to other agencies and organizations.

The first step is to understand the client's needs and develop a plan for advocating for the client.

## Refer to:

|                                     | <b>PAGE</b> |
|-------------------------------------|-------------|
| Tool #23: Steps to an Advocacy Plan | 63          |

A case conference is an excellent format in which to share information about the client and advocate for the client's needs and concerns. However, you will be most successful if you plan what and how to present at the case conference.

## Refer to:

|                                       | <b>PAGE</b> |
|---------------------------------------|-------------|
| Tool #24: Case Conferencing           | 65          |
| Tool #25: Case Conference Preparation | 66          |

It is also important to review how to present information in the case conference. A successful Peer Advocate is assertive without being aggressive.

## Refer to:

|                                   | <b>PAGE</b> |
|-----------------------------------|-------------|
| Tool #26: Tips on Being Assertive | 67          |

Finally, Peer Advocates can assess their effectiveness in advocating for clients. Reviewing the self-assessment with a supervisor can lead to developing strategies to become even more successful in the future.

## Refer to:

|                                    | <b>PAGE</b> |
|------------------------------------|-------------|
| Tool #27: Advocacy Self-Assessment | 68          |

# Section V: Advocating for Clients

## TOOLS

| <b>TOOLS:</b>                                 | <b>PAGE</b> |
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| Tool #24: Case Conferencing                   | 65          |
| Tool #25: Case Conference Preparation         | 66          |
| Tool #26: Tips on Being Assertive             | 67          |
| Tool #27: Advocacy Self-Assessment            | 68          |

| <p><b>Steps to an Effective Advocacy Plan</b></p> <p>The advocacy plan is developed with input from clients. You can also consult with your multidisciplinary team members who have expertise in your client’s area of need, and your supervisor.</p> |  |
|---|--|
| <p>Step 1.</p> <p><b>Define the Problem and Identify Solutions</b></p>  | <p>A. Describe the problem</p> <ul style="list-style-type: none"> <li>• Clients present with multiple needs. It is important to define specific problems and prioritize them.</li> <li>• Write out a short statement of the problem.</li> </ul> <p>B. Describe the ideal solution and list alternate acceptable solution(s).</p> <ul style="list-style-type: none"> <li>• List the issues and the results you hope to achieve.</li> <li>• Prepare your client for compromise. Because you may not get everything you desire, identify alternatives to the ideal outcome that would also be acceptable.</li> </ul>  |
| <p>Step 2.</p> <p><b>Identify Resources and Information Needed to Support a Solution</b></p>  | <p>A. Resources/information</p> <ul style="list-style-type: none"> <li>• List the information/resources you already have and the information/sources you need to reach the desired outcome.</li> </ul> <p>B. People who can help achieve the solution</p> <ul style="list-style-type: none"> <li>• List the people who can help you achieve your solution.</li> <li>• Describe how they can help you.</li> </ul>   |
| <p>Step 3.</p> <p><b>Advocate for your Client</b></p>   | <p>A. Identify decision makers, people to talk with to advocate for your client</p> <ul style="list-style-type: none"> <li>• List the decision maker(s) who can give you what you want</li> <li>• Note: Decision Makers are always people, not agencies</li> </ul> <p>B. Develop a message to use when advocating for your client</p> <ul style="list-style-type: none"> <li>• List the 3 most important points to cover.</li> <li>• Describe why your position deserves support.</li> <li>• Provide clear, concrete information to support your position.</li> <li>• Focus on needs, and your proposed solution:</li> <li>• List the needs our position would address.</li> </ul> |

|   |   |
|---|---|
|   | <ul style="list-style-type: none"> <li>• Explain why each need is important.</li> <li>• Explain how your position/idea will meet each need.</li> </ul> <p>C. Meet with decision makers and use your message to advocate for your client</p> <ul style="list-style-type: none"> <li>• Be direct and clear.</li> <li>• Use appropriate eye contact and other non-verbal communication skills.</li> <li>• State what you want in an assertive manner.</li> <li>• Listen for their response to your position.</li> <li>• Answer questions and clarify information. □</li> </ul> |
| <p>Step 4.</p> <p><b>Assess the Outcome and Identify Next Steps</b></p> | <p>A. Agreements Reached</p> <ul style="list-style-type: none"> <li>• What agreements were reached?</li> <li>• List any remaining issues and the plan to address them.</li> </ul> <p>B. Next Steps</p> <ul style="list-style-type: none"> <li>• List the tasks that must be completed, include who will do what</li> </ul>  |

### **Case Conferencing**

Case conferencing is a gathering of providers who work with a specific client. Case conferencing can be a casual meeting between a few team members or a more formal meeting with agencies outside your own. The goal is to think together about identifying problems, coming up with solutions, and developing next steps.

When presenting a client in a case conference, you may want to answer the following questions first.

|   |  |
|---|--|
| <b>1. What do I want to achieve with this client? What does the client want to achieve?</b>                               |  |
| <b>2. What are the issues or problems in the way of this goal?</b>  |  |
| <b>3. What interventions have I tried? What worked in the past?</b>   |  |
| <b>4. What was the client's response to the interventions?</b>  |  |
| <b>5. What are possible interventions I can try now?</b>  |  |
| <b>6. How will I work in collaboration with the client, and what could get in the way of our collaboration?</b>           |  |
| <b>7. How will I work in collaboration with other staff or providers?</b>   |  |
| <b>8. Do I need help or resources in implementing this intervention?</b>  |  |
| <b>9. If the client doesn't respond to this intervention, or if the behaviors becomes more serious, what can be done?</b> |  |

**Case Conference Preparation**

**Before you meet for a case conference with someone outside of your agency, make sure to:**

- Be well rested
- Know the material
- Practice the presentation
- Know your goal
- Organize your notes
- Check all your materials
- Note the address and how to get to the case conference
- Arrive early

### **Tips on Being Assertive**

- Be prepared.
- Know what you want to say and how you want to say it.
- Be prepared for potential obstacles or resistance.
- Use body language that communicates confidence.
- Make eye contact.
- Stand or sit up straight.
- Monitor your emotions.
- Focus on the solution, not on blaming the other person.
- Be calm and open, not angry, aggressive or abrasive.
- Be concise and straightforward in your message.
- Speak clearly, firmly, and loudly enough to be easily heard.
- Use fewer words for more effect.
- Use “I-statements” to identify what you want.
- Don’t apologize, or make excuses for your position.
- Respond to your audience.
- Listen for their response to your advocacy message.
- Answer questions and clarify information when asked.
- Be firm.
- Do not back down.
- Negotiate a compromise rather than give in completely.
- Stick to your goal, and do not allow yourself to become distracted.

### **Advocacy Self-Assessment**

Complete the following to see how you are doing as an advocate. Then, discuss this self assessment with your supervisor.

- A. Recall a time when you advocated for a client.**
  
- B. What was the issue?**
  
- C. How did you determine this was a client's needs?**
  
- D. What did you want to happen?**
  
- E. What happened?**
  
- F. What could you have done differently?**
  
- G. What are three steps you can take to be a better advocate?**

# Section VI: Confidentiality and Boundaries

Confidentiality means that you can share information about the client with your supervisor or other clinic staff as needed, and in some cases you must share the information. Confidentiality also means that you and the clinic's other staff will not share client information with anyone outside of the clinic, unless the client gives you permission.

**Refer to:**

|                                      | <b>PAGE</b> |
|--------------------------------------|-------------|
| Tool #28: Explaining Confidentiality | 71          |

Although you are bound by confidentiality, clients are *not* obligated to keep information about you confidential. You should therefore decide what personal information you are willing to share with clients.

**Refer to:**

|   | <b>PAGE</b> |
|---|-------------|
| Tool #29: Checklist on Confidentiality Issues | 72          |

Some information you get from clients you will have to share with your supervisor and/or your team. Be clear with your client about the difference between “confidential” and “secret” and let the client know what information will be shared.

**Refer to:**

|  | <b>PAGE</b> |
|--|-------------|
| Tool #30: Sharing Information with your Team | 73          |

As a Peer Advocate, you can probably identify with your clients more than almost anyone else on your team. Some of your clients may even be people you know: they could be family, friends, people you've had sex with or shared drugs with, or just people you could run into on the street, on a bus, or in a grocery store.

While this familiarity can be a strength to your work, it can also be problematic. Even when you identify with the experiences of the client, you do not really share the same life as your client. To be effective as a Peer Advocate, it is important to maintain professional boundaries in your work.

Boundaries refer to limits defined by a worker, a client, or the policies and procedures of an agency. Supervision reinforces boundaries by helping you see where boundaries are blurry, and then coming up with ways to set and maintain limits. Talk with your supervisor to learn how to set and maintain boundaries and how to handle difficult situations.

**Refer to:**

|  | <b>PAGE</b> |
|--|-------------|
| Tool #31: What to Do About Typical Boundary Violations | 74          |

# Section VI: Confidentiality and Boundaries TOOLS

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| Tool #30: Sharing Information With Your Team           | 73          |
| Tool #31: What to do About Typical Boundary Violations | 74          |

**Explaining Confidentiality**

| Principles  | How to explain it to a client   |
|---|---|
| Laws protect information about a client that you learn about through serving that client.   | <p>“Confidentiality laws mean that I cannot tell anyone outside of the clinic anything about you, unless you give me your written consent.”</p> <p>“I can’t even let someone know you get services here, or that I know you.”</p> <p>“The only time we would ever reveal information without your consent would be if you are a danger to yourself or someone else. In that case, I’d talk to my supervisor and she would contact 911 or the police, to get you help. She wouldn’t reveal any information about HIV.”</p> |
| The professional standard is very high for protecting HIV information.  |   |
| The agency or anyone working for the agency—including peers— <i>cannot</i> release information without the patient’s written consent.                             |   |
| This rule is absolute and is not open to interpretation. However, if a client is a harm to self or others your supervisor must report that.                       |   |
| No matter what your relationship is outside the clinic, you must not reveal information to anyone outside of the clinic without written consent from your client. |   |
| Inside your clinic, you must share information with your supervisor, and other team members, on a need to know basis.   | <p>“I want to make sure you can trust me with the things you want to share with me.”</p> <p>“I will not tell anything to anyone outside of the clinic, unless you give me written permission.”</p> <p>“I also don’t keep secrets from my supervisor. Whatever you share with me, you’re also sharing with my supervisor.”</p>   |
| As a client yourself, you probably already understand that sharing information without consent would make clients less likely to trust you.                       |   |

**Checklist on Confidentiality Issues**

*Being a Peer Advocate may sometimes feel like you're more of a 'friend' than a staff person. However, setting and maintaining boundaries about what you do and do not share about your personal life is your choice. Protect your confidentiality, not just the client's. Talk with other Peer Advocates and your supervisor about how to respond in the situations described below.*

| <b>Sample Question</b>   | <b>Your Answer</b> | <b>Who can you talk to about this issue?</b> |
|--|--------------------|--|
| Do I want my clients to know my HIV status?  |                    |  |
| How do I protect my own confidentiality?   |                    |  |
| Does my job 'out' me as a person living with HIV/AIDS?   |                    |  |
| What should I do if I have trouble taking my own meds?<br><br>Do I share that with the multidisciplinary team?   |                    |  |
| How comfortable am I sharing about...<br><br>My drug use?<br><br>My HIV status?<br><br>My medication regimen?<br><br>My sex life?<br><br>My sex work?<br><br>My experience with domestic violence?<br><br>My experience with prison? |                    |  |

**Sharing Information with your Team**

*Directions: Think of how you would respond in each of the situations below, and write your responses in the space provided. Then, consider who you would tell on your team about this issue. Be sure to check your responses with your supervisor.*

| Scenario   | What to say to the client | Who to bring issue to |
|--|---------------------------|-----------------------|
| A client tells you they aren't taking medications as prescribed.   |                           |                       |
| You hear from a neighbor that one of your clients is shooting drugs, but the client denies she is using. |                           |                       |
| Your client threatens to hurt him or herself, or someone else.   |                           |                       |
| Your client asks you not to tell anyone else that her boyfriend beats her.                               |                           |                       |

**What to Do about Typical Boundary Violations**

*Think about how you would respond in each situation below, and write your responses in the spaces provided. Then, talk with your supervisor about how to handle these situations.*

| The Situation  | You can respond by... |
|--|-----------------------|
| A client asks you for money...   |                       |
| A client flirts with you, wants to have sex with you, or touches you sexually...   |                       |
| A client asks you for information about another client...  |                       |
| A client asks you about your personal health and you do not want to share...   |                       |
| A client asks for your home phone number   |                       |
| You see the client when you are out shopping. You wonder if you should say "Hi?"   |                       |
| A client sees you when you are off work and eating at a local restaurant. You are having a few drinks with your meal (you are over 21 years old). Your client buys you a drink and comes over to chat. |                       |