Strengthening HIV Care

A Manual to Help Small Organizations Make Big Change in Communities of Color
Dear Friends:

On behalf of the National Minority AIDS Council, I am pleased to share with you this manual, “Strengthening HIV Care: A Manual to Help Small Organizations Make Big Changes in Communities of Color.” The transition from general HIV prevention and awareness activities to a whole range of clinical and testing services can be overwhelming.

This manual provides tools and detailed information to faith and community-based organizations currently navigating the infrastructural challenges often encountered when expanding and diversifying HIV/AIDS services. Each chapter addresses an individual service delivery subject—from nutrition to clinical case management—and is written by subject experts whose guidance and advice reflects not only their academic backgrounds, but also their professional experience.

More than a “how to” guide, the manual provides insight into delivering HIV/AIDS care in communities of color that reflects the unique needs of minority populations, which have been disproportionately impacted by the AIDS epidemic since it began over twenty years ago. Despite medical and legislative advances in recent years, disparities in access to healthcare and education, as well as the stigma associated with the virus, have contributed to the rising number of HIV cases among minorities. The Centers for Disease Control and Prevention (CDC) reports that people of color represent 70 percent of all new HIV cases each year.

NMAC commends the efforts of faith and community-based organizations that are seeking ways to better serve their clients. Since 1987, NMAC has promoted and mobilized leadership in communities of color to combat HIV/AIDS. We work to strengthen the capacity and infrastructure of minority CBOs and to promote sound, national HIV/AIDS policies that are responsive to the unique needs of these communities.

We hope the information provided here will help readers increase their organizations’ capacity to provide comprehensive and compassionate HIV/AIDS care.

Yours in the struggle,

Paul A. Kawata
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The National Minority AIDS Council (NMAC) would like to thank the many people who contributed to this manual. (Their personal biographies are listed in Chapter 6). Writers included:

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✧ Abdin Noboa, PhD, writer for “Moving Toward HIV Service Delivery”
✧ Joseph Telfair, PhD, writer for “HIV Counseling, Testing and Referrals”
✧ Ada Ivonne Vazquez, PhD, writer for “Clinical Case Management”
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Finally, NMAC appreciates the work of its staff, Indira Belizaire, Pamela Johnson and others. Their patience and dedication made this project a success.

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CHAPTER 1

Getting Started
Who Should Read This Manual?

This manual is for agencies with limited resources and a desire to expand their HIV/AIDS work. It is also for agencies that are new or are trying to revise their role in HIV/AIDS service delivery. Specifically, it is a primer — a starting point — to help agencies learn how to provide HIV-related care services for people living with HIV/AIDS (PLWH/A) from racial and ethnic minority communities.

Smaller agencies doing HIV-related work often have prevention education as their main focus. Expanding into HIV care and support services can seem daunting.

✧ Where should we start?
✧ What services are needed?
✧ What kind of staff do we need?
✧ What funds are available?
✧ What standards and protocols exist to guide us?

If that sounds like your agency, you should read this manual. It describes steps you can take to get ready for, and manage, change.

What Can You Do with This Manual?

Addressing the needs of PLWH/A requires compassion, commitment and the will to make things happen — even when they seem impossible. This manual highlights some practical steps to take to expand your work into HIV care and support services.

Whatever you decide, develop an action plan to guide you. Some first steps might include:

✧ **Learn More.** Look up resources listed in this manual and seek technical assistance.
✧ **Determine What is Needed.** Think about what services are needed in your community. Look at needs assessments that have already been done. Don’t reinvent the wheel or duplicate what’s already there.
✧ **Decide What You Want to Do.** You might want to set up a new program. Or, you may decide to partner with other agencies in your community to do the work. You may even want to improve the HIV work you already provide by adopting guidelines, standards and/or best practices.

✧ **Think about Managing Change.** Your organization may need to change if you take on new work. Examples include: getting new funding, staffing, management, recordkeeping, and developing written policies and procedures.

### What is in This Manual?

This manual has six chapters.

**Chapter One: Getting Started** — which you are reading now, explains the purpose of this manual. It also talks about what is important in providing HIV care in any program. This includes: cultural competency, maintaining confidentiality about client information, client empowerment and evaluation.

**Chapter Two: Moving Toward HIV Service Delivery** — provides information about development and change within community-based organizations. It also identifies various organizational requirements for HIV program development and service delivery.

**Chapters Three, Four and Five: HIV Counseling, Testing and Referrals; Clinical Case Management; and Nutrition Services** — provide an overview of three services that have been identified as more practical for low-resource agencies to consider taking on. They include:

✧ HIV Counseling, Testing and Referrals;
✧ Clinical Case Management; and
✧ Nutrition.

These services are not the only ones critical to HIV/AIDS care. Others include — for example — outreach to get PLWH/A into care, and primary care services to help PLWH/A manage their HIV disease, substance abuse and mental health counseling. Also, many support services exist to help clients manage their health and overall needs, like transportation and housing.

**Chapter Six: Biographies** — includes personal biographies of the people involved in the development of this document.

The sponsors, writers, advisors and editor of this manual are well aware of the dedication and compassion low resource organizations show toward the communities they serve. We hope that this manual will help you to strengthen your commitment to PLWH/A through improvements to your organization, staff and service delivery.
WHY DID WE DEVELOP THIS MANUAL?

Your quest to provide HIV/AIDS services for people of color is part of a long history of community-based efforts to improve access to health services. Over nearly two decades, the following work has been undertaken to promote the delivery of health care and support services to racial and ethnic minority communities. This manual is a small contribution to this rich history.

✧ In 1986, the Secretary’s Task Force on Black and Minority Health of the United States Department of Health and Human Services (DHHS)¹ wrote a report describing reasons for high levels of sickness and death among minorities—as compared to the general population. It examined cancer, heart disease, drug and alcohol abuse, diabetes, homicide, suicide and accidents, infant mortality and low birth weight. This report set the stage for future studies and interventions to reduce racial and ethnic minority disparities (or differences) in health care.

✧ In 1998, community leaders and the Congressional Black Caucus fought for new resources to address the growing number of African-Americans becoming infected with HIV and dying from AIDS. In 1999, the White House declared a “severe and ongoing crisis” for HIV/AIDS in African-American communities. The Minority AIDS Initiative (MAI) was created as a result. The goal of the MAI is to: (1) improve access to HIV care and treatment in communities of color (including African-Americans, Hispanics/Latinos, Asian/Pacific Islanders and other racial ethnic minority groups); (2) increase the capacity of minority community-based organizations to provide HIV-related services; and (3) develop new programs to reduce disparities in PLWH/A.²

✧ In 2000, a review of 400 studies on disparities in access to preventive, diagnostic and therapeutic services was conducted by Robert Mayberry and other researchers at the Morehouse School of Medicine.³ Their work focused on HIV/AIDS as well as other areas covered in the 1986 Secretary’s Task Force Report. The researchers found significant differences in access to health services. These differences could not be explained by factors like:

- A person’s income and education (or socio-economic status);
- Whether or not a person has health insurance;
- The advancement or severity of a person’s disease;
- Other diseases the person might have (also called co-morbidities);
- The amount of different services available to a person in their community; and
- Individual patient preferences.

The researchers came to this conclusion:

Race and ethnicity are important factors in why access to health care services differs from one group to another.

✧ In 2000, Congress re-authorized (renewed) the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.⁴ The CARE Act is a federal program, first started in 1990, that pays for HIV/AIDS care for those who lack resources to pay for the care they need. The 2000 re-authorization included many new requirements for DHHS to fulfill. Some of those requirements included:
• Improving the planning and distribution of funding to meet the greatest needs and to address disparities in access to health care
• Building partnerships among organizations that provide health care and social support services, and
• Helping organizations in underserved communities improve their ability to meet the needs of PLWH/A.

In 2002, the Institute of Medicine5 (IOM) published a report titled, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. The report highlighted strategies to decrease health disparities, like making sure that:
• The general public knows that health disparities exist in the United States;
• Health care providers (e.g., doctors, nurses and dentists) understand the importance of using published clinical guidelines established by professional organizations when providing care to all patients regardless of race, income, education, etc.;
• Health care providers do not benefit financially from reducing or denying access to services; and
• Health care providers use language interpreters when treating patients who do not understand or speak English well.

In 2002, the DHHS Office of Minority Health6 published a set of fourteen standards for Culturally and Linguistically Appropriate Services (CLAS). These standards were developed and reviewed by governmental officials, non-governmental groups, health care accrediting organizations, health care providers and patients. They are organized into three areas: 1) culturally competent care; 2) language access services; and 3) organizational supports for cultural competence. The standards are to ensure that the same high quality services are provided to all who enter the health care system, regardless of personal characteristics.

**Issues in HIV Service Delivery**

You need to do some things for your clients, no matter what HIV-related services you provide. These cross-cutting issues include:

✧ Providing services that are culturally and linguistically appropriate;
✧ Keeping client information strictly confidential;
✧ Teaching clients how to get, understand and use health information; and
✧ Evaluating your work, and the quality of services you provide, to see if it is making a difference.

Each of these is discussed below. You will also find more information on these issues in the chapters that follow.

**Cultural and Linguistic Competence**

Culture and language have a considerable impact on the delivery of care. This includes:

✧ Access to care for clients (e.g., How do you deliver care? How do clients like to get care?);
✧ Quality of care provided (e.g., Does anything get in the way of your clients getting the best care?); and
✧ Client retention in care (e.g., What can you do to make sure that clients return regularly for the services they need?).

Your ability to recognize and address differences in culture and language is key to building good relationships with your clients.

**What is Cultural Competency?**

As defined by the DHHS, Office of Minority Health:

“Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. ‘Culture’ refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious or social groups. ‘Competence’ implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities.”

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In other words, cultural and linguistic competency is the ability to work effectively with someone who has a different language or cultural background. Examples of cultural differences include: viewpoint, life experience, religion, behaviors, sexual preference, dress, religious belief and income. Cultural competency also is the ability to address the needs of different clients without prejudice or judgment.

*Culture is More Than…*

Many people think of culture in terms of a person’s racial or ethnic background. However, culture is much more complex than just race or geographic origin. Let us consider the characteristics of Cheryl and Mike, two African-Americans who go to their local community-based organization for a substance abuse support group.

<table>
<thead>
<tr>
<th>Cheryl</th>
<th>Mike</th>
</tr>
</thead>
<tbody>
<tr>
<td>45-year old, African-American woman</td>
<td>41-year old, African-American man</td>
</tr>
<tr>
<td>Born in Chicago, IL</td>
<td>Born in Atlanta, GA</td>
</tr>
<tr>
<td>Enjoys gospel music and reading spiritual books</td>
<td>Single parent of a teenage girl</td>
</tr>
<tr>
<td>Occasionally shares needles with friends to use drugs</td>
<td>Enjoys sports and dating different women</td>
</tr>
<tr>
<td>Spent three years in prison for possession of illegal drugs</td>
<td>Drinks a lot of alcohol every day</td>
</tr>
<tr>
<td>Diagnosed with AIDS upon release from prison</td>
<td>Mother passed away from cancer, father from a stroke and brother from a car accident</td>
</tr>
<tr>
<td>Never tested for HIV</td>
<td></td>
</tr>
</tbody>
</table>

✧ What do Cheryl and Mike have in common?
✧ How are their life experiences and substance abuse problems different?
✧ What things might motivate Cheryl to make a change in her life?
✧ What might motivate Mike to make a change?
✧ Do you think they might use different words or expressions when talking about the same thing?

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TIPS ON CULTURAL COMPETENCY

Cultural and linguistic competency in health and social services requires providers to:

✧ Develop a good relationship with each client as an individual.
✧ Never make assumptions about a client’s behaviors, thoughts or feelings.
✧ In a respectful way, ask for the information needed to understand each client’s personal situation, experiences, specific needs and preferences.
✧ Share important information with each client in a way that he or she can understand easily.
✧ If the client and provider speak different languages, someone should be available to help translate or interpret what is said. (Do not assume that you can use a client’s family member or a friend to translate. This can be very inappropriate, because clients are often fearful that others will learn about their HIV status.)
✧ Also, remember that even people who speak the same language (e.g., English, Spanish and Creole) can use different words or combinations of words within that language to say the same thing.
✧ Find out what resources, skills or information the client has that can be helpful to addressing their needs.
✧ See the provider and the client as partners who work together to create a plan of action that works best for the client.
✧ Do not judge clients. Be open and accepting of a client’s personal choices.
✧ Stay on top of the legal requirements for cultural competency.

Managers of organizations must make sure that all their staff understand the need for cultural and linguistic competence in service delivery. They must also identify specific steps on how to demonstrate and measure it.
Answers to these questions help us understand the cultural and linguistic backgrounds of Cheryl and Mike.

As another example, let’s consider these two Hispanic/Latina women who go to the same community-based organization to get tested for HIV.

<table>
<thead>
<tr>
<th>Carmen</th>
<th>Rosita</th>
</tr>
</thead>
<tbody>
<tr>
<td>25-year old, Mexican American woman</td>
<td>55-year old, immigrant from Ecuador</td>
</tr>
<tr>
<td>First in her family to go to college</td>
<td>Lives with her husband and five children in Queens, NY</td>
</tr>
<tr>
<td>Moved to New York from California to go to graduate school</td>
<td>Catholic</td>
</tr>
<tr>
<td>Enjoys having intimate relationships with men and women</td>
<td>Works two jobs (as a housekeeper in a large hotel and a dishwasher at a local restaurant)</td>
</tr>
<tr>
<td>Recently sexually assaulted walking home from the library</td>
<td>Recently found out that her husband is HIV positive</td>
</tr>
</tbody>
</table>

✧ What do Carmen and Rosita have in common?
✧ What concerns might Carmen have about getting an HIV test?
✧ What about Rosita’s concerns getting tested?
✧ Is it safe to assume that they both are fluent in the same language?
✧ How might the same provider interact differently with each client?

The information provided above about these clients is limited. But there is a lesson to be learned. People can be very different on many levels — even when they appear to be similar on the surface.

**Privacy, Confidentiality and Risk Management**

Privacy and confidentiality is important to care for many reasons:

✧ Patients must trust that their providers will safeguard their personal information. This is even more important for HIV/AIDS because of stigma and discrimination (negative feelings, beliefs or behaviors toward people with a certain characteristic) that still exists when it comes to HIV and AIDS. Many researchers and policymakers have documented
how privacy and confidentiality can affect health care delivery (see the Belmont Report published by DHHS).9

State laws and federal regulations like the Health Insurance Portability and Accountability Act (HIPAA)10 require providers to protect client information. Confidentiality means that all client information must be kept in strict confidence: only people who must know the information for purposes of delivering care can get the information. Confidentiality might be breached when clients and providers can be seen or heard by others. It might also happen when written information is left unattended or kept in a place where it can be accessed by those who do not have permission. Confidentiality of client information must be protected in terms of how it is handled:

- In conversations (e.g., in a counseling session, with other organization staff, in waiting areas, with family members or friends of the client);
- On paper (e.g., hand written notes on writing paper, formal letters from other providers about client issues, client assessment or in-take forms and client records); and
- In electronic format (e.g., e-mail, database, spreadsheets, tables and documents).

TIPS ON CONFIDENTIALITY

- Federal regulations (under privacy provisions of HIPAA) require most organizations to have written protocols (or procedures) for managing client information. These protocols should include specific instructions on how to store information, move information from one location to another, share information with providers in other organizations, reproduce information and destroy information. There should be protocols for verbal, written and electronic information. All staff should understand and follow them without exception.
- Maintaining confidentiality is an important part of risk management (protecting the organization from being taken to court for wrongdoing). Because mistakes do happen, all organizations should have malpractice insurance to cover the costs of any negative consequences that may result for the organization, or more importantly, the client. Malpractice insurance should be specific for the types of services your organization provides.


Health Literacy and Client Empowerment

According to the American Medical Association, almost half of all adults in the United States may have trouble understanding common health information like forms for health insurance, instructions on how to take prescriptions, test results, etc. See American Medical Association web page at http://www.ama-assn.org/ama/pub/category/8115.html. (Accessed 06/19/03.) In addition, many clients do not tell their providers that they are having trouble understanding the information they receive. This often is because of fear or shame. Some of these adults, who are said to have “low health literacy,” will probably be among the clients you see.

TIPS ON LOW LITERACY

The Center for Health Care Strategies, Inc. suggests that organizations working with clients who have low health literacy do several things to improve their services. Suggestions include:

✧ Create an environment (e.g., a pleasant atmosphere, television and playroom for children) where clients can feel comfortable asking questions about health information. Rather than asking a client to read or fill out a form, first sit down and talk to them about it. Next, give them the option of taking the form with them and returning it to you later. This way, the client might not be embarrassed by answering sensitive questions on the form in front of you.

✧ If you think a client is having trouble, tell them that many clients often have trouble reading or understanding these materials. Ask if they need help.

✧ Use a “teach back” strategy. To do this, ask clients to state in their own words the information you have just shared with them.

✧ Develop a personal health plan of action with the client that fits into their regular routine.

✧ Put different colors or pictures on your client’s medication to help them remember how and when to take them.

✧ Do not give too much information at one time. Spread the information you need to share across several visits.

11. See the Center for Health Care Strategies web page for facts about health literacy at http://www.chcs.org/resource/hl.html. (Accessed 06/19/03.)

Empower Your Clients

When it comes to getting health care and talking to providers, clients often feel powerless and without a voice. This may be from not understanding health matters (low health literacy). It can also be due to not knowing how to speak up for oneself.

Health literacy levels can change from one client to another. Literacy is influenced by: how well the client can read, how many years of formal education they completed, self-confidence and experiences with other providers.

Organizations can teach their clients how to understand the health information they are given and how to use it to their benefit. With self-advocacy skills, clients can be more active and vocal when it comes to their health and well being. Clients can use self-advocacy skills with their doctors to get what they need. Clients also can use self-advocacy skills with their families, co-workers or employers.

There are many people who have written about self-advocacy and community empowerment, such as social worker Barbara Solomon;\(^\text{13}\) community planners, John Kretzmann and John McNight;\(^\text{14}\) and the National Center for Chronic Disease Prevention and Health

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Promotion in the Centers for Disease Control and Prevention (CDC). Please read their work for more information.

**Evaluation and Quality Management**

Every organization should have a plan to examine the work they do, and to use this information to document their work and improve their services. Evaluation and quality management are designed for this purpose.

✧ **Evaluation** involves measuring the work you do. This information is used to “assess the extent to which objectives have been achieved, identify needed improvements, and/or make decisions about future programming.”

1. Evaluation can be looked at in two general ways:
   - What work did you do? This is called *process* evaluation. It measures *effort*, like what services you delivered and how many people you served.
   - Did your work make a difference for your clients’ health status? This is called *outcome* or *impact* evaluation. It examines the *effect* of your work. Funders usually want you to conduct both process and outcome/impact evaluations.

✧ **Quality management** means using information to manage and improve the services that it provides.

Evaluation and quality management can be used to design and improve programs, as well as to encourage staff to improve their work. It also can help you make a case for support of your organization to a Board of Directors, your private or government funders, the local media or the people in your community that you want to serve.

Evaluation and quality management both call for the collection of data (or information) in a standard way over time, and then asking important questions about that data. For example:

✧ You may want to know whether your services are being used. To do this, you would do process evaluation by counting the number of service units you provided (e.g., number of patient visits).

✧ You may want to know if the substance abuse services you provide lead to a decrease in injection drug use by those who participated in your support group. You would use outcome evaluation in this case.

✧ You may want to know if your hours of operation are good for the types of clients you want to come in for services. You would do quality management to examine the way you deliver your services, and figure out what changes to make to improve things.

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TIPS ON EVALUATION AND QUALITY MANAGEMENT

✧ Include evaluation and quality management as an ongoing part of your organization’s work. In this way, it can be seen as less of a burden, and rather as part of the regular work you do.

✧ There are many different ways and tools used to do evaluation and quality management. When developing an evaluation or quality management plan, you will need to answer at least the following questions:
  • What question(s) do you want to answer about your work?
  • What kinds of data or information will you need to answer the question?
  • When will the data be collected? Or, is it already available?
  • If you need to collect new data, what method or tool (e.g., survey forms, discussion groups and interviews) will you use? How will you store or maintain the data needed?
  • How will the data be processed or analyzed (e.g., Who will review or examine the information? Will qualitative data (words) may require a different type of analysis than quantitative data (numbers))? 
  • When you collect or select the data you think is important, how do you determine if change has occurred, or if a certain standard is being met?
  • What will you do with the findings? How will you share the findings, and with whom will you share them?

✧ Evaluation and quality management are activities that may require you to talk with some experienced researchers, read more information, become familiar with technical terms, learn new computer programs, hire new staff or get some practice working with others to be successful. While there are many books and articles on the subject, we recommend two in particular.
  • The first is called How to Design a Program Evaluation, by evaluators Carol Fitz-Gibbon, Joan Herman and Lynn Morris. The second is called Evaluation: A Systematic Approach, by Peter Rossi and Harold Freeman.
We also recommend that you review the evaluation materials developed by the Health Resources and Services Administration, HIV/AIDS Bureau, located in the US Department of Health and Human Services. These guides were developed specifically for the evaluation of HIV primary care and support services.


“The first casualty in research is poor thinking. The second casualty in research is poor planning. The third casualty in research is poor execution.”

— Llewellyn J. Cornelius
Steps toward Making Change

Before taking on HIV-related services, an organization must determine if it is ready for change. Does the agency have a commitment to address the needs of PLWH/A? Is there capacity to expand current activities? Following are some steps to consider in deciding whether your agency is ready for change:

✧ **Examine the Agency’s Readiness to Change.** Evaluate your mission, vision and goals. What does your agency currently do, and what might have to change to make way for new services?

✧ **Assess What is Needed.** What service gaps exist in your area?

✧ **Choose the Right Services.** What gaps can your agency fill?

✧ **Develop a Detailed Plan of Action.** Outline how you will make the change happen. What funding is available? What do we need to do to staff the effort? What requirements do we need to meet?

✧ **Assess Whether or Not Staff is Ready to Take Action.** Make staff fully aware of all aspects discussed above, and assess its readiness and ability to put these discussions into action.

These steps can take some time to complete before an organization begins a new activity. Once the new services begin, monitoring and evaluation must take place to ensure that things are going well.

Following is a deeper discussion of some of these steps.
Examine the Agency’s Readiness to Change

Change is a natural and continually occurring event. As many say, “change is the only constant in life.” The ability to change keeps an organization vibrant, alive, and relevant. Community-based organizations must stay aware of changes affecting their community on local, regional, and national levels.

✧ **Think about Change.** Regardless of size, organizations operate from the tug and pull of “reflection” (thinking, processing, weighing options) and “action.” There must be balance between the two. Overly reflective organizations can suffer from too much analysis. On the other hand, busy organizations may not allow enough time to step back and take a look at what is happening in and around them.

✧ **Create a Climate Receptive to Change.** Managers must learn to create conditions that make information sharing and productive change occur in natural and ongoing ways. Letting staff know that managers are willing to consider and allow reasonable changes can be an exciting process. First, it encourages people to identify concerns. The identification of concerns motivates people to make a change. Motivated people volunteer to organize meetings, call friends, or do canvassing. These are the processes, for example, that position an organization to be ripe for the creation of a great plan of action. Since progress is not possible without change, the challenge is to maintain order amid change.

✧ **Have a Process on Hand.** Your organization must be constantly on the watch for how to get the latest information and how to decide among various opportunities. We suggest that organizations have a process set for regular “environmental scanning,” or checking for new information in the world around you. This process will let you collect, consider, and use information over the long term.

• **Write it Down.** Do not let ideas about change stay in the head of one or two people. This information should be written and shared throughout the organization.

• **Get Lots of Input.** Ideas and directions regarding organizational change should flow from the top down, as well as from the bottom up. All staff can make helpful contributions to the change process. Clients and community members are also important sources of information and organizational change. After all, you exist to serve your clients and community. It is highly recommended that clients be involved in change processes. You just never know where the next great idea might come from. Besides, grants programs sometimes require you to get client feedback in designing your program.

✧ **Follow Up.** While ideas are many, few organizations put them into practice. Implementation of a good idea can lead to improved quality of life for your clients and more money in the bank. Effective organizations follow through on good ideas and put them into practice.
Assess What is Needed

The above step is making your agency “fluid,” so that it can think about change as part of its ongoing thinking and planning for the future. This step is looking outside your agency to determine what needs exist. After all, your agency should not launch into a new service without figuring out if a need exists. Here are some steps:

✧ **Look at Formal Needs Assessments.** Community needs assessments often are conducted as an objective way to decide what types of change will be most beneficial for a community to make. A needs assessment is “a process of collecting information about the need for services among PLWH/A — both those receiving care and those not in care — to determine the extent to which a particular service is needed in a given community…”[20] The information or data collected during a needs assessment can be helpful in determining what service needs exist in the community, which needs are greater than others, and what barriers to care exist. Organizations use this information as a starting point in deciding what services to add, change or expand.

✧ **Be Ready for Input — From Everywhere.** As stated above, you should get lots of input in thinking about change. This is because different types of information can drive change. Sometimes, it can occur because managers are not happy with the way things are. Calls for change can also arise from a study about your organization or the community. Change may also be driven by something as simple as money; funds may be available to start a new service.

✧ **Manage the Input.** With all of this input, calls for change can create tension within an organization — among service providers, managers, other staff and board members. Change can also create tension outside an organization — with clients and community. That’s because all of these stakeholders may have different and contradictory perspectives about what should happen. All voices, within and outside of the organization, must be listened to attentively and respectfully. Following the advice of one voice as a short-term solution often will lead to long-term problems.

Choose the Right Services

So far, you’ve created a climate that’s open to change, and you’ve looked in your community to see what is needed. Now, you need to make the right choice on what HIV-related services to undertake. Looking at the service gaps you identified above is a major step, but below are some additional things to consider:

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Think How Change Might Affect Your Agency. Consider how service delivery changes might affect your agency’s guiding forces (vision, mission, values), staff and ability to financially sustain itself. Consideration of this may require an organizational needs assessment.

Make Choices. Organizations should change in a way that is appropriate for both the organization and the community. For example, agencies should not try to take on too much work or too many services. Prioritize what you do.

Consider Partnering with Others. As you contemplate your role in HIV care, realize that most communities already have a network of providers who work together (collaborate) to deliver HIV/AIDS services. This is because HIV/AIDS care involves lots of services, ranging from medical care to support services like case management and transportation. Agencies often work in partnership so that clients can get referred more easily and information can be shared more readily.

As you think about what your agency might do, think about how your agency can fit in to this network. When collaborating with others, organizations should have formal agreements that outline each organization’s roles and responsibilities:

- If the exchange of money is involved in the collaboration, this agreement would take the form of a contract. 21
- If there is no money exchange involved, it would take the form of a Memorandum of Agreement or Understanding.

Find a Mentor to Help Guide You. It can be helpful to bounce your ideas off of someone who has gone through a similar experience. The conversation could save you valuable time and money. Other providers can provide mentoring services to your organization. Because of competition that often exists among organizations in a community, you may find that the best mentor is outside of your local community. Mentor or peer organizations may be able to:

- Guide you through the change process;
- Give you insights into what funders are looking for; or
- Share models on how to provide a particular service.

Develop a Detailed Plan of Action

Once you’ve decided what change to make, you need to outline a plan to make it happen. Obviously, you need to get money. You also need the manpower to manage the program and deliver the services. There are also service requirements — what certification standards or guidelines do we need to follow?

21. For more information about Memorandums of Understanding, visit the Communities Advocating Emergency AIDS Response (CAEAR) Coalition Foundation website, and download their materials on formal linkages at http://www.caear.org/foundation/Title_I_Resource_Center/resources.htm#formal. (Accessed 07/04/03.)
Below is a discussion of just some of these considerations.

**Long Range Plans**

Programs come and go, but organizations are meant to stay. At their inception, organizations must plan for self-preservation and continued maintenance. Attached to the vision and mission of the organization are its goals and objectives. They must be sustainable over time or must change as needs change.\(^{22}\) Plans for multiple sources of funding and ultimate financial independence must be begin early.

Sustainability, however, is more about good planning and good leadership than it is about money.

**Leadership**

There is no one type of best leader. We tend to respond to different types of personalities and different styles of leadership. Different tasks also require different styles and types of leaders. Besides, everyone can be a leader in his or her own way. For example, authoritarian leadership (one person or small group with authority makes decisions) may be necessary at times, especially when a group is struggling for survival. However, this leadership style does not easily foster initiative, creativity or responsibility among all members of an organization. Collective leadership, on the other hand, can strengthen the capacity of everyone, and create specific circumstances where full use is made of all members. It avoids closed circles and secrecy. To lead collectively is to study questions jointly, find the best solutions, make decisions openly and benefit from the experience and intelligence of each member.

An effective leadership structure (or a board of directors) helps both individuals and community groups get what they want. Without community buy-in for your agency to carry out assigned tasks, organizations become frustrated and isolated. One of the reasons coalitions fail is because leaders do not fully understand how their organization fits within collective efforts and community needs.

Leadership is a skill that many people can develop if they are willing to take the time.\(^{23}\) It does not happen overnight. The role requires tremendous sensitivity and a genuine desire to work with people.\(^ {24}\) Leaders appeal to the common feelings and hopes that bind a group together. Leaders give back to a group a sense of itself and an appreciation of untapped

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potential. Leaders also help others become leaders themselves. They can also dispel the fears many of us have about tackling issues around HIV/AIDS. In communities where there is a great deal of stigma toward HIV/AIDS, an organization may choose to add to its strategic plan special community outreach and education efforts to improve public opinion and community acceptance of these efforts.

**Staff**

Any change you decide to undertake will succeed, or fail, based upon how much effort you put into helping your staff achieve their highest potential. This means training them and also valuing their contributions. Staff have the uncanny ability to live up to the highest, or the lowest, expectations of supervisors. Here are some ideas.

✧ **Look within.** Organizations that recruit from within to fill vacant positions tend to be more active in staff development. These organizations also have higher staff retention rates. Staff loyalty increases when organizations make real investments in employees and provide opportunities for promotions.

✧ **Train Your Staff.** Training opportunities can contribute to a positive organizational culture. Staff development is win-win. As individual development is promoted, program effectiveness increases, and the organization develops greater capacity. Also, staff often view opportunities for growth as a sign that the organization cares about them. Topics for staff development can follow the topics highlighted earlier. They include, for example: clinical care, cultural competence, confidentiality and other topics.

✧ **Develop Staff Over Time.** Staff development is more than a series of training events. It is an ongoing developmental process for both the organization and individual staff members. The process serves to motivate staff to increase job performance, advance professional skills, obtain licenses, become better informed and promote career development. In some instances, staff can take a short leave of absence for specialized training with the understanding that the person will return to the workplace and put newly acquired knowledge to work.

✧ **New Hires.** In addition to developing staff from within, organizations may have to hire new people. These new faces can provide more technical expertise; keep up with changing demographics in the community; or fill voids. Organizations must hire a qualified and diverse workforce at all levels to survive and prosper. Use various venues to advertise your vacancies. Make sure your job descriptions are detailed with the specific knowledge and skills you are looking for listed clearly. Be sure to post job descriptions on websites designed for the type of professional you want to hire.
Get the Right Mix of Staff. Look across your organization, and be sure you have a good mix of people with different professional and personal characteristics. If people in the organization, for example, do not reflect the diversity of the surrounding community, then its staffing practices may not lead to the best outcome for clients. Rather than simply tolerating diversity, organizations must value differences. Instead of counting heads to fill quotas for diversity, organizations must learn to make all heads count.25

Requirements

Requirements usually exist for agencies in order to get funds to deliver HIV services — and to actually deliver those services. Written protocols (or guidelines and procedures) must be in place for the protection and safety of the organization, its staff and its clients. Protocols assure that minimum standards are being met and best practices are applied at all levels of the organization. Accounting systems must be used to manage funds appropriately while providing high quality services.

Most of these requirements can be placed into two general categories: (1) organization requirements and (2) service delivery requirements.

**Organization Requirements**

✧ *Vision, Mission, Values.* The organization’s vision, mission and values must guide all plans and activities. Everyone must work toward goals and objectives that relate to these three guiding forces. Part of this is understanding that the organization’s greatest asset is its staff. The organization should have a structure that allows for active participation and shared leadership among its staff that is not based on title and rank. The collective wisdom and talents of all staff can do more for an organization than individuals in positions of power.

✧ *Operating Procedures.* Organizations must have clear policies, systems and structures for programs to function effectively. These may relate to the roles and responsibilities of staff, training, addressing disputes, documentation of activities, record keeping, the allocation (or distribution) of space, ensuring access to the facility for people with physical disabilities, misuse of funds, the allocation of costs, fiscal issues and others.

✧ *Reporting.* If you receive funding from the federal government, you will face some of the strictest requirements for the submission of standard forms and reports and for fiscal accountability. Similarly, the state government may require an additional set of forms and reports. Oftentimes, these are patterned after federal requirements, but there are subtle differences to which special attention must be paid.

**Service Requirements**

Organizations must be sure that clients receive services that are provided according to certain standards. These often take the form of treatment protocols, practice guidelines and best practices. Such standards are often established by government agencies, professional organizations, formal research and common experience. In addition to these standards, HIV services also should be delivered in a professional and client-sensitive manner. This includes paying attention to culture and thinking about the hoped for outcomes from the services. Service providers must have the service delivery knowledge, skills and experience required to meet these standards.

In the following chapters you will learn about important issues for the delivery of select HIV primary care support services. It is also important that you check listed resources for additional information. You also need to closely review all funder documents to be sure you are following their requirements.

Funder requirements for service delivery often relate to how various services are provided and under what conditions. Examples are as follows:
Licenses or certifications that must be in place
Certain types of staff
A minimum level of hours worked per week
Equipment or facility characteristics may be required (e.g., private counseling rooms and wheelchair accessibility)
Clinical protocols and guidelines
Required participation in publicly funded programs like Medicaid or Medicare (and the reimbursement dollars they provide to help pay for service delivery), which will require your agency to have billing set up for their programs. Medicaid and Medicare have their own set of requirements to be addressed.
Depending on the services you are providing, you may have to register your program with your state health department and fulfill their requirements.

While this is not a complete list, we hope it helps you to see that service delivery is not something to take lightly. But you can learn how to do it. Just ask.

_The first step toward change is acceptance. Once you accept yourself, you open the door to change. That’s all you have to do. Change is not something you do, it’s something you allow._

— Will García, HIV/AIDS consumer
References on Organization Management


This book represents one of the most seminal works produced in the area of prejudice research. Though dated, the information is still relevant. Racial dynamics continue to be the same in today’s society, and Gordon’s approach to the issue of contact and prejudice is without parallel.


View excerpts at www.betances.com. Dr. Betances is a masterful speaker. He talks about going beyond race and gender to better understand diversity. This CD is a best seller, and carefully frames the issues of race in the context of diversity and pluralism.


Fitz-Gibbon’s writings on evaluation are easy to read and serve as basic primers. This is written for lay audiences, using non-technical language. It is part of a larger series of “how to” books on evaluation.


While a bit dated, the authors provide an easy-to-follow, ABC approach to leadership development in the community. It is very highly recommended.


Kahn approaches the field of leadership from a consumer and grassroots perspective. This is a must read, though written several years ago.


Kotter represents one of the most quoted authors in the field of organizational change. Of his many publications, this one is basic in that it distinguishes leadership from management functions. He stresses visionary leadership and motivation, rather than paper-pushing and organizational maintenance.

This is one of the simplest and most to the point books on diversity management. If you have time for only one book on diversity, this should be at the top of the list. There is much confusion in the field between EEO, Affirmative Action and Diversity. This presentation is helpful in distinguishing between them.

NMAC. *Strategic Planning for AIDS Service Organizations: A Practical Guide and Workbook*. Washington, DC.

NMAC. *The Program Development Puzzle: How to Make the Pieces Fit*. Washington, DC.


Linney, Jean and Wandersman, A. *Prevention Plus III: Assessing Alcohol and Other Drug Prevention Programs at the School and Community Level*. University of South Carolina: Department of Psychology.

Available from the National Clearinghouse for Alcohol and Drug Information. Telephone: (800) 729-6686.


Stine’s book is one of the classics in HIV/AIDS data and up-to-the-minute information on the pandemic. It is updated yearly. Every HIV/AIDS program should have a copy.


In community work, expertise in conflict resolution and problem-solving are important skills. This book explains how to become proficient in these areas in an easy and practical manner.


Of the many books on program evaluation, this is the most popular. It is also easy to read. It was first published over twenty years ago, but continues to be a best-selling book in the field of evaluation. It is a classic.
HIV Counseling, Testing and Referrals
CHAPTER 3

HIV Counseling, Testing and Referrals

The previous chapters talked about how your organization could determine if it was ready for change and how it could develop an action plan for change. Once you go through those steps, you can consider putting services in place to provide care for HIV-infected and affected persons. Chapters 3, 4 and 5 describe three possible services: HIV counseling, testing and referrals; clinical case management; and nutrition. There are many others that you can consider as well, so these are just examples, although they may be more practical for low-resource agencies to consider taking on.

In Chapters 3, 4 and 5, main sections are organized as follows:

✧ **About This Service** — basic information about the service
✧ **Issues in HIV Counseling, Testing and Referrals** — areas for special attention
✧ **Setting It Up** — some thoughts about how to go about creating these services in your agency

**About This Service**

HIV counseling, testing and referral is an intervention to help people learn their HIV status, how to reduce the risk of transmitting HIV and — for those testing HIV-positive — how to get into care. These are much needed services, because anywhere from 42 to 59 percent of those living with HIV disease in America are untested, untreated or both, according to CDC estimates. One-third of the 670,000 people who know their HIV status may not be receiving care. An additional 180,000 to 280,000 people are not even diagnosed. These sobering facts say that people need more help in learning their HIV status and getting into care if infected.
HIV Counseling

HIV counseling requires some of the same basic counseling skills as other types of counseling. Examples include being a good listener; helping the client problem simplify complex information; and showing genuine empathy. However, the nature of HIV and AIDS makes this counseling unique. HIV/AIDS related counseling requires:

✧ Explicit discussion of sexual and, in some instances, illegal (e.g., substance abuse and sex work) practices;
✧ Explicit discussion of coping, care, support, death and dying;
✧ Knowledge of culturally and linguistically competent care — counselors probably will encounter clients who speak a different language; may be of a different education, socio-economic and literacy level; and hold opinions and values very different from their own;
✧ Becoming aware of one’s own biases and stereotypes that could interfere with effective counseling; and
✧ Understanding the various psychological and social issues faced by those who decide to get tested. Counselors should be aware of them and use probes to determine which ones are of concern to the client.

As part of their training, counselors must become aware of and overcome concerns they have about their own knowledge and skills for counseling regarding HIV. Effective training and skill building will help them overcome concerns such as:

✧ Ability to provide HIV test results to clients
✧ Ability to manage the reactions of clients, partners and families to positive test results
✧ Fear that they do not possess the necessary skills for HIV counseling of groups they are encountering for the first time
✧ Ability to control their own emotional reactions to the work

HIV Testing

HIV testing must occur only with devices that have been approved in the United States by the Food and Drug Administration (FDA) for diagnostic purposes. There are a number of different devices that test different bodily fluids (i.e., whole blood, serum, plasma, saliva and urine). Some devices allow for specimen (sample of body fluid) collection procedures that do not use injection needles. These devices can be less invasive and more acceptable for people who fear needles or would rather they not be used. They also allow for HIV testing to occur outside of a health care setting (e.g., in the home) and for test results to be provided within minutes after the test is taken (rapid testing technologies). They can increase the convenience of HIV testing of all.
After counseling and testing, clients move into a process of HIV referrals. This is where programs make sure that people get into care. Simply referring clients to services is not enough. This is because many people learn their status and still fail to get into care. Agencies with close ties to people in a community can, with special efforts like follow-up with clients, help people make that often difficult link to services.

In the referral process, case managers or other providers work with clients to assess and prioritize their immediate needs. Clients receive assistance from case managers in identifying the services they can receive, learning about organizations that provide needed services, setting up appointments and providing transportation and other types of assistance. Case managers must be sure that HIV positive clients: get medical evaluation and HIV care; learn how to prevent AIDS; learn how to protect others from infection; and get other social service needs met. HIV negative clients may need referrals to help reduce their risk of infection in the future, or referrals for social support needs.

**Working with a Client**

The decision to get tested for HIV can be emotionally complicated. Persons thought to be at risk for HIV, following a personal risk assessment, should be voluntarily tested. If a client is considering testing, it is important that they understand what the test consists of, and exactly what the results mean.

**Explain the Test**

One misconception is that the HIV test determines whether or not a person has AIDS. Therefore, when a person decides to have an ‘HIV test,’ it is important that he/she should understand the following:

✧ When someone gets tested for HIV, he or she is not being tested for the human immunodeficiency virus (HIV) at all, but instead for the presence of antibodies to the HIV.

✧ Only a very small amount of blood or saliva is required for HIV antibody testing. (OraSure, at the time of this manual’s printing, is the only federally approved oral-fluid test. It tests fluids from inside the mouth.)

✧ A negative result means that there were no HIV antibodies detected at the testing time and that either: a) they do not have an HIV infection, or b) they do have an HIV infection, but have not yet developed antibodies to it. HIV antibodies may not show up if the client is tested less than six months after his or her exposure to HIV. It often takes up to six months for the body to react to the virus and produce the antibodies.

✧ A positive result means that HIV antibodies were detected, and a confirmed test means that client has been infected with HIV. Therefore, the counselor must remind the client that someone who is positive can infect other people with HIV through: a) vaginal, anal or oral sex; b) sharing intravenous needles; c) transfusion, transplantation or artificial in-
semination; or d) maternal transmission to a baby before or at birth, as well as through breastfeeding. The counselor also should remind the client that a positive HIV result is not a diagnosis of AIDS. An HIV infection usually results in AIDS, but not with all HIV infected people. It does indicate the presence of an HIV infection; the infected person should seek medical evaluation and treatment immediately, with the understanding that with good care, years of life without manifesting AIDS are possible.

- Because assurance is psychologically significant for anyone who decides to get tested, the importance of confirmatory testing should be discussed. For accurate results, two different tests are used. The first test screens for the antibodies, and is called the ELISA (enzyme linked immunosorbent assay) test. If the ELISA test results are positive (meaning antibodies are detected) then these results are confirmed by either the immunofluorescent assay (IFA) or the Western Blot tests. (Urine testing for HIV antibodies is not as sensitive or specific as blood testing.)

**Returning for Test Results**

Clients must be strongly encouraged to return for the results of their test and information to understand what it means. In fact, many clients fail to return for their results. To get a commitment from the client to return:

- Acknowledge that the client may be anxious about returning for results. Suggest a way for them to cope with the anxiety about returning. For example, if they feel comfortable, they can bring a friend or talk to someone about their plans to return for test results on a specific date.
- Assure the client that the test results will be held in the strictest confidence.
- Ask the client why they think they can benefit from knowing their status.
- Provide an appointment to return for test results.

Consider creative ways to use incentives to get clients to return for results. Examples include food coupons, meals, transportation vouchers or other items based on client needs. Before you do this, check to make sure that your funders allow you to use their money for this purpose.

Be sure you are explaining test results correctly to clients. Check for their understanding.

**Assess Client Needs**

As part of the pre-test risk assessment, the counselor must employ an approach that allows him/her to cover some essential tasks. It is ultimately important that the counselor establishes a positive relationship with the client. This is commonly referred to as establishing client rapport. From the outset, the counselor must describe the purpose of the session; the expected duration; and the desired outcomes for the session. Seek agreement from the client as to the objectives of the session, and to maintain focus throughout the session. In other words, “start
from where the client is.” During the session, be polite, professional and display respect, empathy and sincerity to the client. Become involved and invested in the process, and convey an appropriate sense of concern and urgency about the client's HIV risk behaviors. Seek to deal with the client's concerns in an open, non-directive and straightforward manner. As a counselor, be honest about what you, your agency or others can and cannot do for the client. Structure and boundaries can be helpful to the client.

**Risk Reduction**

Part of a pre-test and post-test risk assessment is to determine a client’s risk for HIV. This is because the counseling that goes with the encounter is more than just a means for learning one's HIV status. It is also a way to understand and learn how to reduce one’s risk. Counseling must include the development, implementation and monitoring of a Personalized Risk Reduction Action Plan. Such a plan allows the client and the counselor to identify current and past behaviors that put the person at-risk for HIV. It also can identify strategies clients and their partners can use to reduce or eliminate these behaviors. Specific efforts should include:

- Work with the client to develop a realistic plan for reducing HIV risk. Identify realistic, concrete and small steps the client can start with to achieve his/her goal (some successes are important for motivation).
- Acknowledge that the plan may be challenging, and that it addresses the specific behaviors identified by the client during the risk assessment phase of the session.
- Discuss previous attempts made by the client to reduce risk, the personal barriers experienced and the perceived personal benefits to trying harder.
- Acknowledge successes the client has enjoyed in the past and as they occur. Work with the client to develop a plan for monitoring and evaluating progress towards achieving her/his risk reduction goals.

**Partner Notification and Referrals for Positives**

If a positive HIV test is obtained, HIV positive clients must receive referrals for HIV care and treatment. Clients may be hesitant, fearful or too devastated to enter care, but counselors must work with and encourage clients to do so. Please see the next chapter for more information on referrals and case management.

Also, with a positive HIV test, the process of partner notification becomes a necessary step in the client service and support process. In some states, partner notification is an option for the counselor to conduct. Counselors should discuss with clients the benefits and challenges of notifying partners. In other states, partner notification is mandatory for the public health system to conduct with clients. Clients should be informed of the law. Other critical points about partner notification that must be well understood by counselors and clients are as follows:
Notification must always be face-to-face and in private in order to assure, to the greatest extent possible, that the partner being informed is the one who was named by the partner.

Partners should be notified of possible exposure, not that they are infected.

The source of information about their possible risk must never be revealed or acknowledged.

No records are kept on HIV-infected people using partner notification. Any notes kept during the process must be completely destroyed after notification (e.g., by shredding papers).

Every effort is made to protect the privacy and confidentiality of both parties (i.e., HIPPA and confidentiality trainings, locked files and limited file room access).

**Issues in HIV Counseling, Testing and Referrals**

Below is more detail on some facets of HIV counseling, testing and referrals:

- Targeting services
- Cultural and linguistic competency

**Targeting Your Services: Client Outreach and Recruitment**

Client outreach and recruitment for HIV testing — finding the highest risk populations — can be improved by taking steps to target your work and to plan your efforts. Consider the following:

- **Work with Other Agencies.** Outreach to other agencies to reach persons who are already linked to other systems of care, but not to HIV resources. Examples include social service agencies (e.g., homeless shelters and substance abuse clinics) that have high risk clients.

- **Target High Risk Areas.** Street and community outreach that involves direct communication with at-risk groups where they hangout or live (e.g., streets, abandoned buildings and shelters).

- **Work with the Community.** Notify the community of the type of outreach your agency will be conducting.

- **Work with Leaders.** Bond with leaders in the community. Develop good working relationships with gatekeepers (individuals who can help you gain access to the community) who are the key players in getting to know who’s who and what’s going on.

- **Work with Other Agencies.** Partner with others in your community doing similar work. You can share resources, ideas on what works and refer clients in the same manner.

- **Distribute Your Materials Widely.** Provide HIV prevention kits (condoms, literature, survival kits) to potential clients and outreach agencies. Distribute colorful, eye-catching street flyers that are appealing to the target group. Hold an event that attracts the target group.
✧ Use Different Techniques. Train staff and, if possible, utilize staff representative of the target group. Conduct outreach during appropriate hours for the target group.

Cultural and Linguistic Competency in HIV Testing

Populations at risk for HIV are very diverse. There are two important steps agencies and programs can take to adjust to serving these populations.

✧ Learn about Your Population. The first is to find out as much information as possible about the population, particularly their:
  • Cultural and linguistic characteristics;
  • Understanding about HIV/AIDS;
  • Beliefs and practices as it relates to HIV risks;
  • Service delivery needs;
  • Personal strengths and assets that may be helpful;
  • Willingness to come into care and take treatment; and
  • Impression of the organization and providers as a whole.

✧ Train Your Staff. Once you’ve learned your client population’s cultural issues, go to the next step. Train and work with counselors and other staff regarding what has been learned about the community and how best the organization can serve them.

Setting It Up

HIV Counseling, Testing and Referral

There are thousands of programs throughout the nation that provide HIV counseling and testing. In addition, most people get an HIV test through their own doctor. Your community probably has a counseling/testing site, although one may not be located in your specific area. You can find out by calling the local health department.

Below are some things to think about in running such a program — or even working with one by referring your clients to such sites.

Staffing

The typical staffing level is dependent upon the number of clients being served and where and how they are reached. You should ask other providers in your area who do this work. Consider the following in calculating your staff needs for HIV counseling and testing work:
Number of Staff to Provide Adequate Coverage. If this is a clinic or agency-based effort, consider having one person during a workday handle all clients. However, have at least two people who are trained to provide this service. Many clinics that are open five days a week use two full-time and one part-time employee to conduct HIV counseling, testing and referrals. This is necessary to handle busy times and to have somebody on hand in case one trained staffer is on vacation or out sick.

Handling Street Outreach. A street outreach counseling and testing effort might work well with one staffer, but safety concerns or the level of work may require two staff.

Staffing: Client to Staff Ratio

The level of staff you need will, ultimately, be determined by the level of demand you get. In general, an HIV counseling session can last as little as 15 minutes but much more for a more intense client intervention. For street outreach, some programs see as many as 25–30 people per day at 10–15 minutes each per intervention.

Protocols for HIV Counseling, Testing and Referrals

Protocols for how to conduct CTR have been developed by the CDC, with input from others like HRSA. They are called HIV Counseling, Testing and Referral Standards and Guidelines. The recommendations are based on evidence from all available scientific sources. Where there is little or no evidence about the best approach, the opinions of specialists doing the work are used. Be sure to read these guidelines closely before you start providing services.

Training requirements/certifications are given and mandated by the state, and are based on CDC guidelines. The CDC guidelines dictate topic areas that must be covered during trainings (e.g., immunology; virology; prevention methods; prevention; HAART; how to conduct HIV CTR services; and periodic updates).

Funding

Needs and priorities of funders change over time, but the following are resources worth checking for sources of funding for an HIV counseling, testing and referral program:

- Contact the CDC funded Community Planning Group27 in your state to determine what funds are being allocated to HIV prevention planning activities.
- DHHS’s Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Substance Abuse Prevention (CSAP)28 has funded a grant initiative entitled, “Targeted

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Capacity Expansion Initiatives for Substance Abuse Prevention (SAP) and HIV Prevention in Minority Communities: Services Grants.” This initiative helps community-based organizations expand their capacity to provide and sustain effective, integrated substance abuse prevention and HIV prevention services in high risk minority communities disproportionately impacted by the HIV/AIDS epidemic.

- The CDC\textsuperscript{29} has an initiative focused on improving the capacity of African-Americans and Latinos to engage in HIV prevention research called the “Initiative to Build Capacity in Black and Hispanic Communities and among Researchers who Conduct HIV/AIDS Epidemiologic and Prevention Research in these Communities.” This may serve as a venue for agencies seeking to partner with researchers to conduct HIV prevention research.
- Some foundations provide general funding for health care initiatives. Two include The Robert Wood Johnson Foundation and the Commonwealth Fund.\textsuperscript{30}

\textsuperscript{29} See http://www.cdc.gov/od/pgo/funding/03097.htm.

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FOR ALL SERVICES

Keeping the Program Going

Regardless of the service you provide, keeping the effort going over time requires:

- **Vision.** How does the service fit within your agency’s long-term plans and vision for good health for the community?
- **Support.** Long-term understanding and support can come from key stakeholders (e.g., clients, community and other agencies). Perhaps most important: support needs to take the form of ongoing funding and staffing of the effort.
- **Ongoing Assessment.** Buy-in and input should come from those who have a stake in the services. Get feedback from staff, clients and funders on the need for your services; how good a job your agency is doing in delivering quality services; and how effective the services are in helping clients manage their HIV disease.
References on HIV Counseling, Testing and Referrals


Cross, TL, Bazron, BJ, Dennis, KW, Issac, MR. *Towards a Culturally Competent System of Care, Volumes 1 and 2.* National Institute of Mental Health, Child and Adolescent Services System Program (CASSP) Technical Assistance Center, Georgetown University Child Development Center, 1999.

Outlines a conceptual model for practitioners to use in determining the extent to which their program has achieved cultural competence. The criteria to make this judgment is laid out, and the steps necessary for meeting this criteria are detailed.


Critical to understanding how to design and use programs to engage and assess the understanding and behaviors of those receiving health education messages. This book provides a very straightforward discussion of the more common theoretical approaches. The advantage to practitioners is the provision of examples relevant to service delivery.


Provides a framework for understanding how individual, group and societies understand and explain sickness, illness and disease. Full of examples and diagrams, the book can be of direct use to practitioners as they attempt to design programs or trainings for service or work with diverse individuals and cultures.

CHAPTER 4

Clinical Case Management
About This Service

HIV treatment — the drugs and the care itself — is very specialized. Many people with HIV have multiple health conditions, like Hepatitis C and substance abuse. They need to be addressed so that HIV care can succeed. Just one example is lower levels of adherence to HIV drug regimens that might happen due to untreated mental health and substance abuse problems. The stigma of having HIV/AIDS also makes care more difficult: some clients fear being seen going to the doctor, and others lack family support like emotional and financial help.

Dealing with these complications can be easier if the client and provider have a collaborative partnership. Case management is designed to help make that happen and help clients secure services to meet their many needs.

Defining Case Management

According to the Case Management Society of America:

“Case Management is a collaborative process, which assesses, plans, implements, coordinates, monitors and evaluates options and services to meet an individual’s health needs through communication and available resources to promote quality cost effective outcomes” 31

The key to this definition is the collaborative process. Clients must be well-informed about their HIV care if they are to be equal partners with their providers. The collaborative role of the case manager is to encourage and support client self-management. Helping clients take on this active role requires teaching clients about self-advocacy and increasing their health literacy. Case managers, too, must advocate for their clients.

Case management is often seen as having multiple steps. On the front-end, there is intake to assess client needs. Later steps and ongoing activities involve linking clients to care and ensuring that they get what they need. These steps are described below and in Figure 1. When these steps are followed, case management can begin again: reassessment; refocusing goals and needs; and tapping into new services.

✧ **Intake.** This is the initial contact with the client to collect basic client information (e.g., age, gender, race/ethnicity, presenting needs and concerns). This helps the case manager get an initial understanding of the client’s immediate issues.

✧ **Assessment of Needs.** This involves collecting more in-depth information about a client’s situation and functioning to identify individual needs. This information is used to develop a comprehensive service/care plan. Assessment usually covers medical and psychosocial, educational and skill development needs.

✧ **Development of Care Plans.** A care plan will likely include goals; resources to address those needs; and actions needed to make this happen. Effective case management planning includes working in partnership with a client because many clients know what their needs are and can help focus the plan.

✧ **Implementation of the Plan.** Implementation of the care plan may include linking clients to services; monitoring service delivery; and ongoing assessment and reevaluation of needs. In more detail, this might include:

- **Collaborative Goal Setting:** the empowering practice of helping clients to take ownership of their care by jointly establishing care goals.

- **Interventions Planning for Needed Services:** the process of executing specific case management interventions that will lead to accomplishing the goals set forth in the care plan.

- **Resource Identification:** the ongoing process of identifying needed services.

- **Linkages:** the ongoing process of linking clients to services.
• **Advocacy for Clients:** regular support to the client through counseling or referral to such services. Within a case management context, counseling is more effective when focused on advice giving, information sharing, problem solving, reality testing and socialization skills.

• **Monitoring:** the ongoing process of confirming and assessing the delivery and use of services. To do this, the case manager maintains regular contact with clients and providers.

• **Reassessment/Reevaluation:** the process of determining if the care plan is helping the client reach desired goals and outcomes. This review is done at regular intervals. Changes in the care plan — in part or in whole — can happen if progress is not being made.

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**FIGURE 1**

```
<table>
<thead>
<tr>
<th>Intake</th>
</tr>
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<tbody>
<tr>
<td>Age • Gender • Race/Ethnicity • Needs &amp; Concerns</td>
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<table>
<thead>
<tr>
<th>Assessment of Needs</th>
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<tbody>
<tr>
<td>Medical • Social • Psychological</td>
</tr>
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<table>
<thead>
<tr>
<th>Development of Care Plans</th>
</tr>
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<tbody>
<tr>
<td>Goals • Resources • Actions</td>
</tr>
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<table>
<thead>
<tr>
<th>Implementation of the Plan</th>
</tr>
</thead>
</table>
| Collaborative Goal Setting • Interventions
| Planning for Needed Services • Resource Identification • Linkages • Advocacy for Clients • Monitoring • Reassessment/Reevaluation |
```
Issues in Case Management

Below is more detail on some case management activities:

✧ Assessing client needs
✧ Maintaining confidentiality
✧ Adherence

Assessing Client Needs

The first step to the provision of case management services is the in-depth assessment of client medical and psychosocial needs. It also should review the client’s perceived needs, goals, strengths, resources, beliefs and concerns. Regardless of the assessment topic, the process should be collaborative with the client. This can be done by using open-ended questions and exploring issues that are important to the client. It is commonly accepted that if you can meet a client’s urgent social services needs (e.g., housing, food, health insurance and transportation), their HIV/AIDS medical needs can be addressed more successfully.

✧ Use Tools to Collect Information on Client Needs. Collecting information about client needs requires use of appropriate assessment tools and protocols. Many such tools already exist.
✧ Topics to Assess. Assessment tools should examine critical areas like: health history, substance abuse history, sexual history, demographic information, social support systems and risk behavior practices.
✧ Assessment is Ongoing. This is because client needs priorities, strengths, barriers and skills continually change over time.
✧ Examine Special Needs. Different ethnic and cultural groups may present with specific needs. Examples are: childcare as a barrier to health care for women; access to medications for newly released offenders; testing and healthcare for homeless persons; and language as a barrier to access services for non-English speaking clients. Providing these services can help clients get services and remain in care.

Maintaining Confidentiality

Because case management involves working with many providers and care systems — and lots of information sharing — special attention needs to be given to maintaining confidentiality.

If clients feel that their confidentiality is being protected, they are more likely to trust providers. This confidence can help delivery of services work better. For example, clients might be more forthcoming with information about their care needs. Partner notification
services that are provided during HIV counseling and testing can also work better if clients feel that their confidentiality is in good hands.

Various national, state and local laws require information about AIDS and HIV be kept confidential. In general, confidentiality laws strictly limit how and what HIV related information can be disclosed to another party. Provisions in these laws are generally as follows:

- HIV related information can only be shared if authorized by a signed special HIV release by the client.
- Only certain types of providers may receive the information.
- The person who has been given the information (i.e., referral resource, provider) must keep it confidential.

One federal law that includes confidentiality requirements is called the Health Insurance Portability and Accountability Act (HIPAA). It contains safeguards to protect the privacy of medical information. HIPAA regulations cover the privacy of medical records and other personal health information, and outline how such information may be transmitted in electronic, written or oral forms. While case management providers deliver many services, including health care, there has been some lack of clarity about whether or not case managers are “covered entities” under HIPAA. Caution and further investigation by each individual agency is highly recommended.

**Adherence**

Adherence means helping clients comply with complex treatment requirements for their HIV disease, particularly antiretroviral regimens. This is accomplished through educating and increasing client health literacy. Patient education about HIV treatment and related illnesses helps them take greater control of their care and, therefore, their lives. An aspect of the adherence process is to teach clients how to interact effectively with their doctors and to manage their illness (e.g., how to build a partnership with your doctor; how to prepare for medical appointments; and how to use social supports available).

A case manager can support adherence in many ways. Examples include:

- Explain basic clinical care.
- Make referrals and follow-ups to make sure that clients have access to needed medical and social services.
- Identify and manage client discomfort, preferences, vulnerabilities and needs in accessing services.
✧ Monitor the care plan and referrals to guarantee that the client is receiving the best quality of services, especially services that are culturally and linguistically appropriate.
✧ Advocate and network to make available to clients best practices in treating HIV/AIDS.

Setting It Up
Designing Case Management for Your Agency

There are a number of models of case management. No models of case management are universally accepted, and no case management model is appropriate in all settings with all populations. Thus, the case management selected should be most appropriate to the needs and characteristics of your client population, as well as the objectives and resources of your agency.

Here are some things to keep in mind when developing a case management program for your organization.

Type of Clients

Characteristics of the target population (i.e. women, youth, ex-offenders, gay, bisexual and transgender) affect the range of case management tasks delivered. Your clients will also affect the way your services are marketed and delivered. For example:
✧ Female clients may need services, such as child care, perinatal care and access to family supports. Many of these services are delivered by specialized providers or systems, such as obstetricians, pediatricians or social welfare programs targeted to low income women and their families.
✧ Young clients are often sensitive to being associated with HIV care. Your agency may need to take extra steps to maintain confidentiality for your clients.
✧ Some clients are best reached by working with other systems. In the case of ex-offenders, you should work closely with corrections systems so that individuals can more smoothly transition from the jail to the outside.

Staffing

In staffing your case management program, pay attention to clearly outlining job duties; orientation and training of staff; supporting them over time; and making sure that each case manager is not overburdened with clients. Consider the following in particular for case managers:
Ensure that staff receive ongoing supervision. Staff supervision should include: ongoing reflective practice, case review and support for the case manager.

Be aware of, and responsive to, any special needs for staff training and credentials, such as: clinical/counseling interventions, particularly as it applies to new medications and treatment resources; advocacy and case management; networking, linkages and follow-ups; building partnerships with clients; and best practices in teaching and supporting self advocacy.

**Staffing: Client to Staff Ratio**

Depending on client characteristics and the intensity of case management activities, an ideal active caseload may be 10–35 clients per case manager. There is quite a bit of discussion in the field regarding the optional client/staff load for case management.

The common wisdom has been that the optimal caseload is one case manager to 10–15 clients, since larger caseloads (> 30 clients) may lead the manager to become more reactive (to crises) rather than proactive.32

However there is some research which suggests that the size of the case management caseload may depend on the intensity of case management services. For example in one program33 a case load of 10–15 cases per case manager was used for intensive case management. For more routine case management, the caseload was as high as 30–35 cases per case manger.

**Protocols for Case Management**

Clear procedure and protocol manuals are necessary to ensure that services are delivered according to a standard of care. For case management, protocols have been developed by many states and agencies. To obtain these standards:

- Contact your local or state health department.
- Go to the HRSA HIV/AIDS Bureau website. (See http://hab.hrsa.gov, and visit the “Tools” page.)
- Contact the National Association of Social Workers at http://www.naswdc.org/.


Collaborating with Other Agencies

Since case management is a lot about referring clients to services, case management agencies need to work with other agencies very closely. To make this happen:

✧ Establish informal and formal agreements. These can take many forms. Memoranda of Understanding (MOU) are formal statements that outline how agencies will work together. They also include language that addresses liability and confidentiality issues to protect clients and the organization.

✧ Contractual agreements also are written agreements but often relate to working relationships in relationship to funded projects and the exchange of funding.

✧ Community resources and partnerships often exist in the form of planning groups, advisory bodies and informal networks of providers.

FOR ALL SERVICES

Cultural and Linguistic Competency

Culture and language have a considerable impact on access to care, quality of services and retention in care. A case manager’s cultural competencies — including cultural, gender and lifestyle — can help in building successful bonds with clients. Basic guidelines to ensure equal access and quality health services to culturally and linguistically diverse populations include:

✧ Assess the ethnic/cultural needs of clients.

✧ Know culturally appropriate resources and assets available in the community. For example, ensure that referral providers can address client needs appropriately.

✧ Train staff to work effectively with clients with respect to their cultural and linguistic diversity. Also, consider how the composition of staff reflects the diversity of the client population. Cultural differences between staff and clients almost are inevitable. Staff should be aware and respectful of those differences.

✧ Offer clients the opportunity to participate and give feedback regarding the design of programs and services, including any cultural and linguistic issues.
Funding

There are many potential sources of funding for HIV case management. Consider the following:

✧ The Ryan White CARE Act fills gaps in care for those who lack other resources. Case management is a service commonly provided under the CARE Act because it helps clients access other sources of care prior to using CARE Act dollars. To learn more, see the HRSA HIV/AIDS Bureau website at http://hab.hrsa.gov.

✧ Case management is typically paid for (reimbursed) under such public funders as Medicaid. To get reimbursement payments, however, agencies need to be Medicaid-certified. To learn more, contact your state health department’s Medicaid division, or go to the Centers for Medicare and Medicaid Services website at http://www.cms.gov.

✧ Many states and communities fund HIV case management. Case management is also funded under other programs as part of general health services (i.e., not HIV-specific) for low-income individuals. Examples include case management provided in maternal and child health programs and case management tied into community health centers. To learn more, contact your local or state health department or go to the HRSA website at http://www.hrsa.gov.
References on Clinical Case Management


An excellent overview of literature and current practices of HIV Prevention Case Management. It also includes definitions and core features of Case Management and a wide list of references.


One of the first published critical reviews of preventive case management. Presents a detailed discussion of the main elements of case management, including history and best practices. This piece emphasizes health education and risk reduction.


An excellent and useful guide in conducting outcomes evaluation. Presents the basics of case management and evaluation, including definition, functions and suggestions for practice. In addition, it has an excellent list of references and resources.


This article presents a client empowerment model for care by presenting data and practice that illustrates favorable outcomes when patients are the key participants in their help care process.


A collection of articles that summarize the basics of case management. It also includes a good description of different case management approaches and models.


This article presents clear arguments to sustain that health literacy is a fundamental aspect in the health and treatment of people living with HIV/AIDS.

Defines what HIPAA is; who must comply; who is covered; patient rights; and other HIPPA information.


This is the final report of a two-part Case Management evaluation founded by the AIDS Institute in New York. The data for this study was collected during 1997–1998. The study examines the needs of case management clients, success rates of case managers in providing services needed and variations by case management model.
About This Service

More and more, HIV care is being managed over the long term, as a chronic disease. The body needs greater amounts of energy to consistently fuel itself — even if viral load is being controlled by medications. Good nutrition can help:

- **Boost the Immune System.** Good nutrition helps to strengthen the immune system. Poor eating habits can further reduce the body’s ability to fight infection and can result in more infections.
- **Fight the Effects of HIV Disease.** Poor absorption of nutrients, which is common among people with HIV, contributes to wasting. This often results in malnutrition. As a result of malnutrition, the frequency and severity of infections experienced by the individual with HIV/AIDS further affects the immune system. Common health concerns related to HIV/AIDS often include oral thrush, loss of appetite and diarrhea, all of which impacts food intake.
- **Drugs Work Better.** HIV/AIDS medications often require food intake in order to be more effective (e.g., to aid in absorption and metabolism of the drugs).

HIV-related nutrition services are designed to promote health and wellness. They can help clients boost their immune systems and better fight infections. To effectively do this, nutrition services — assessment, intervention, education and surveillance — should be part of the core treatment plan for each individual. This helps keep a focus on nutrition over time. The following are some steps in making nutrition an ongoing part of HIV care.

**Nutrition Screening**

Clients should be screened for nutritional problems during their first visit with a health care provider.

- **Use a Simple Screening Form.** Each client should complete a simple nutrition screening form. Staff can quickly identify clients who need immediate nutrition assessment and care.
✧ **What to Assess at Baseline.** A baseline nutrition screening should include height, weight, usual weight, unintentional weight loss or gain, chewing/swallowing difficulties, change in appetite, change in body composition and serum albumin level. These data can usually identify the majority of HIV-positive clients at nutritional risk.

✧ **In-Depth Assessment.** A more in-depth screening tool should include further anthropometric, biochemical, clinical, dietary, drug-nutrient interaction, oral motor, self-feeding, environmental and financial assessments. Take careful nutrition history of each client and assess usual food intake, paying special attention to calories, protein and fluid intake.

✧ Ask questions about herbal preparations, vitamin or mineral supplementation, alcohol, cafffeinated foods and beverages, tobacco, over-the-counter-medications or recreational drug use.

**Nutrition Plan Development**

The nutrition plan should be based on the client’s current health status and should be integrated into overall treatment goals, as follows:

✧ **Tie it to the Client’s Treatment Needs.** Because nutrition needs vary according to the development of the disease and the client’s treatment regimen, the plan should be tied to the person’s treatment plan.

✧ **Tailor it to Client Needs.** Nutrition intervention must be person-centered. To do this, collect as much information about the client as possible. This may consist of eating habits including food intake; oral motor skills; self-feeding capability; and ability to purchase, prepare and store food safely. Use this information along with the client’s nutritional status to help provide an appropriate, person-centered intervention plan. Revise or modify each client’s nutritional needs as is necessary.

**Implementing the Plan: Helping Clients Change Eating Habits**

After completing a nutrition assessment — and working with the client and health care team — the nutritionist should target behaviors for change. To do this, work with the client to accept recommendations and prioritize behavior changes.

✧ Clearly explain benefits of the behavior change.

✧ Work to make changes fit into, rather than overload, daily routine.

✧ Persuade the client to learn from setbacks and to troubleshoot when a setback occurs.

✧ Consider group support activities.

✧ Use role-playing to practice behavior change or skills developed in a safe, supportive, non-threatening setting.

✧ Encourage the client to keep a food record before each visit with the nutritionist so that the eating plan can be assessed and eating problems pinpointed.
Issues in HIV Nutrition Management

Below is more information on nutrition management for HIV:

✧ Ensuring access to nutritious and safe food
✧ Keeping food clean
✧ Taking vitamins and minerals
✧ Cultural and linguistic competency

Ensuring Access to Nutritious and Safe Food

Work with the client to insure that food is available in the home at all times. To do this:

✧ Maintain a Safe Supply. Help the client to develop a “safe food amount level” for the home, like a four-day supply of food. At this level, the client should immediately alert case management staff and use available resources to increase food security. This is especially important if the client’s medications are best taken with food.

✧ Know about Food Resources. Ensure that the client is aware of available community resources that provide food and transportation. A nutrition program can also help enroll clients in these programs, often through a case manager. These resources include local food voucher programs, such as food stamps or food commodities, food pantry or soup kitchens, food banks, meal on wheels and congregate meal sites. Other resources include churches and other social service groups.

Keeping Food Clean

Safe food handling, preparation and storage ensure that persons with HIV/AIDS who eat a well-balanced diet can reap all of the health benefits. A healthy body is equipped to handle many germs, but when the immune system is weakened, as with HIV/AIDS, the body becomes less able to fight off germs. Therefore, people with HIV/AIDS become more vulnerable. Any illness, including those caused by food, can further weaken the immune system. To guard against this, food should be handled, prepared and stored in a safe way.

✧ Storage. To reduce the risk of food poisoning, promptly transport perishable food items home from the store and immediately store in a safe place.

✧ Cooking. Cook food thoroughly to destroy bacteria and other pathogens (e.g., bacteria and parasites).

✧ Eating. Eat food within 15–30 minutes of preparing and immediately refrigerate leftovers.

✧ Water Safety. Boil tap or well water for at least 1–3 minutes before drinking or cooking with it. Avoid untreated water altogether. Where available, choose filtered and/or bottled water, which is processed to eliminate most pathogens.
Taking Vitamins and Minerals

HIV/AIDS often results in higher needs for certain vitamins and minerals and can also lead to malabsorption and increased nutrient losses. Therefore, dietary supplementation should be recommended, in addition to regular nutritious eating. Nutritionists can help clients understand:

✧ **Supplements Do Not Replace Good Eating.** Explain that dietary supplements, including vitamins and minerals, are an addition to a healthy eating pattern and not a replacement. Also, discourage the use of mega doses of vitamins and minerals to boost immune system since they can be harmful to normal body processes.

✧ **Preparing High Energy Supplements.** Whole meal replacements and prepackaged enteral formulas such as Advera, Boost and Ensure may be recommended based on the client’s gastrointestinal function, nutrient needs and medical condition. If clients are encouraged to make their own nutrient-dense dietary supplements, such as enriched fruit-based or milk-based shakes, emphasize the importance of sanitation and safety, as well as sticking to the correct ingredient quantities for these home-made foods.

✧ **How to Handle Anemia.** Anemia is common in individuals living with HIV. When anemia is present, serum ferritin levels or erythropoietin status should be checked before supplementing with oral iron. This is because inappropriate use of iron supplement can hinder the immune system. Also, rule out sickle thalassemia or other genetic conditions often prevalent in African-Americans.

Cultural and Linguistic Competency in Nutrition Services

When it comes to food, be aware of differences and similarities — among individuals and across ethnic minority groups.

✧ **Take Nothing for Granted.** Do not assume that the caregiver and client have the same understanding of words, ideas or instructions.

✧ **Keep Food and Nutrition Instructions Simple.** Use visual aids such as pictures, videotapes, foods and demonstrations to help communicate information when language is a barrier. Avoid using technical terms or professional jargon. Repeat as necessary to ensure client understanding. When appropriate, use role-playing to help assess the client’s level of understanding.

✧ **Providers: Deal with Your Prejudices.** Preconceived judgments are easily picked up by clients and can threaten provider–client relationships. Foods that are delicacies to one group may be unacceptable to another. As a health care provider, keep your sense of humor. Refrain from making negative statements about the diets of other cultures.

✧ **Learn about Your Clients and Their Diets.** The nutritionist should become familiar with eating habits and food preferences of cultural groups served. Encourage clients to
participate in demonstrations of meal preparation. In this way, they can get a better understanding of the nutritive value of favorite dishes. If the nutrition provider is unfamiliar with foods the client is consuming, ask the client to bring in food labels. Also, familiarity with the diets of the ethnic groups served shows your interest in that group, and is essential for successful counseling and intervention. In addition, find out what foods are used for medicines or to promote health. If clients are using such foods, this may be a sign that the client has health concerns that you have not been told.

✧ **Educate Clients on Nutrition.** Help clients learn how to develop meals that are culturally and ethnically familiar, nutritious and, where applicable, quick and easy to prepare. One-pot-meals, such as stews, soups and lactose-free milk based beverages are good suggestions. Realize that both the expense of treatment, and the inability to work, can affect income and leave less money available for food.

## Setting It Up

### Effective Management for Nutrition Programs

Setting up an effective nutrition program involves multiple steps. Examples include: securing funding; staffing; setting up a record-keeping system; and delivering nutrition services according to standards. Below are highlights. Also see the AIDS Nutrition Services Alliance website at http://www.aidsnutrition.org for more details on how to set up a nutrition program.

### Staffing

As with all services, staffing your nutrition program requires attention to clearly outlining job duties, training staff, supporting them over time and making sure that they are not overburdened with clients. Consider the following in particular for a nutrition program:

✧ You can either hire new nutrition staff or make sure that existing staff have knowledge of nutrition resources. Nutrition professionals may be recruited from national and local credentialing bodies such as the American College of Nutrition, the American Dietetic Association, the local department of health and other professional health organizations.

✧ Professional, as well as social, groups; clubs; churches; health fairs; job fairs; wellness screenings; and the Internet are also very effective recruitment tools.

✧ At least one senior nutrition staff with expertise in HIV/AIDS should be on site. (See “Protocols/Certification Requirements” below.)
Staffing: Client to Staff Ratio

In general, one nutritionist can serve 200 patients as a total caseload. As a daily caseload, one nutritionist should be able to handle 6 to 10 clients. No more than 10 per day is recommended.

Protocols/Certification Requirements

The following are protocols and certification requirements for your consideration in doing HIV nutrition work.

✧ **Staff Credentials.** Nutrition credentials are provided by multiple entities. You should consider having a nutritionist who is credentialed by a professional group, such as the American Dietetic Association’s Commission on Dietetic Registration, as a Registered Dietitian (RD), or the American College of Nutrition, as a CNS (Certified Nutrition Specialist). That person should also be licensed in accordance with state laws where applicable.

Also, professional and para-professional nutrition staff should keep up with continuing education in the field of infectious diseases (which includes HIV/AIDS) to maintain standards of client care; ensure professional certification requirements are met; and maintain licensure.

✧ **Guidelines.** Nutrition guidelines should emphasize the benefits of good nutrition; preventing illnesses caused by improper food handling; educating clients on ways to cook, handle and store food; and eating defensively to prevent opportunistic infections. The guidelines should provide education around solving problems such as the presence of nausea, diarrhea, sore mouth, sore throat, exhaustion and taste change. These guidelines also should address the importance of drug-nutrient interaction, and how to maintain appropriate weight status, especially muscle stores.

Several HIV nutrition guidelines exist. They include:

- **Health Care and HIV: Nutrition Guide for Providers and Clients.** Developed by HRSA's HIV/AIDS Bureau, this guide can be accessed at: http://hab.hrsa.gov/CATIE. (Conduct search using the keyword “nutrition.”)

- **Nutrition Guidelines for Agencies Providing Food to People Living with HIV Disease.** Developed by the AIDS Nutrition Services Alliance, the guidelines are available at: http://aidsnutrition.org

✧ **Insurance for Staff.** Be sure to retain malpractice insurance for all nutrition professionals and the organization as a whole. Professionals can get independent insurance plans or as a group.
Continuous quality management should be used to identify nutrition needs of your clients, as well as any technical assistance and training your program might require.

Record Keeping

Nutrition programs need to keep current and complete records for all clients.

- Records should be understandable and legible.
- Every entry should be signed and dated by the person recording the entry. Signatures should be legible, and should be followed by professional acronyms or practitioner license numbers.
- Records must be kept confidential and in accordance with organizational, professional and state regulations.

FOR ALL SERVICES

Recruiting and Retaining Clients

- Recruitment. In recruiting clients, target high risk individuals and areas.
  - Contact the local department of health; HIV/AIDS counseling and testing centers; local health care facilities, including in and out-patient clinics; homeless or temporary shelters; churches; soup kitchens; half-way houses; pharmacies or drug stores; and social service areas.
  - Secure referrals by building referral networks through community agencies, and by promoting methods for screening clients in clinics and hospitals.
- Retention. Once enrolled, steps can be taken to help retain clients.
  - Point out the goal of the intervention. (For example, nutrition intervention is to strengthen the body’s immune system to fight infections and to prevent progression of the HIV illness.)
  - Encourage and support participants to become peer supporters and advocates of their own health care. This may serve as a powerful retention tool.
  - Remind participants that good nutrition can also help reduce the risk of secondary infections that often accompany the disease.
Funding

The following are potential sources of funding for HIV nutrition services:


✧ **Other potential sources include:** the Ryan White CARE Act (see [http://hab.hrsa.gov](http://hab.hrsa.gov) or locate your local or state HIV/AIDS care planning group); American Dietetic Association; United States Department of Agriculture; Food and Drug Administration; the CDC; and pharmaceutical companies.

> *Taking medicine without healthy eating is like washing your hands and then drying them in mud.*

— Goulda Downer
References for Nutrition and Dietetics


Users get information on health and nutrition-related information. Also includes current scientific positions and clinical research on a variety of issues, including nutrition and HIV/AIDS.


A nutrition resource for nutrition and dietetic professionals. Users of this site get access to current research in nutrition and diseases, including HIV/AIDS and related health organizations.

American Dietetic Association. Medical Nutrition Therapy across the Continuum of Care. Developed by ADA and Morrison Health Care, Chicago IL.


Provides access to the international nutrition clearing house center. Provides annotated list of health and nutrition education.


Users get information on position papers and Food and Nutrition Science Alliances (FANSA) nutrition meetings.


Provides information on a wide variety of health related topics for health professionals. Gives information and a list of nutrition-related non-FDA Web sites.


Users get health and nutrition-related information, and can download complete texts and graphics of several educational documents.


    Provides a detailed list of antiretroviral drugs and their possible adverse nutritional effects. It lists precautions for concomitant drug use, gives description of the interaction and includes possible macronutrient deficiencies.


    Provides a detailed outline of nutrition screening, intervention and treatment modalities of the HIV patient. Nutritional surveillance to prevent mortality and morbidity is also fully addressed.


    Provides news releases and food and nutrition information with detailed description of many consumer service programs, for example, food stamps.
CHAPTER 6

Biographies

Original Writers

Nutrition Services:

Goulda A. Downer, PhD, RD, LN, CNS
President and CEO of her Washington, DC-based METROPLEX Health and Nutrition Services, Inc., Dr. Goulda A. Downer continues to be involved in clinical, academic, research and public health activities with major emphasis on nutrition. Dr. Downer was appointed to serve as a member of the United States Food Advisory Committee, of the Food and Drug Administration (FDA), in 2001. She continues her academic responsibilities at Howard, Georgetown and George Washington Universities, in Washington, DC. In addition to her local HIV-related nutrition work, she works internationally on food security and HIV/AIDS-related projects in Sub-Saharan Africa on behalf of the United States Agency of International Development (USAID). As a nutrition and HIV/AIDS preceptor for physicians and physician assistants, she also provides training to professionals, paraprofessionals and advocates who care for underserved and minority populations. She is part of the cultural competency team who wrote the "Be Safe NMAETC Cultural Competency Model," which addresses specific cultural and linguistic issues necessary to successfully work with peoples of African descent who are HIV-positive. She has been the recipient of numerous awards, including a certificate of appreciation from the National Institute of Health for outstanding assistance in facilitating the implementation of the National Physician's Network to improve cardiovascular health in the African-American community.

Organizational Development:

Abdín Noboa-Ríos, PhD, CPhil, EdM, MA, AB, post-PhD, Sixth-Year Degree
Dr. Abdin Noboa-Ríos has worked in the fields of mental health, education, organizational development and research evaluation for over 30 years. His work experience ranges from having directed community-based organizations, to that of working at all three levels of government: city, state and federal. He has also taught psychology and methods courses at
three universities. Currently, he practices in the private arena. His educational background includes six earned degrees from four universities, including UC Berkeley and Harvard University. Among other studies, he has also completed two post-doctoral internships. Dr. Noboa-Ríos has written over fifty articles, four manuscripts, one book and has been editor of two other books. He has also served on the editorial board of several journals, and is former editor-in-chief of three other journals.

HIV Counseling and Testing:

Joseph Telfair, DrPH, MSW/MPH
Associate Professor, Department of Maternal and Child Health and Pediatrics,
UAB Schools of Public Health and Medicine
Since November 1999, Dr. Joseph Telfair has served as Maternal and Child Associate Professor at the University of Alabama, Birmingham School of Public Health. Dr. Telfair has a 25 year history of direct service, clinical, teaching and research work on economic, access, education and support issues concerning children; adolescents; families; and those at-risk for HIV and other STDs. His specializations are program evaluation, community-based program development, practitioner skill building, collaboration, evaluation, social epidemiological, culturally competent service delivery studies of the poor, persons in rural areas, persons with chronic conditions and persons of color. Dr. Telfair has a BA in psychology from California State University at Northridge; a MSW and MPH from University of California at Berkeley; and a DrPH from Johns Hopkins University. He also was a post-doctoral fellow at University of North Carolina, Chapel Hill.

Clinical Case Management:

Ada Ivonne Vazquez, PhD
Dr. Ada Ivonne Vazquez was born and raised in Puerto Rico. For the last 15 years, Dr. Vazquez has lived and worked in New York City, where she has played a leadership role within the fields of HIV/AIDS and criminal justice. As an educator, Dr. Vazquez has trained young people in the art of human services and counseling. In addition, she has performed duties as director and evaluator of several large social service programs in New York City. Currently, Dr. Vazquez is the senior director of the Fortune Society Drop In Center, a 24-hour center dedicated to serve and support recently released inmates from Rikers Island. Dr. Vazquez holds a doctorate degree in counseling psychology.
Advisory Board Members

Clinical Case Management:

Janet M Briggs, MSN, RN, ANP-c
Janet Briggs is currently the HIV/AIDS Coordinator for the Cleveland VA Medical Center that has a catchment area covering most of northern Ohio. In this position her duties include coordinating the HIV testing and counseling program; coordinating the on-site HIV clinic; providing continuity to the Cleveland VA HIV caseload; and acting as a primary care provider to a panel of patients within that caseload. She also was instrumental in establishing a community-based program for HIV care at the Free Medical Clinic of Cleveland, and, as a volunteer, has carried a panel of patients within that caseload since its inception. Briggs also has had funded research, has published in multiple peer-reviewed journals and has presented locally and nationally in HIV/AIDS.

Nutrition:

Katherine Dennison, BS, RD/LD
Katherine Dennison is a graduate from the University of Texas at Austin with a BS in Nutrition. Her honorary awards include Kappa Omicron Nu; University Honor List; and Dietetic Intern of Distinction Award from New York-Presbyterian Hospital Weill Cornell Medical Center Dietetic Internship. Dennison holds a license in dietetics, is a registered dietitian, and is certified in Food Retail Management. She received her training and dietetic internship in clinical dietetics at New York-Presbyterian Hospital Weill Cornell Medical Center, in New York City. She then provided her clinical knowledge and skills at Bellevue Hospital Center’s AIDS Program in New York City and North General Hospital in Harlem. She has practiced HIV/AIDS nutrition for several years, and is now the Director of Nutrition at Carl Vogel Center. She also is Chair of the DC Area Nutrition Alliance, a group of Washington, DC metropolitan area registered dietitians specializing in the nutritional needs of individuals with HIV/AIDS.

HIV Counseling, Testing, and Referrals:

Charles C. Releford Jr., MA
Charles C. Releford Jr. is currently serving as the Director of the New Minority Male Consortium on Health at Morehouse College in Atlanta, Georgia. This research project, funded by the US Department of Health and Human Services, Office of Minority Health, is focusing on issues related to the current health disparities that exist in minority male populations. He most recently served as the team leader for cultural competence in the Mental Health HIV/AIDS Services Collaborative program in the Rollins School of Public Health at Emory University, and is the former Director of the Cork Institute on Black Alcohol and Other Drug Abuse at Morehouse School of Medicine. Releford completed
his undergraduate studies, in 1981, at Morehouse College. During his matriculation at Morehouse, he was chosen as a Community Clinical Psychology Fellow, funded by the National Institute of Mental Health. Releford received a National Institute on Drug Abuse Fellowship to study toward a MA degree in clinical psychology from Fisk University/ Meharry Medical College; he received his MA in 1983. He has served as a grant review specialist for the State of Georgia, Substance Abuse Services Section; Substance Abuse and Mental Health Services Administration, Center for Substance Abuse Treatment and Prevention; and the US Department of Education.

Clinical Case Management:

Joseph Rukeyser, PhD

Dr. Joseph Rukeyser is a medical educator and curriculum developer with experience in academic, public health and community-based education settings as well as in pharmaceutical advertising and medical education. Since the early 1980’s he has been part of the professional and community response to the HIV/AIDS epidemic, having served as one of the original education volunteers with the Long Island Association for AIDS Care. His patient and clinical HIV education curricula are part of the standard educational programs offered by the New York State Department of Health AIDS Institute, for which he served as clinical education specialist and as its Director of Educational Services. He also directed a community-based HIV/AIDS clinical trials research program in New York and New Jersey, and was the Director of Education for the HRSA-funded AIDS Education and Resource Center at the State University of New York at Stony Brook. Dr. Rukeyser regularly publishes medical update articles in HIV Positive Magazine in addition to his scientific and educational publications and presentations at major HIV/AIDS conferences. He is currently an education and evaluation consultant to various private, federal, state and local health-related organizations.

HIV Counseling and Testing:

Steve Walker

Steve Walker is president of SLW Consulting, LLC, and has extensive experience in providing, developing and directing community and organizational direct service and capacity building programs from more than fifteen years as an activist, educator and administrator in the field of HIV/AIDS. He served as the first President of Houston’s African-American Lesbian and Gay Alliance (AALGA); Executive Director of the Donald R. Watkins Memorial Foundation; and Director of HIV Prevention Programs for the Houston Department of Health and Human Services (HDHHS). In these capacities, Walker has gained exceptional skills in the areas of evaluation, quality assurance, organizational development, fiscal management, technical presentations, curriculum design and development, technical writing, grant writing, advocacy, personal skills enhancement, lecturing, strategic planning, facilitating HIV/AIDS educational workshops, case management, managing the community planning process and developing training protocols and manuals.
Editors

Llewellyn J. Cornelius, PhD
Dr. Llewellyn Cornelius is currently a professor, and the associate director, of the Institute for Human Services Policy at the University of Maryland, School of Social Work. He received his doctorate from the University of Chicago, School of Social Services Administration, and has extensive research experience in examining access to Medical Delivery and the Outcome of Care for African Americans and Latinos. His recent accomplishments include being the recipient of the University of Chicago's 1996 Elizabeth Butler young alumni award for his contributions to health care research on African-Americans and Latinos, and being inducted into the Honor Society of Phi Kappa Phi.

Alan Gambrell
Alan Gambrell, independent consultant (WordPortfolio, Inc.), provided editorial assistance on this document. He has worked with HRSA's HIV/AIDS Bureau since its inception on a variety of HIV/AIDS technical documents, along with other federal, national and state agencies on HIV/AIDS, as well as other public health issues.

Supporting Networks of HIV Care Project

Justification/Rationale: Research shows that increasing access to care does contribute to reducing disparities in health outcomes for HIV infected persons. There is evidence that inadequate levels of HIV-related health care and support services exist in racial/ethnic minority communities, and in communities experiencing rapidly growing or emerging epidemics. Small-to-moderately sized organizations, including faith and community based organizations, tend to have an established mission and commitment to address the needs of the underserved. However, these organizations also are often in need of assistance to improve their infrastructure and capabilities to address the growing needs of their clients and communities. Inadequate technical assistance resources exist to help organizations, like those mentioned above, to respond more effectively to HIV/AIDS through expanded service delivery (including medical evaluation and clinical care, oral health care, mental health services, clinical case management, treatment education, substance abuse treatment, adherence support, etc.) Due to their small-to-moderate size and limited discretionary funds, these organizations often are not able to purchase technical assistance services on their own.

In Fiscal Year 2002, HRSA awarded MAI funding in the form of two cooperative agreements to implement the Supporting Networks of HIV Care Project. The goal of the project is to increase access to comprehensive, high quality care for racial/ethnic minority communities severely impacted by HIV/AIDS. We have worked to achieve this goal by offering free technical assistance to small-to-moderately sized organizations, including faith- and community-based
organizations. The technical assistance is provided through the delivery of on-site individualized instruction; regional skills building workshops; and the development and dissemination of resourceful materials. The technical assistance offered is tailored to each organization’s specific needs to develop, improve or expand comprehensive HIV primary care, treatment and support service delivery.

To ensure that the appropriate organizations receive this technical assistance, specific eligibility criteria were established as follows:

✧ Organization’s primary service delivery site must be physically located in or near a community whose residents are at risk for, or living with, HIV are predominantly racial/ethnic minorities.
✧ At least a three-year history of providing some primary health care or support service to minority residents in their surrounding community is required to demonstrate some initial organization capacity for service delivery and a commitment to serving communities of color.
✧ Commitment to accomplish and report progress on an action plan developed for their organization in collaboration with a technical consultant to increase their service capacity.
✧ Lacks the financial resources (discretionary funding) to obtain this type of assistance independently.

The demand for on-site technical assistance has been significant. The project started receiving requests for service in late January 2003. As of July 2003, the project has received a total of 320 requests for technical assistance services. Below is some descriptive information about the organizations submitting requests:

✧ 84 percent currently provide some direct service to people living with HIV/AIDS.
✧ 46 percent have total HIV program budgets under $100,000.
✧ 68 percent are AIDS service organizations.
✧ 88 percent are physically located in a community of color with high HIV rates or at high risk of HIV infection due to evidence of HIV risk behaviors — substance abuse, unprotected sex.
✧ 74 percent have mostly racial/ethnic minorities in key staff positions (program supervisors, managers, direct service providers).
✧ 59 percent of organizations need help with strategic planning, 57 percent with resource development and management; 54 percent with program evaluation and data collection; 49 percent with organization development and infrastructure; and 48 percent with staff and board development and management. (These are the most frequently requested areas for technical assistance.)

In addition to the provision of on-site technical assistance, the Supporting Networks of HIV Care Project is undertaking the following activities:
1. **Regional Intensive Trainings (RIT).** Five RITs are being offered to participants requesting assistance. Six 2–3 hour workshops are offered in the following areas: HIV clinical services overview; developing effective linkages to improve access to comprehensive care; providing HIV primary medical care; providing clinical case management services; providing HIV counseling, testing and referral services; work plan development; program evaluation; and fiscal management. Participants receive travel subsidies and registration is free. The first RIT was held June 2003. A total of 180 evaluation surveys were completed across the six modules offered. The majority of participants (82.8 percent) reported a “moderate” to “great” increase in knowledge as a result of their participation in the training. The majority of participants (61.1 percent) also rated their ability to explain the information they learned to someone not at the training as “good.”

2. **Strengthening HIV Care: A Manual to Help Small Organizations Make Big Change in Communities of Color.** This manual provides insight, definitions and instruction on the delivery of three services considered appropriate for low resource organizations seeking to grow and move toward HIV primary care service delivery. These services include: HIV counseling, testing and referrals; clinical case management; and nutrition services. The manual will be approximately 70 pages in length. It will be disseminated in early 2004 to organizations requesting technical assistance through the project in these areas and to other organizations who have requested assistance through other MAI funded activities. The manual also will be available on-line on the project’s web page at http://www.hivta.org and the National Minority AIDS Council website.

3. **Minority CBO Challenges Study.** Several discussion groups were held with minority CBOs around the country to talk with staff about the challenges their organization experiences when working to develop, expand or improve HIV primary care programs. Information received will be analyzed and disseminated in a recommendations report that reviews identified challenges and outlines strategies to help address them. Some of the challenges frequently identified in the maintenance or expansion of HIV primary care programs include: 1) finding money to support program growth and maintenance over time; 2) state variation in funding opportunities; 3) becoming financially self-sufficient; 4) recruiting and retaining qualified and dedicated personnel to ensure quality and stability in the provision of care; and 5) adapting to new trends and keeping up with new service requirements. Print and electronic versions of the report will be produced and disseminated in effort to improve future capacity building initiatives.

4. **Project Evaluation.** To clearly identify the impact of provided on-site TA, formal evaluation plans were developed prior to the start of service delivery. The evaluation will answer the question of the degree to which organizations receiving technical assistance were able to 1) add a new HIV/AIDS related service to their organization; 2) expand or improve existing HIV services; 3) have specific, detailed and time framed action plans in place for the long
term addition, expansion or improvement of HIV services in their organization; and 4) the establishment of formal linkages (with Memorandum of Understanding) with other organizations in their community to ensure comprehensive service delivery. The evaluation also will answer the degree to which new services were established in geographic communities most severely impacted by HIV/AIDS and experiencing new and emerging HIV epidemics. The evaluation of the regional trainings will answer the degree to which participants in the training report 1) an increase in knowledge and skill in the areas covered during the trainings; 2) an ability to explain the information they learned during the workshops to others not in attendance; 3) specific activities they plan to carry out as a result of the training; and 4) an intent to use the information and materials received frequently in their HIV related work.