

A GUIDE TO **CBO**  
Adherence  
Programs

**until it's over**  
**AIDS ACTION**

adherence

AIDS Action is the national voice on AIDS. We are committed to advocating for people affected by HIV/AIDS “Until It’s Over” – until no more people become infected with HIV, until people living with HIV have the care and support they need, and until a cure is found.

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## AN ADHERENCE OVERVIEW

*Antiretroviral regimens are complex, have major side effects, pose difficulty with adherence, and carry serious potential consequences from the development of viral resistance due to non-adherence to the drug regimen or suboptimal levels of antiretroviral agents. Patient education and involvement in therapeutic decisions is ... especially critical for HIV infection and its treatment.*

— *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents* (April 23, 2001)

The advent of combination drug therapies as the standard of care in 1996 made adherence the cornerstone of HIV/AIDS care. Initially, this treatment — HAART (highly active antiretroviral therapy) — was heralded as the possible end of AIDS, and researchers began to talk of eradication. While clinical studies have since proven otherwise, combination therapies are still the best line of defense against the virus and bring the promise of longer, healthier lives to many people living with HIV.

From the beginning, this promise has been tempered by the rigors of HAART regimens, which have required taking potent drugs in complex regimens of 20–30 pills a day. Although many drugs are now becoming easier to take on less frequent schedules, HAART can cause debilitating side effects and is thought to require near perfect — 90-95% — adher-

ence in order to achieve maximum and durable suppression of viral load.

In light of these realities, clinicians have been developing strategies to help clients adhere to HAART, and AIDS service organizations have been critically important community-based partners in this effort. AIDS Action, with support from the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau, sought to capture the experiences of a variety of community-based organizations (CBOs). We visited six diverse CBOs, finding an array of innovative adherence strategies and programs. AIDS Action developed *A Guide to CBO Adherence Programs* to share these ideas with CARE Act programs serving Americans living with HIV disease.

While the programs presented in this guide are unique, they share a focus on

translating the science of adherence into community-based settings, tailoring adherence to specific needs of clients from their neighborhoods and communities. A 1999 AIDS Action survey indicated that adherence support and education has been the service most often added by CBOs in recent years.

## **USING THIS DOCUMENT**

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This document is for CBOs just starting an adherence program and those who want to expand or enhance an existing program. It offers information on how the programs were started, how they operate, how they are funded, and how staff interact to address wide-ranging client needs. Staff and client experiences are highlighted, including feelings clients express about being HIV-positive and about the impact of adherence programs on their lives, as well as fears and concerns some continue to have about treatment.

“Common Elements and Building Blocks” describes aspects common to the featured adherence programs, including:

- individualized adherence planning;
- commitment to meeting client-identified needs;
- complete and unbiased information;
- strong support systems;
- nutritional counseling;
- connections to mental health and substance abuse treatment;
- strong linkages among medical providers and support services;
- commitment to culturally competent programs; and
- use of adherence tools.

“Profiles in Adherence” offers details on each program, including length of operation, major program components, staffing, funding sources, and client demographics. Also discussed are ways in which the programs differ and special features of each. Contact information is provided for CBOs who want to learn more.

“Clearing the Hurdles” outlines challenges common to adherence programs, including strategies for:

- sustaining program funding;
- building program capacity;
- using existing evaluation tools; and
- creating relationships with medical and support services providers.

“Measuring Up: Evaluating Adherence Programs” describes CBO experiences and challenges related to evaluating their programs and services and includes a discussion of the limitations of methods used to measure adherence.

## **DEFINING ADHERENCE PROGRAMS**

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For purposes of this guide, AIDS Action defines an adherence program as services and supports designed to help HIV-positive people make informed decisions about their treatment and — when the decision is to take HAART — to help them follow the prescribed treatment regimen. Because difficulty following a HAART regimen can be tied to many life circumstances, addressing both medical and non-medical needs is key to adherence support.

HAART often involves intense and painful side effects, as well as toxicities that themselves can become life threatening. For this reason, AIDS Action considers HAART failures to be treatment failures, not failures of the individuals taking HAART. Even as AIDS Action and CBOs promote adherence programs to support people who are on HAART, we must also continue to advocate for the development of better, easier-to-use HIV/AIDS drugs. Consistent with the research literature and the most current treatment guidelines, AIDS Action believes that no individual should be automatically excluded from consideration for HAART because he or she exhibits behaviors or characteristics associated with nonadherence. The decision to start a HAART regimen must be made jointly by the physician and person living with HIV disease.

## **CHOOSING PROFILED PROGRAMS**

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The CBO adherence programs outlined in this document are a snapshot of programs underway or in development around the country. They were selected from an initial screening survey sent to AIDS Action's network of 3,200 community-based providers. The survey asked the following five questions:

- Do you have a defined (freestanding) adherence program?
- How long has your program been in existence?

- What are the components of your program?
- Do you have any strategies for evaluating services for traditionally underserved populations?
- Does your program provide linkages to medical providers and social services?

Approximately 60 CBOs responded; 20 were selected for review. AIDS Action staff conducted lengthy interviews with each of the 20 before choosing several for site visits. Site visit selections were made to ensure geographic distribution, including urban and rural programs, and a focus on traditionally underserved populations, such as women, young gay men, and people of color, as well as people who are multi-diagnosed with HIV and substance abuse or mental illness and those who are marginally housed or homeless. Site visits included intensive discussions with clients, staff, and others collaborating with the program, such as health care and mental health professionals, nutritionists, social service providers, and program evaluators.

Six programs were chosen: Action Point in San Francisco, the Cuate program at Bienestar Human Services in Los Angeles, the Medline Program at AIDS Partnership Michigan in Detroit, Carl Vogel Center in Washington, D.C., Project Teach at Harlem Directors Group in New York City, and the Medication Adherence Program at Southern Colorado AIDS Project in Colorado Springs.

## About Adherence

In 1996, the “protease revolution” changed the standard of HIV/AIDS care to combination therapy. Suddenly, people living with HIV were expected to manage a complex treatment regimen that combined two new classes of drugs — protease inhibitors and non-nucleoside analog reverse transcriptase inhibitors — with an existing class, nucleoside analog reverse transcriptase inhibitors. The resulting drug “cocktails” have been associated with a remarkable drop in AIDS deaths in the U.S. and other countries that could afford these expensive therapies.

## Complex Regimens

But with that good news came the bad. Right from the start, clinicians realized that the new combinations of drugs would not be easy to take. A typical treatment regimen can involve taking dozens of pills every day following a rigorous schedule that directs which pills should be taken at what intervals. Further complicating matters, some pills can be taken only on an empty stomach, while others must be taken with high-fat foods. Certain drugs also require refrigeration, adding yet another layer of difficulty to some treatment regimens. All of this complexity has the same goal — keeping the drugs at a high enough level in the body that they are able to suppress HIV replication.

And suppress replication they did. Soon after starting therapy, many people living with AIDS were reporting renewed health as the virus sank to then-undetectable levels in the blood. In fact, viral suppression was so effective that after a year some optimistic researchers and patients speculated that it might be possible to stop taking the drugs permanently and began to talk of a cure. Unfortunately, it soon became apparent that the existing drugs are not a cure and do not work in the long term for at least half of the people who take them.

## Treatment Failure

There are many reasons for such treatment failure, among them resistance to one or more of the drugs from previous therapy, infection with a drug-resistant strain of the virus, or an inability to use the drugs successfully because the regimen is too hard to follow or side effects are too burdensome to endure.

Researchers are already creating better, easier to take and tolerate drugs with fewer side effects. In the meantime, clinicians and community-based service providers are looking for ways to help people succeed to the maximum extent possible with existing drugs. Adherence programs are designed to address the factors that an individual can control and to help him or her understand treatment options and get the most out of currently available therapies.

## Factors Affecting Adherence

Clinicians and researchers agree that there are many gaps in what we know about adherence. But some things are clear. Almost anyone can successfully adhere to a HAART regimen, given the proper monitoring and supports. When HAART moved from clinical studies to the community, there was widespread speculation that drug users, homeless people, and others living in stressful and unhealthy circumstances would never be able to adhere to HAART and should not be offered the drugs. Both research and practice, however, have demonstrated that high levels of adherence can be achieved among even the most vulnerable people living with HIV disease, provided they receive adequate support.

The *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents* (April 23, 2001) lists among the many factors positively affecting adherence: the availability of emotional and practical life supports, an ability to fit medications into daily routines, understanding that poor adherence leads to drug resistance and that taking all doses is important, keeping clinic appointments, and adherence support tailored to individual needs and circumstances such as homelessness or drug use.

Among the factors negatively affecting adherence are: poor patient-physician relationship, lack of patient education, active drug and alcohol use, active mental illness, unstable life circumstances, discrimination, domestic violence, lack of reliable access to primary medical care and medication, an inability to identify medications, and fear or experience of metabolic or morphologic side effects. Adherence programs that mitigate these factors and provide flexible, sustained support can help people living with these difficulties achieve adherence levels comparable to the general HIV-positive population.

## Bright Spots in Treatment Research

HIV remains a wily adversary, but researchers are gaining ground. An increasing number of effective HAART regimens are available with twice daily dosing and no specific food requirements, considerably easing the adherence burden for many.

Researchers are also experimenting with periodic, scheduled HAART cessation — or structured treatment interruption (STI) — for people with durable suppression of their viral loads. STI is a carefully monitored interruption of combination therapy that is designed to strengthen the body's immune response to HIV at the same time it gives people taking the drugs a “vacation” from the rigors of HAART. STI is still highly experimental and should not be undertaken outside the context of a carefully controlled research setting. The very existence of such research will complicate adherence if it encourages people to stop and restart therapy on their own, without physician approval and monitoring.

Such factors as gender, race, socioeconomic status, educational level, and a past history of drug use do not reliably predict poor adherence.

— *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents* (April 23, 2001)

# Chapter TWO

## COMMON ELEMENTS AND BUILDING BLOCKS

**A**lthough adherence programs are as diverse as the communities they serve, certain elements are common to successful programs:

- individualized adherence planning;
- sharing complete and unbiased information with clients;
- commitment to meeting client-identified needs;
- nutritional counseling;
- strong support systems;
- connections to mental health and substance abuse treatment;
- strong linkages among medical providers and support services;
- commitment to culturally competent programs; and
- use of adherence tools.

This chapter examines each of these elements, with examples of how they operate in the programs AIDS Action visited.

### **INDIVIDUALIZED ADHERENCE PLANNING**

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Working with clients individually and tailoring services to client needs are key. Successful programs build relationships with each client in order to understand his or her unique concerns, desires, and motivators, and they spend as much time as necessary with individual clients to accomplish this. Many clients interviewed say that health care providers may have

little time to talk with them about HIV/AIDS drugs and answer their questions. One client relates, “My first doctor never even told me how to take the medications. He just handed me the prescription and told me to go to the drugstore.” Program staff observe that such experiences can leave clients confused, frustrated, frightened, and even misinformed.

Both clients and CBO staff emphasize the importance of trust between client and provider. Clients express appreciation for the time, patience, and support extended to them by adherence program staff. They say that these trusting relationships empower them to take control of their own health care decisions and make them feel more positive about themselves and their capacity to deal with HIV disease.

Clients stress that their adherence programs enable them to be honest about their attitudes, the way they live, and the behaviors that affect their well-being. Several say they are able to talk honestly with staff about drug use or missed doses, things they find difficult to divulge to their health care providers for fear of being judged or reprimanded. Some clients even express fears that being honest about missed doses will result in their drugs being taken away altogether.

Individualized adherence planning also forms the basis for data collection, by

helping programs track individual progress, revise treatment plans, and anticipate needs. At the Carl Vogel Center in Washington, D.C., treatment specialists do extensive client assessments. Clients are asked about their knowledge of HIV and HAART and whether they want to start antiretroviral therapy. Once staff understand the direction a client wants to take, medical milestones are documented, including lab values and other vital statistics. Substance abuse and mental health treatment are also discussed and noted, as are nutrition and housing needs. After the initial assessment is complete, clients and staff work together to design a plan that reflects the goals set by the clients and addresses potential barriers to success. Staff make referrals for services outside the program as needed.

### **Complete and Unbiased Information**

Providing clients with complete and unbiased information about treatment options and how to live with a HAART regimen — if they choose HAART — is at the core of individualized adherence planning. For many people living with HIV disease, a CBO adherence program is their primary source of treatment information tailored to their individual needs and circumstances.

Many programs provide both one-on-one information sharing and classes. At Harlem Directors Group and AIDS Partnership Michigan clients can attend sessions on HIV disease and treatments. Classes generally begin with an overview of initial infection and virus replication, modes of transmission, opportunistic infections, and progression to an AIDS diagnosis. Subsequent classes address the range of treatment options, which includes HAART as well as complementary therapies and the option of remaining

treatment naive. Other sessions might cover how to make the most of the services the program offers and how to get other services in the community. Completion of adherence classes often-times is marked by a graduation ceremony or by a certificate or other token to recognize client accomplishment.

### **MEETING CLIENT-IDENTIFIED NEEDS**

Joint planning between clients and staff ensures that CBO adherence programs address needs as identified by clients. Perspectives on medications, concerns about side effects, fear of treatment failures, and difficulties fitting their treatment regimens into their daily lives are all areas in which clients may identify needs. The adherence programs visited address these needs in a variety of ways, including formal and informal peer support, individual and group instruction, and counseling.

### **Views of the Medications**

Clients view the drugs in varied ways. Some see them as a return to normalcy or as a way to stay alive. Others view them skeptically, refusing to take them and choosing instead to preserve their options in anticipation of better treatments in the future. Still others, concerned about side effects, wonder, “If I feel good now, why take something that makes me feel bad?” Clients on both sides of the choice — those who decide to take the drugs and those who do not — express concerns about how decisions they make now will affect them down the road. Will taking drugs now limit their options for future treatments? If they don’t take the drugs and progress to AIDS, what will be their treatment options once they get sick? CBO adherence programs offer a safe and

*Joint planning between clients and staff ensures that CBO adherence programs address needs as identified by clients.*

Self-report should include a short term assessment of each dose that was taken over the recent past (e.g., the past 3 days), and a general inquiry regarding adherence since the last visit, with explicit attention to the circumstances of missed doses and possible measures to prevent further missed doses. It may also be helpful for patients to bring their medications and medication diary to clinic visits.

— *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents* (April 23, 2001)

supportive environment for clients to explore their fears and concerns over time and make informed treatment decisions.

### **Side Effects**

Some clients refuse HAART for fear of intolerable side effects. Others stop taking the drugs when side effects become unmanageable. Concerns about side effects can take both a physical and emotional toll. Giving up a regimen makes some feel as if they have failed, as if their options are fading, or as if something is wrong with them because they cannot tolerate drugs that their friends are taking without major problems. For these reasons, side effects management is an integral component of the programs profiled in this guide. Clients are assured that side effects are normal, given the potency of the drugs, and are taught strategies for minimizing the negative impact of the drugs on their bodies. Programs urge physicians to include treatments for likely side effects with the first HAART prescription.

### **Fear of Treatment Failure**

Fear of treatment failure is another across-the-board concern. Clients who are still healthy or have yet to experience an opportunistic infection are especially concerned about limiting future treatment options if they start on HAART now. One man in Colorado Springs said he had been afraid to take the drugs because they hadn't worked for several of his friends. Another man in New York said he is not on the drugs because he isn't convinced they work, "I'm on a protease-sparing regimen," he said, adding that he is taking medication to prevent opportunistic infections. As with other client fears, providing complete and unbiased information within the context of

a trusting provider/client relationship enables CBO adherence programs to support informed client decision making.

### **Fitting HAART Into Daily Life**

Fitting dosing schedules, related nutrition requirements, and care of the drugs themselves into daily life is a major concern. Clients often feel that the complexity and frequency of dosing has radically altered the way they live, including work and home routines, meals and food choice, and social activities. "People find it hard to structure their lives to the regimens," said a peer educator and client at Project Teach at the Harlem Directors Group in New York City. Identifying clients' existing daily routines and strategizing with them on how to fit the drugs into existing routines is key to adherence support.

## **NUTRITION COUNSELING**

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Nutrition counseling and meal planning are essential to successful adherence. One client at Bienestar in Los Angeles was troubled when her doctor gave her a diet that included unfamiliar foods such as tofu, which she had never eaten, but none of the beans, steak, fried cheese, and tortillas that are her staples. She never tried to follow the diet, continuing to eat her own kind of food and take the medications. Bienestar solves such dilemmas by offering food that fits clients' cultural preferences while complementing their treatment regimen. Bienestar's food bank is stocked with fresh vegetables and fruit, rice, and black and red beans, all essential staples of the Latino community in Los Angeles County. The Southern Colorado AIDS Program (South CAP) also maintains a food bank.

AIDS Partnership Michigan establishes links with area nutritionists to help clients navigate the relationship between diet and exercise and adherence outcomes. Program staff believe that people who feel healthier tend to be more optimistic about their treatment and prognosis. The Carl Vogel Center uses an on-site nutritionist to develop workable meal plans with clients and to find easy recipes for meals that will complement clients' treatment regimens.

Providing food and nutritional supplements creates informal opportunities for adherence staff to touch base with clients. At South CAP clients picking up food often ask advice about meal planning and talk about how they are doing following their regimens. At the Carl Vogel Center, the CBO's on-site dietician offers clients samples of nutritional supplements and advises them on how to get the most out of the supplements. The dietician coordinates client appointments with times the adherence staff are available so that clients can get their questions answered.

## SUPPORT SYSTEMS

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Many people living with HIV disease receive support from family, partners, and friends, and this support can be a remarkable boost to adherence. Others, however, have few people to whom they can turn. Clients often say that managing their HIV disease would be impossible without the support of their adherence program, particularly the camaraderie and the moral support clients offer each other and the information they share about treatments and strategies for overcoming difficulties.

Some clients describe their adherence programs as a welcome opportunity to release tension related to their disease,

which they describe as still carrying stigma, shame, and guilt. In many adherence programs, people living with HIV disease are learning to see themselves and their disease differently, which enables them to take control of their lives and make informed decisions about treatment.

More formal peer support also is key in many adherence programs. Clients often relate best to peers, and a peer-based component can generate a sense of ownership in the program. Harlem Directors Group stations Project Teach peers at clinics in its network to help clients build strong relationships with their health care providers. The program views its peer component as an effective way to empower clients to take responsibility for planning their own care. Project Teach peers help clients get the most out of visits with their physicians. Clients who train to become peer educators also can learn valuable skills that will aid them in seeking other employment opportunities.

## MENTAL HEALTH AND SUBSTANCE ABUSE TREATMENT

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Many people living with HIV disease also are affected by mental illness. Depression, bipolar disorder, and schizophrenia are some of the conditions that without proper medication and treatment can affect an individual's ability to take medications on time, make doctors appointments, and maintain good nutritional habits — all key to adherence to HAART.

Every profiled adherence program serves people living with HIV who are in need of treatment for substance abuse or who are mentally ill. Adherence staff forge linkages to mental health and substance abuse treatment centers. AIDS Partnership Michigan uses in-house staff and

Education of family and friends regarding the importance of adherence, as well as recruitment of family and friends to become participants in the plan for medication adherence can be invaluable.

— *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents* (April 23, 2001)

agreements with local hospitals and substance abuse treatment facilities to ensure that clients receive prompt referrals and quality care.

### **STRONG RELATIONSHIPS WITH OTHER PROVIDERS**

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Adherence programs are bridging the gap between social services and medical care. This is essential to integrating adherence activities into the other services clients receive — a key factor for success. Adherence staff coordinate their programs with client case managers and work with medical providers to make them more aware of the non-medical needs of people living with HIV. Case managers and other CBO staff often have relationships established with local medical and social service providers that adherence staff can build on. Case managers also can help adherence program staff track client progress. With informed consent from the client, case managers can get client medical records that adherence staff and sometimes even clients have a hard time getting.

Adherence staff often frame the adherence program to health care providers as a way for clients to have the individual attention that physicians want them to have but are often unable to provide themselves because of time constraints. Program staff say that this perception of mutual benefit is essential for successful relationships among adherence staff, medical providers, and case managers.

### **RELATIONSHIPS WITHIN THE CBO**

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Adherence programs that are part of a larger community-based organization must invest in creating a secure place for the program within the CBO and ensuring

seamless service delivery to clients. The adherence program director generally begins this process by meeting with other staff in the agency to describe the goals of the program and to talk about barriers to client adherence. The initial discussion with CBO staff stresses the benefits to clients of having all agency departments coordinating with the adherence program and supporting clients' efforts to follow their treatment regimens. Case managers, mental health counselors, nutritionists, and other CBO staff are often asked to help screen clients to assess how they are doing with adherence and find out if they need help.

### **COMMITMENT TO CULTURAL COMPETENCE**

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The adherence programs visited all are committed to acknowledging, understanding, and respecting the racial, ethnic, cultural, and religious backgrounds of the people they serve. Such cultural competence provides a firm foundation upon which staff and clients can communicate about adherence.

At Bienestar, Spanish-speaking treatment advocates work with several clients who, because of language barriers elsewhere, had come to believe that certain HIV/AIDS medications would kill them. This kept them not only from taking the prescribed drugs but also from even seeking care for their HIV. Bienestar's staff were able to allay those fears by speaking the same language and, in some cases, by having experienced those same misunderstandings themselves.

Some African American clients are wary of medical providers and reluctant to accept claims of the safety and efficacy of HAART. CBO adherence programs that acknowledge the history behind these cul-

*Adherence programs are bridging the gap between social services and medical care. This is essential to integrating adherence activities into the other services clients receive — a key factor for success.*

tural attitudes towards medicine — including the infamous Tuskegee experiment — are in a better position to structure their programs and services to be of most use to their clients. Project Teach is completing a monograph on factors that can contribute to differing rates of adherence in communities of color.

Wherever possible adherence programs try to provide access to peers and support staff who are of the same gender and cultural background as program participants. At Bienestar, adherence program staff work with a women’s program coordinator, who helps mothers manage child care and caregiving responsibilities while also carving out time to take their medicine and keep medical appointments.

## ADHERENCE TOOLS

Participating in antiretroviral therapy requires individual commitment and continuing support, including help simplifying complex regimens whenever possible. Adherence tools can help remind individuals about the what, how, and when of their therapy.

### **Tools to Explain the Regimen**

The first step for many clients is learning about the drugs. Adherence programs typically spend much of their time with clients going over each drug and mapping out a plan for how several groups of drugs, all with differing requirements, can be taken over the course of a day. With support from pharmaceutical companies, many adherence programs get for their clients detailed medication charts that illustrate in color each class of HIV drug and each drug within the class. Programs also have developed their own charts and

use similar materials constructed by other local and national organizations.

Adherence staff help clients use these materials as a daily guide to their regimens, the dosing instructions, and possible side effects and drug interactions they should monitor.

### **Tools for Scheduling**

Part of the challenge in facilitating adherence is matching clients’ daily activities with their treatment regimens so that they don’t miss doses. Clients can time their regimens in several different ways. Most programs provide pill boxes that staff help clients fill. Pill boxes that break medications down into weekly and daily sets are helpful because they allow clients to take them inconspicuously to work and other places. At Action Point in San Francisco, clients can store their medications at the on-site pharmacy and come in daily to receive their medications. A part-time pharmacist is available to answer questions. Action Point reports that on-site storage is particularly helpful for clients who are homeless or marginally homeless and may not have access to a safe, stable place to store or refrigerate their prescriptions.

AIDS Partnership Michigan, through an agreement with an adherence tool company, has obtained watches for its clients. Staff program the watches to coordinate with each client’s treatment regimen. The watches set off a timer when it is time to take a dose and provide written instructions on the watch face about how and with what foods to take the prescribed dose. The watches can be reset when a regimen changes, but only by staff. Action Point offers clients a web-based paging system that notifies clients when it is time to take their pills.

#### **Interventions Associated with Improved Adherence**

- Pharmacist-based adherence encounters/clinics
- Adherence encounters at each visit, often multi-disciplinary
- Reminders, alarms, pagers, timers on pillboxes
- Patient education aids, including regimen pictures, calendars, stickers
- Clinician education aids (e.g., medication guides)

— *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents* (April 23, 2001)

# Chapter Three

## PROFILES IN ADHERENCE

The CBO adherence programs in the following profiles have much in common, but each is also unique, built on a careful analysis of client and community needs and flexible enough to evolve as these needs change. Each also has been designed with an eye toward the future of HIV care and the growing importance of adherence support.

This chapter profiles six adherence programs: Action Point in San Francisco, Bienestar Human Services in Los Angeles, AIDS Partnership Michigan in Detroit, Carl Vogel Center in Washington, D.C., Harlem Directors Group in New York City, and Southern Colorado AIDS Project in Colorado Springs. Concluding the chapter are Tables 1 and 2, which offer strategies for improving adherence, as identified in *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents* (April 23, 2001).

### PROGRAM PROFILES

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#### **Action Point**

Established in San Francisco in 1999, Action Point was born out of a recommendation by the Adherence Task Force of the Mayor's Summit on HIV/AIDS. It is a program of the San Francisco Department of Public Health. The unusually high cost of housing in San Francisco has resulted in

a high rate of homelessness and near-homelessness among vulnerable people; over 3,000 people living with AIDS are on a centralized waiting list for housing. This means that many people with HIV disease are living on the streets, in shelters, or in transitional housing. According to Action Point medical director Josh Bamberger, among the urban poor in San Francisco who are living with HIV/AIDS, only 30% are on HAART, compared to 88% of HIV-positive gay men in the city.

Located South of Market Street in San Francisco, Action Point is in a storefront within a single-occupancy hotel, close to several bus lines and the subway system and steps away from the San Francisco AIDS Foundation, where clients can get help with money management, housing, and medical care. Treating the urban poor on their own turf was Action Point's goal from the start.

Daily, Action Point clients face poor and unstable housing, lack of regular income,

and poor access to health care and proper nutrition. Despite these realities, Action Point staff were confident they could develop a program that would arm clients with the tools, knowledge, and support that would enable them to adhere to their treatment regimens as well as anyone else. They knew that adherence tools alone would not be enough for people who are without strong support systems, trusting relationships with health care providers, access to good information about drugs, or a system for management of medications.

Responding to these needs, Action Point set out to launch a comprehensive, flexible

program based on trust, time, good primary care, and an inviting environment in which clients could get medications and learn the skills they need to manage their treatment regimens. First and foremost, Action Point wanted to be immediately visible and accessible, which meant opening for business in street-level space, where people could easily walk in.

Moving Through the Program. Action Point nurses assess clients and then work with them to develop an individualized adherence care plan, based on client readiness to begin a treatment regimen, other medical and non-medical needs, and lifestyle. The decision to take HAART is

## Action Point

Clients: The homeless and near-homeless urban poor.

Staff: Part-time medical director, public health nurses, case managers from the San Francisco AIDS Foundation, physician/acupuncturist, and part-time pharmacist.

Hours: Open six days a week, from noon to six p.m.

Funding and Program Costs: Serves 100-150 clients at a cost of \$4,200 per client per year, with funding from the City and County of San Francisco.

Referrals: Referrals from providers, CBO staff, jail and prison officials, or by self-referral or referral from friends. Relationships with the county correctional system and the health department TB clinic facilitate referrals.

Entry Criteria: Within six weeks of initial contact with clinic staff, clients must have a diagnosis letter verifying that they are HIV positive, have a CD4 count < 500 or a viral load > 10,000, and have a relationship with a primary care provider. Staff help clients meet these guidelines.

Services: Medication management, nursing services, acupuncture, and referrals to substance abuse treatment and mental health services.

Evaluation: Significant clinical benefit. After the first five months of program operation, 67% of clients were presenting once a week; 60% of clients had a viral load < 500 copies/mil, compared with 32% at entry.

*First and foremost, Action Point wanted to be immediately visible and accessible, which meant opening for business in street-level space, where people could easily walk in.*

**Action Point is committed to addressing clients' substance abuse and mental illness by providing prompt referrals to counseling and treatment, improving housing and food stability, and raising clients' self-esteem and ability to take charge of their own care and treatment.**

made by the client, not the staff. Clients who need to learn how to take pills on a schedule are able to practice using vitamins. Clients already taking HAART, or ready to begin, are walked through their prescriptions, possible side effects and how to manage them, and potential drug-drug and food-drug interactions. Clients generally store their medications at Action Point where they are dispensed by the pharmacist, who sees clients eight hours a week, or by other staff members. The great majority of Action Point clients get their medications through ADAP or MediCal, California's Medicaid program.

Staff meet regularly to discuss challenges and share information and experiences. Action Point's medical director reviews all client charts and consults with the nurses as needed. The nurses consult with clients, medical providers, and other CBOs providing support services. Case conferences are organized on a case-by-case basis for clients who are also receiving services from other CBOs. Clients stay in the program for varying lengths of time, based on their individual needs.

After surveying their clients and drawing on their own experiences as HIV care providers, Action Point decided to include on-site acupuncture in the array of services it offers. Clients point to the sense of calm and healing they experience after receiving acupuncture and say that it helps them cope with side effects. Action Point uses a variety of adherence tools, including pagers and Medi-sets. Action Point also offers a \$10 cash incentive to clients who keep their weekly appointments.

Action Point is committed to addressing clients' substance abuse and mental illness by providing prompt referrals to counseling and treatment, improving housing and

food stability, and raising clients' self-esteem and ability to take charge of their own care and treatment. During off-hours, the Action Point space is used by unaffiliated, but complementary, needle exchange and medical care programs.

Special Feature — Adherence Support Where People Live. Action Point provides a welcoming and stable place for clients in the neighborhood where they already are. The Action Point space is set up to make clients feel relaxed and easy about being there just "hanging out," no matter their treatment status. This open welcome has been critical in building a feeling of community and belonging, as well as a sense of trust they say is often missing within the health care system. Clients are welcome to drop in any time the center is open, in addition to regularly scheduled meeting times with providers. Staff make every effort to spend a significant amount of time with program participants.

Action Point's bright and welcoming space includes comfortable furniture and open areas for clients to visit with each other. In addition to the existing storage space for medications, program staff are planning to build extra storage space where clients can keep other possessions. A laundromat across the street enables clients to clean their clothes with tokens Action Point provides.

### **Bienestar Human Services**

Bienestar, a CBO with strong roots in the community, strives to be a one-stop-shop, offering a wide array of services. Bienestar's Cuate program — "buddy" in Spanish — helps clients adhere to HAART and tailor their treatment regimens to their own lives, while getting the most out of the American health care delivery system.

## Bienestar Human Services Cuate Program

Clients: A primarily monolingual Mexican American community with little knowledge of HIV or treatments. The Cuate Program serves 40 clients a month.

Staff: Program director, Bienestar case managers.

Program Cost: \$10,000 total annual budget for Cuate, with a per client cost of \$83.

Referrals: Largely by word-of-mouth. Bienestar treatment advocates, case managers, and the program director also identify clients who experience barriers to adherence, such as finances, traditional family roles, and homophobia.

Entry Criteria: Open to any Bienestar client.

Hours: Open 9:00 a.m. - 7:00 p.m. Clients can schedule special times, if needed.

Bienestar Services: Case management, prevention services, support groups, treatment advocacy, nutrition counseling and food bank, child care services, and translation/interpreter services.

Evaluation: Quantitative and qualitative evaluation of individual client and overall program success. Quantitative evaluation documents client use of medications, information on medical history and lab values, factors affecting willingness to adhere to medications, and any co-factors for clients with multiple diagnoses that affect their ability to adhere to medication.

Qualitative evaluation involves both formal and informal conversations with clients that gauge the evolution of their attitudes about and experiences with HAART and with their medical providers. Participants have opportunities to provide other feedback in a variety of ways, including annual retreats, client social functions, support groups, and appointments with staff. In some cases, client feedback has resulted in the addition of new services, such as new support groups.

*Bienestar's Cuate program — "buddy" in Spanish — helps clients adhere to HAART and tailor their treatment regimens to their own lives, while getting the most out of the American health care delivery system.*

The Cuate program began when Bienestar noticed that many clients want to try combination therapies but find the complexity of the regimens overwhelming. Many are alienated from a medical system in which Spanish speakers are few and personal connections with providers are decreasing — the very reason many clients show up on Bienestar's doorstep.

Bienestar created Cuate to educate clients about the benefits and realities of HAART. "Some of our clients have been afraid of taking the medications because they thought they might die or suffer severe injury due to the side effects. While HAART isn't for everyone, it's at least important that clients have correct information about it," says program director Gustavo Arguelles, who works hard to be

***Integrating family relationships into an individual's adherence plan is key to the program's success in the Latino community.***

a true friend to clients. As part of the community, he was able to design a program that was part science and research, and part “familia.” Having an agency like Bienestar behind him — a community resource for 11 years — considerably bolstered his efforts.

Moving Through the Program. The first visit is an extensive assessment with the program director, during which medical and social histories are recorded. After he orients newcomers to the Cuate program, they work together on an individualized plan. Some clients need referrals for mental health counseling and substance abuse treatment. Others need to go over the intricacies of their treatment regimens. Many Cuate participants take part in support groups and get groceries through the food bank, which is stocked with the staples of Latino kitchens.

In subsequent visits, clients talk with the program director about their progress, including any stumbling blocks. Physician time constraints, language barriers, and a lack of experience talking authoritatively to medical providers can lead to misinformation and misperceptions about HAART — all of which adversely affect how clients approach treatment regimens and weigh decisions about starting treatment.

Helping clients learn how to communicate with medical providers and be active in their care is a primary program focus. Although staff sometimes do go with clients on doctors' visits, the goal is for clients to be empowered in their own health care decisions. Cuate's program director reports seeing that happen with clients who continue to work through the program, learning strategies to help them get the information they want and need. Clients participate in the program for a length of time consistent with their specific goals and needs.

Special Feature — Cultural Competence. Accommodating cultural norms, religious beliefs, dietary traditions, and similar factors is central to the Cuate program.

Many Cuate clients work in low-paying, demanding jobs in the Los Angeles service sector, jobs that provide little opportunity and less privacy for HIV-positive people to take care of their health. They do not have the luxury of joining a gym to exercise or even of taking time off when they feel sick. Concerned about drawing unwanted attention to their HIV status, some clients don't want to use adherence tools, such as pill sets and alarm watches. Working with them to develop written schedules is an effective way to map out treatment strategies.

Integrating family relationships into an individual's adherence plan is key to the program's success in the Latino community. Family is of primary importance to many Bienestar clients of Mexican, Salvadoran, and Honduran heritages, among others. Cuate works with program participants to bring family life and treatment regimens together. This is especially critical for women, many of whom neglect their own health to meet family responsibilities. Bienestar providers say that many women do not speak about their illness with their families because they are focused only on family well-being. With help from Bienestar's women's program, these women are learning to tend to their own needs. One client says that she kept her HIV status from her family for over three years. Now, after nearly a year in the Cuate program, she is fully committed to her HIV regimen and has the unwavering support of her family, who keep her coming back to Bienestar.

Language remains a constant barrier to communicating about HIV treatments and

to a productive, continuing dialogue between health care professionals and Latinos living with HIV/AIDS. Cuate points to the dearth of written materials available in Spanish on the importance of adherence to HIV treatments. Staff also say that health care providers who see their clients often don't speak Spanish and cannot explain to them the differences among the classes of HIV medications, or possible contraindications and side effects. To address the language barrier, Cuate provides clients with a two-page questionnaire to take on visits to the doctor's office, with guidance on what kinds of information they should be receiving. Staff also may accompany monolingual clients to medical appointments to ensure that clients receive and understand information critical to helping them achieve better health.

### **AIDS Partnership Michigan**

Medline is the adherence program at AIDS Partnership Michigan (APM) in Detroit. APM — created in 1983 through the merger of two organizations — is the largest case management program in Michigan. AIDS Partnership Michigan's 25 staff and 250 volunteers serve 1,400 active

clients each year, tapping into the agency's long-standing relationships with gay community centers, churches, local CBOs, and medical facilities like Henry Ford Hospital and Detroit Medical Center. APM services include an AIDS hotline, HIV counseling and testing, behavioral health services, support groups, case management, emergency financial assistance, transportation, hot meal delivery, and a speakers bureau.

In the late '90s, APM staff observed a growing need for a program to address clients' confusion over new HIV treatments. When surveyed, over 50% of clients taking HIV medications said they were having adherence difficulties. In response to this growing problem, staff drafted a proposal for a demonstration program and sought a grant from the Jewish Fund, and the Medline program was born.

Medline program director, Mike Leopold, and APM associate executive director, Hank Milbourne, devised the initial concept for the adherence program after studying the adherence literature and choosing a long-term approach to adherence that would offer clients an ongoing support system to build self-sufficiency.

*To address the language barrier, Cuate provides clients with a two-page questionnaire to take on visits to the doctor's office, with guidance on what kinds of information they should be receiving.*

## AIDS Partnership Michigan Medline

Clients: Primarily people of color, especially African Americans, heterosexual substance users, youth, and gay men.

Staff: Program director, APM case managers and nurses.

Funding and Program Costs: \$800 per client per year, with a total Medline budget of \$180,000. The program is funded by the Michigan AIDS Fund, Title IV of the Ryan White CARE Act, and the Children Affected by AIDS Foundation. APM hopes to reduce program costs to \$500 per client per year as more clients enter the program.

Referrals: Primarily through word of mouth, and through APM case managers and case managers from other local agencies.

Hours: Both day and evening classes available.

Services: Peer education, individualized adherence planning, and medication monitoring. Future plans include adding employment training, starting a food coop, and creating work opportunities for graduates.

Evaluation: Evaluation with the University of Detroit, Mercy. Evaluation uses two outcome measures: quality of life and adherence to HAART. Evaluators assess clients at three points during the first 12 weeks of the program and then again at six months after initiation. Quantitative measurements including viral load, CD4 counts, self-reports, pill counts, number of opportunistic infections, and number of hospitalizations. AIDS Partnership Michigan regularly seeks client advice on how to structure the peer education component.

*“Building trust with your clients and listening to them is paramount,” says Medline program director.*

“Building trust with your clients and listening to them is paramount,” says Medline program director. He stresses that client input into program design is critical to success. “You can’t assume that you know what’s best for them.” Also key to Medline’s success is the high level of enthusiasm for the program among AIDS Partnership Michigan staff. Collaboration occurs at many different levels. AIDS Partnership Michigan has case managers on site at medical clinics in the Detroit area to speak with doctors on behalf of Medline clients. Staff also encourage other local CBOs to offer clients intensive education on medication and side effects — to

put clients in the driver’s seat on the path to improved adherence and informed client decision-making.

Moving Through the Program. The Medline program is 12 weeks long, with two weeks of intensive assessment followed by 10 weeks of classes. The program curriculum incorporates three modules. The first focuses on behavior modification, the second on monitoring and education, and the third on “aftercare.”

The first module is two weeks long — an initial assessment period during which each client has five nursing visits to assess

client health status, lifestyle, and need for support services. Clients are paired with a buddy and are given a personalized medical alarm wrist watch, a diary system to track medications taken and side effects experienced, a medication planner, and medication information sheets. They are also given help constructing diets and meal schedules, as well as setting up exercise programs. To instill a sense of inclusion and camaraderie, each client is also given a tee-shirt emblazoned with the words “Body Guard.”

In the third week of the Medline program, clients begin to take weekly classes. Classes are taught by staff nurses and designed to provide a rounded HIV/AIDS education tailored to HIV-positive clients. Classes encompass:

- the history of HIV;
- the immune system and how HIV disables it;
- opportunistic infections;
- current treatments and those in development;
- nutritional supplements;
- alternative medications;
- strategies for recognizing and coping with side effects;
- getting the most out of medical appointments;
- working with a case manager; and
- stress management.

Realizing that they had an important opportunity to work prevention messages into the program, staff created a class on safer sex and less-risky options, to which clients have been very responsive.

Medline staff believe that all their clients can absorb complex health information if it is presented appropriately. Therefore, the Medline curriculum is presented in the most basic of laymen’s terms, and materi-

als are written at a literacy level that nearly all clients can understand. Classes last about two hours, with the second hour dedicated to touching base individually with clients, such as reviewing daily adherence diaries.

Once clients complete the program — all the classes in no particular order — they receive a diploma and are formally inducted into the “Body Guards.” Medline staff say that many of their graduates cherish their diploma. Graduates attend a retreat to discuss what they’ve learned and to meet other Medline clients. Medline program director says, “This aftercare group gives individuals a social outlet, increases their access to evolving HIV information, and provides opportunities to increase self-esteem by giving back to the HIV/AIDS community.” The group is facilitated by AIDS Partnership Michigan, but is peer controlled. They produce a regular newsletter and work with both affected and infected members of the community. AIDS Partnership Michigan also is talking with area universities to see if they can arrange course credit for clients who complete the Medline program.

Special Feature — The Buddy System: Empowerment Through Self-Sufficiency. “Life will get better. I can have an impact. I have control of my life.” That is the driving philosophy of the Medline Program. Through Medline, AIDS Partnership Michigan’s goal is to ensure that clients can not only manage HAART therapy but also make good health care decisions and act on them.

A centerpiece of the Medline program, the buddy system offers clients opportunities to form lasting relationships with other clients. This helps them gain support and learn new skills that enable them to better deal with their HIV disease. Matching

*“Life will get better.  
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clients with buddies encourages support and camaraderie. Many clients have formed long-lasting relationships with their buddies and count on these friendships when adherence becomes difficult, when they are relapsing in their recovery from drug or alcohol addiction, or when they experience a break with a partner or a job loss.

Body Guards learn how to become good patient advocates, including how to speak with providers and express their health needs and how to find and secure support services. Staff also report that Body Guards come through the program with improved self-esteem, which they track through follow-up assessments and through regular interactions with Body Guards.

*Body Guards learn how to become good patient advocates, including how to speak with providers and express their health needs and how to find and secure support services.*

### **Carl Vogel Center**

Started as a buyer's club in 1990, the Carl Vogel Center in Washington, D.C. is dedicated to a team approach to treatment education and counseling and to the

notion that client decision making is at the heart of adherence. "Our focus is on developing our clients' ability to make treatment choices. Informed decision making is the core of our program," says executive director Ron Mealy, who has had his own struggles with treatment decisions arising from a past regimen that he now feels was too taxing for him and made daily living difficult.

The goal of the Vogel Center's adherence program is to improve clients' overall quality of life, which the Center believes may or may not involve HAART therapy. As the adherence program's chief architect, the Vogel Center director got his initial ideas from presentations at national and international conferences, as well as from information sharing among staff and other CBOs. He decided that a program focusing only on taking medication would fail to address the many related issues that affect health and well-being. Therefore, the program supports and promotes client decision making about all treatment options.

#### **Carl Vogel Center**

Clients: Primarily gay and bisexual HIV-positive men; 20% are Latino.

Staff: Dietician, treatment advocate, massage therapists, and acupuncturists.

Funding: Primarily grant-funded, including support from Glaxo SmithKline and Bristol Myers-Squibb; additional support from Title I of the Ryan White CARE Act.

Services: Nutritional counseling and support, case management and complementary therapies, including massage therapy and acupuncture. Peer-based services are provided through an agreement with the HIV Community Coalition. Future plans include adding a primary care doctor on site, at least part-time, and shoring up linkages with medical and support service providers, especially those focused on communities of color. Staff also plan to produce more material in Spanish to accommodate a growing Latino client population.

Moving Through the Program. Upon admission to the program, each client participates in a baseline health assessment. This assessment includes measuring client knowledge of HIV. Clients fill out an adherence questionnaire indicating whether they are taking medications and which ones, as well as to what extent they are able to follow their treatment regimens. Medical records are obtained with permission from the client, and program staff schedule a discussion with the client's doctor. This communication continues as long as the client is in the program.

Following this initial assessment, clients begin to chart their own course by working with a treatment specialist and nutritionist to set individual goals and objectives. They learn how to monitor their own health status and medication taking. Clients are asked to perform a three-day recall of all medications taken and any scheduled appointments or lab work. They then pick two other measurements of success from self-reports, pill counts, and clinical markers such as CD4 or viral load levels. Staff follow up by phone with each participant at least once a month.

Client needs are met through services at the Carl Vogel Center and through collaborative arrangements with providers around the city. The Center has strong collaborative agreements with area clinics to provide clients with medical services, and with the Sunflower House, a residential facility for people living with HIV and their families. The Vogel Center is home to an extensive library of information on HIV, where clients can spend time learning about the disease and getting the latest information about research, treatment, support services, and community events. Staff also provide educational workshops and participate in local town meetings.

"Measuring adherence and improving quality of life is an elusive goal," says the Vogel Center's executive director, "but we try to do it in a number of ways so we can assess if our program is helping people."

Special Feature — Holistic Medicine Meets HAART. Early in the epidemic few drugs were available to treat HIV disease, and those were prohibitively expensive. That's when the Carl Vogel Center decided that people living with HIV would need a combination of information and education, Western medicine, and complementary therapy to fight the progression of HIV disease. From the beginning, the Vogel Center's adherence program has relied heavily on holistic services, of which complementary therapies are a centerpiece.

A dietician and treatment advocate help clients evaluate the variety of nutritional supplements and herbs available through the Vogel Center, and a Center brochure outlines the risks and benefits of incorporating supplements into a regimen. Most Center clients choose to take supplements to increase their intake of vitamins and minerals and to boost their immune systems. Instead of radically altering the way clients eat, the dietician works with a client's existing diet to incorporate nutritional enhancements.

The Vogel Center employs a licensed massage therapist and an acupuncturist who provide these services free of charge to clients. Program participants find these soothing therapies to be an excellent way of decreasing stress and relieving pain associated with side effects of HAART and HIV-related conditions, such as peripheral neuropathy. Clients say that the program's focus on alternative therapies opened them up to options they never knew existed. They say that acupuncture relieves

*Client needs are met through services at the Carl Vogel Center and through collaborative arrangements with providers around the city.*

their pain and stress, and information about nutritional supplements and diet help them reduce negative side effects.

### **Project TEACH, Harlem Directors Group**

Harlem Directors Group (HDG), which was formed in 1986 as an umbrella group for local direct service providers, runs Project TEACH just down the street from the Apollo Theatre in Harlem, convenient to buses and the subway.

Harlem Directors Group sees itself as a conduit for organizing advocacy and service delivery in Harlem and the Bronx.

Agencies in the Harlem Directors Group network include the Minority Task Force on AIDS, Harlem Congregations for Community Empowerment, Harlem Hospital Center, and Central Harlem HIV Care Network, among others. HDG also has collaborative agreements with Iris House, which provides HIV services to women of color; Borinquen, a Latino HIV service provider; and the Association for Drug Abuse Prevention and Treatment. Project TEACH is the only service program HDG offers. Agencies in the HDG network figure prominently in Project TEACH, providing adherence clients with an array of support services.

*Harlem Directors Group sees itself as a conduit for organizing advocacy and service delivery in Harlem and the Bronx.*

#### **Harlem Directors Group Project TEACH**

Clients: Primarily African Americans and Latinos living with HIV in Harlem and the Bronx. Latinos in the program are mostly of Puerto Rican, Dominican, and Mexican descent. Many clients are women. Many also have multiple diagnoses that include mental illness or substance abuse.

TEACH Staff: Eight peer educators.

Funding and Program Costs: \$100,000, with funding from the New York State Department of Health, Glaxo SmithKline, and Merck.

Hours: Monday-Friday, 10:00 a.m.-4:00 p.m.

Services: Peer education, links to care and services, consultation with physicians and other providers to discuss client concerns and health status.

Evaluation: Evaluation plan contains both quantitative and qualitative elements. Quantitative evaluation measures a range of factors, including client knowledge of HIV and treatment options, use of HIV medications, information on recent medical history, willingness to take medications, and attitudes about and experiences with providers. The qualitative evaluation component uses client focus groups to assess the effect of the program.

HDG stresses the importance of integrating evaluation into the program design from the beginning, “Doing it once you get started makes it harder, because you may not have collected the information in a way that facilitates a good evaluation.”

Harlem Directors Group chose a peer education, psycho-social model as the centerpiece of Project TEACH. Well-trained peer educators are posted at agencies and provider sites around the neighborhood to educate and advocate for clients.

Moving Through the Program. Once an HIV-positive client is referred to TEACH, peer educators help clients get access to care, treatment, and social services, as well as work with them to build productive relationships with their care providers. Peer educators meet weekly with the program coordinator to discuss cases and share experiences and information. The project coordinator also attends bi-monthly meetings of organizations in the Harlem Directors Group provider network to increase collaboration and feedback about the program.

Throughout clients' time in the program, peer educators consult with their doctors and other providers to discuss client concerns and health status. "Collaborations are critical," says Leatrice Wacto, Project TEACH coordinator. "Having a specific person to talk to is really helpful, especially in a client emergency."

Harlem Directors Groups wants to expand Project TEACH. They plan to hire an administrator to manage the program and a health educator to help the peers develop skills that will enable them to move into more advanced positions in the workforce. Harlem Directors Group also wants to reach out further and form new linkages with churches and with senior homes and centers. Staff have seen an increase in the number of older clients and are planning to recruit and train more peer educators in that age group.

Harlem Directors Group stresses the importance of integrating evaluation into

the program design from the beginning, "Doing it once you get started makes it harder, because you may not have collected the information in a way that facilitates a good evaluation."

Special Feature — Peer Education. At the heart of Project TEACH are peer educators, all of whom are or have been clients of the program. Harlem Directors Group trains these peers extensively. They learn about the virus, current treatment protocols and side effects and are also trained in counseling and teaching techniques. After training is completed, each peer must pass a final exam in order to be hired by TEACH. The exam is both comprehensive and intense, covering topics such as the history of HIV, treatment and side effects, clinical trials, risk reduction approaches, legal aspects of doing HIV work, and counseling principles. After passing the exam, peers receive a certificate of accomplishment.

The training program instills peer educators with a sense of professional accomplishment and pride in their work, as well as a desire to move forward with their lives, and, often, the impetus to seek other jobs or go to school. The peer educators, who take their work very seriously, stress how much the program has helped build their self-esteem, providing them with camaraderie and support around their own HIV disease, and helping them better follow their HAART regimens. The exuberance and enthusiasm Project TEACH peer educators have for their work is apparent; they are as well informed about HIV disease as they are excited about providing support to Project TEACH clients.

Once a peer educator is hired, she or he is placed in one of the provider sites in the HDG network or, in some cases, outside

***Harlem Directors Group stresses the importance of integrating evaluation into the program design from the beginning, "Doing it once you get started makes it harder, because you may not have collected the information in a way that facilitates a good evaluation."***

the network. Before a peer is placed, the program coordinator meets with staff at the proposed placement. Her goal is to determine receptivity to having a peer educator on site and to communicate HDG's expectations for an organization's participation in the program, including signing a letter of agreement with Harlem Directors Group.

### **Southern Colorado AIDS Project**

The Southern Colorado AIDS Project (South CAP), serves a 24-county area in

Colorado. Before starting its own adherence program — the Medication Adherence Program — South CAP tried contracting with a home health agency to provide their clients with adherence support. When those adherence services were not adequate, South CAP staff decided to do it themselves, conducting an extensive adherence literature review to guide their program planning. "First and foremost," says Greg Smith, adherence program coordinator, "an adherence program must ensure that clients feel at home in the program and supported in other facets of their lives."

*"First and foremost," says Greg Smith, adherence program coordinator, "an adherence program must ensure that clients feel at home in the program and supported in other facets of their lives."*

#### **Southern Colorado AIDS Project**

Clients: Primarily HIV-positive people of color, people living with HIV who have multiple diagnoses, and those who live in small or rural communities.

Staff: Program coordinator.

Funding and Program Costs: Initial funding from the Ryan White CARE Act — \$9000 for six months. The program's current budget is \$22,000, with \$15,000 of that funded through the county health department. The program is staffed by an adherence coordinator, who is supported by a part-time HIV nurse and South CAP's case managers.

Entry Criteria: Open to all South CAP clients. Readiness determined through a comprehensive assessment process.

Services: Individualized adherence counseling, meal planning, case management, and education workshops for clients on lab values, nutrition assistance, federal treatment guidelines, and resistance.

Evaluation: Both clinical and non-clinical indicators. Increased client knowledge is evaluated through both structured and informal conversations with clients. Clients also have many opportunities to give program staff evaluation feedback throughout their participation in workshops, support groups, and one-on-one discussions. Adherence staff also obtain clinician assessments of client adherence. Quantitative evaluation measures include lab values, such as viral load and CD4 counts, which are reviewed regularly.

South CAP's longstanding relationships with city and county human service organizations, other CBOs, and the county health department where most of its clients receive their primary care, are key to carrying out the adherence program. South CAP advises that starting to build such relationships should take place before the adherence program begins.

Moving Through the Program. Upon program entry, clients complete an extensive questionnaire that assesses their medical history including any prior experience with HAART, social history, knowledge of adherence, and resistance to taking medications. Using that information, the program coordinator and client then develop an individualized adherence plan, with support provided as necessary from South CAP's HIV nurse and case managers.

The program coordinator continually monitors individualized adherence plans with clients and links them to health care providers, pharmacies, and social support services. He schedules client adherence appointments in coordination with their other visits to South CAP, so that adherence is reinforced at every opportunity. The Medication Adherence program is ongoing, with the duration of a client's participation depending on his or her progress.

There is a high level of staff collaboration between the adherence program and the rest of South CAP. The program coordinator keeps the entire South CAP staff informed about emerging adherence issues and the needs of individual clients, and staff meets regularly to discuss and review client progress.

Though resources are limited, staff are thinking about future growth. South CAP

would like to explore permanent funding to sustain and expand the program, to increase the number of educational materials available in Spanish, and to add computer software able to analyze data from client assessments to help South CAP evaluate adherence program outcomes.

Special Feature — Direct CBO-to-Provider Adherence Marketing. There are a handful of internal medicine physicians who care for people living with HIV disease in the program's catchment area, and South CAP estimates that there may be many more primary care providers who also see individuals with HIV and refer them to HIV specialists. In setting up the program, the coordinator determined that in order for providers to participate, the program must first go to the providers. As a registered nurse himself, he recognized that buy-in from area doctors is more likely if he can quickly and concisely inform them about the program and highlight how it can support them in doing their jobs.

Such support can be especially crucial when physicians are challenged by the dwindling amount of time they are given to foster relationships with their patients. Therefore, South CAP distributes program brochures to doctors' offices, outpatient clinics, health maintenance organizations, hospitals, and the county health department. The coordinator also makes presentations to area providers on the latest developments in adherence, meets regularly with the Colorado Springs Visiting Nurse Association, and discusses HIV-related dental care with dental hygienists at Memorial Hospital. South CAP's participation in a health and nutrition-based program run by a consortium of area CBOs is another resource for the Medication Adherence Program's efforts to get the word out to local providers and generate referrals.

*Such support can be especially crucial when physicians are challenged by the dwindling amount of time they are given to foster relationships with their patients.*

Marketing its services to local care providers turned South Cap's adherence program from a one-man show into a chorus of health professionals dedicated to working to together to improve adherence. Marketing to medical providers takes time and requires a clear articulation that program services support, rather than

supplant, the work of other health care providers. "Keeping the focus on the positive benefits of provider participation in our adherence program enables us to build strong linkages that provide clients with quality, well-rounded care," says South CAP's adherence coordinator.

*"Keeping the focus on the positive benefits of provider participation in our adherence program enables us to build strong linkages that provide client with quality, well-rounded care," says South CAP's adherence coordinator.*

Table 1

### Strategies to Improve Adherence: Patient and Medication-Related

- Inform patient, anticipate, and treat side effects.
- Simplify food requirements.
- Avoid adverse drug interactions.
- If possible, reduce dose frequency and number of pills.
- Negotiate a treatment plan, which the patient understands and to which he/she commits.
- Take time, multiple encounters to educate and explain goals of therapy and need for adherence.
- Establish readiness to take medication before first prescription is written.
- Recruit family and friends to support the treatment plan.
- Develop concrete plan for specific regimen, relation to meals, daily schedule, side effects.
- Provide written schedule and pictures of medications, daily or weekly pill boxes, alarm clocks, pagers, other mechanical aids to adherence.
- Develop adherence support groups, or add adherence issues to regular agenda of support groups.
- Develop linkages with local community-based organizations around adherence with educational sessions and practical strategies.
- Consider "pill trials" with jelly beans.

— Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents (April 23, 2001, p.40)

Table 2

### Strategies to Improve Adherence: Clinician and Health Team-Related

- Establish trust.
- Serve as educator, source of information, ongoing support and monitoring.
- Provide access between visits for questions/problems via pager number, including vacation/conference coverage.
- Monitor ongoing adherence; intensify management in periods of low adherence (i.e., more frequent visits, recruitment of family/friends, deployment of other team members, referral for mental health or chemical dependency services).
- Utilize health team for all patients, for difficult patients, for special needs (e.g., peer educators for adolescents or for injection drug users).
- Consider impact of new diagnoses on adherence (e.g., depression, liver disease, wasting, recurrent chemical dependency), and include adherence intervention in management.
- Utilize nurses, pharmacists, peer educators, volunteers, case managers, drug counselors, physician's assistants, nurse practitioners, research nurses to reinforce message of adherence.
- Provide training to support team related to antiretroviral therapy and adherence.
- Add adherence interventions to job descriptions of HIV support team members; add continuity-of-care role to improve patient access.

— *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents* (April 23, 2001, p.40)

## CLEARING THE HURDLES

Implementing an adherence program can be a formidable task. The research on what works is new and evolving, and community-based strategies must evolve to keep pace with changing standards of care for people living with HIV disease.

**T**he CBO programs profiled identify several common challenges to creating and implementing adherence programs, including:

- a lack of long-term funding and resources to build capacity and sustain services;
- staff retention;
- the need to build meaningful collaborations with medical providers; and,
- how to measure success.

This chapter looks at how several community-based adherence programs are clearing these hurdles.

### FUNDING

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With one exception, each of the programs visited is concerned about a lack of resources and uncertain about long-term funding prospects. Most are funded in part by foundation or corporate grants, with the CBO making up the balance of funds when necessary. Some organizations have been able to obtain funding for their

adherence program from CARE Act funds, usually through Titles I or II; some receive funding through their state government.

In general, funds are available for a finite period of time, usually a year or two, which makes programs hesitant about expanding or adding new components when the possibility exists that current services might be curtailed or even shut down. Several CBOs express concern that a lack of funding could impede their efforts to provide the most basic adherence services. At South CAP, a lack of funding means that the program coordinator has fewer hours available to recruit new clients and conduct follow ups with existing clients.

### STAFF RETENTION AND CAPACITY BUILDING

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Many small adherence programs are run by one person whose responsibility it is to secure funding, build links with social service and medical providers, develop and implement care plans with clients, assess client progress, and evaluate the program —

a Herculean task. Adherence staff, who often have been promoted from within an agency, may have backgrounds in treatment advocacy, public health, or medicine. Many work long hours, and the potential for burnout is high. Additionally, some are themselves living with HIV disease and have their own health to protect. Building capacity in adherence programs is essential to retaining current employees and to increasing a program's ability to serve more clients in need.

## **BUILDING BRIDGES TO MEDICAL PROVIDERS**

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Although the community-based adherence programs profiled in this guide succeeded in building effective relationships with medical providers, fostering such linkages can be tricky. Adherence programs use a variety of strategies to connect with providers, including:

- advertising in doctors' offices and community health clinics;
- conducting presentations at provider agencies, associations, and professional groups;
- cultivating new relationships with physicians through repeated telephone calls; and
- using existing relationships as a vehicle for introducing the possibility of provider participation in the adherence program.

Adherence staff and medical providers must negotiate the parameters of their respective roles. Program staff report that some health care providers view treatment advocates as usurping the authority of medical professionals. Establishing collaborative relationships with medical providers enables adherence programs to position community-based adherence as bolstering rather than interfering with the care physicians provide patients and allowing patients

to get the most out of their doctors' advice. Many community-based adherence programs draw up formal cooperative agreements with medical providers that clearly delineate roles and responsibilities.

Community-based adherence programs say this allows them to monitor and evaluate the success of these partnerships. This kind of formal arrangement is something that AIDS Partnership Michigan and the Harlem Directors Group have established with local medical providers.

## **TAKING STOCK AND MEASURING SUCCESS**

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Measuring the success of adherence programs can be elusive. Community-based programs point to the challenge of evaluating both their clients' progress and their programs as a primary hurdle in operating an adherence program. All six of the programs profiled are collecting data and seeking to understand what that data means so that they can fine tune their programs and services, as well as demonstrate success to funders.

There are no precise measurement tools that clearly demonstrate whether or not an individual is adhering to a HAART regimen. Therefore, CBOs must rely on a variety of measures, such as viral load, CD4 cell counts, client recall of pill taking, and a change in health status. Collecting this information can be a challenge. Although linkages with medical providers and case managers are an excellent strategy for better access to client charts and lab values, not all health care providers are willing to share client medical information. In some cases, clients themselves choose not to consent to the release of their charts.

How community-based adherence programs are evaluating themselves is described in more detail in the following chapter.

*Community-based programs point to the challenge of evaluating both their clients' progress and their programs as a primary hurdle in operating an adherence program.*

## MEASURING UP: EVALUATING CBO ADHERENCE PROGRAMS

*The measurement of adherence is imperfect and lacking a gold standard.*

— *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents*  
(April 23, 2001)

Increasingly, funders — both public and private — are expecting community-based organizations (CBOs) to document outcomes from the services they provide. CBOs also want to measure their effectiveness. Yet, many community-based adherence programs identify evaluation as their greatest challenge. Even perfect adherence to HIV treatment regimens does not guarantee a positive outcome in terms of viral load or CD4 counts. And, CBOs say, their adherence programs often result in positive changes for clients other than those that can be captured in the standard measures of health outcomes for people with HIV and AIDS.

“Yes, physical health status is important, but quality of life issues are also critical. I can tell when patients are feeling better by the way they look, and if they seem happy. How do I measure that?” asks the adherence program director at AIDS Partnership Michigan.

This chapter examines why evaluation is considered such a challenge and describes how some CBOs are measuring up.

### HEALTH STATUS AND QUANTITATIVE MEASURES

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Community-based adherence programs carefully chart clients’ medical histories and use many of the same health status and other quantitative measures used by researchers in clinical settings, including:

- viral load — a measurement of the amount of virus in the blood;
- CD4 count — one measurement indicating how well the immune system is functioning;
- self-reports — client reports of how they are keeping to their regimens; and
- pill counts — providers count the number of pills to determine if a client is missing any doses.

### QUALITATIVE MEASURES AND QUALITY OF LIFE OUTCOMES

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Hope, confidence, happiness, and feelings of empowerment are things that program staff can detect but find difficult to document. Client progress in making better

The determinants, measurements, and interventions to improve adherence are poorly characterized and understood, and more research on these critical topics is needed.

*Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents* (April 23, 2001)

health care decisions, deciding to get treatment for drug or alcohol addiction, maintaining more nutritious diets, and returning to work are also signs that adherence programs are working for clients.

Qualitative measures often include conversations that elicit ongoing barriers to adherence, changes in attitude towards medicine taking, and perception of one's prognosis. In addition to providing feedback at individual client meetings and at program-sponsored social events, clients often complete formal evaluation forms. At the Carl Vogel Center clients fill out a treatment assessment form as they enter the program, which is updated periodically to reflect any changes as they progress through the program. Adherence program staff also consult with other providers for information that indicates how well a client is doing following his or her treatment regimen. CBOs use this data not only to revise individual treatment plans, but also to modify the adherence program itself to better meet client needs.

## LINKING WITH EVALUATORS

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The community-based adherence programs AIDS Action visited expressed a desire to create closer links with researchers and evaluators. Every program is interested in partnering with an academic institution around evaluation, and some have already done so. AIDS Partnership Michigan formed a partnership with the School of Nursing at the University of Detroit Mercy. Working with two faculty who have backgrounds in community-based health care, AIDS Partnership Michigan is following program participants over a nine-month period, checking in with clients every three

weeks during the 12-week Body Guard program, then again six months after graduation from the program. They are using lab values, medical status, and quality of life measurements to track outcomes. AIDS Partnership Michigan plans to publish the findings from the program's first year and use the results to enhance the program.

Harlem Directors Group is in the final stages of developing an evaluation structure. It will build on the monograph Harlem Directors Group wrote on HIV treatment and communities of color.

Action Point studied its first few months in operation in an evaluation conducted by the program's medical director and colleagues from the University of California San Francisco (UCSF). Data indicate that Action Point's primary goals are being met, including reducing clients' viral load and increasing CD4 counts, as well as ensuring that clients are in primary care — and drug treatment if needed — and are making moves to secure housing. Staff plan to continue the study and use the results to refine and enhance their program. UCSF also is conducting an ongoing federally funded evaluation of Action Point, in partnership with the program and with San Francisco General Hospital and the department of public health.

The job of measuring both individual client success and that of the overall program depends in part on the availability of resources for evaluating and interpreting data. Southern Colorado AIDS Project and Bienestar are searching for resources that will allow them to better analyze the data they have collected on their programs and clients.

*The job of measuring both individual client success and that of the overall program depends in part on the availability of resources for evaluating and interpreting data.*

Community-based organizations have a long history of creativity and innovation in service to their clients, evolving to meet the changing needs of their clients and their communities. That same willingness to evolve, engage in the process of trial

and error, and try something new is a hallmark of successful adherence programs. We hope the program profiles in this guide do justice to the quality of the programs and the commitment of program staff and the clients they serve.

**until it's over**  
**AIDS ACTION**

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