



# HRSACARE ACTION

PROVIDING HIV/AIDS CARE IN A CHANGING ENVIRONMENT

JUNE 2005

## Service Delivery and HIV-Positive Peers

**H**IV-positive peers work in many agencies funded through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. They provide a variety of services to clients, including outreach, counseling and testing, and psychosocial support. They meet with newly diagnosed patients, offering both a helping hand and a symbol of hope. Peers provide up-to-date information about medication, treatment, and drug trials, and they assist clients in understanding specific aspects of their individual disease processes and management plans. And, perhaps most significant, they provide companionship and social support. HIV-positive peers have been successfully integrated into every aspect of HIV/AIDS service delivery.

The importance of peers doing this kind of work cannot be overstated. An article in the *Hopkins HIV Report* stated:

For most of the rest of their lives after becoming infected, HIV-seropositive individuals are clinically asymptomatic or have mild, nonspecific, and easily manageable signs and symptoms. However, the social framework in which they live is continuous and is perhaps the major determinant of quality of life, and ultimately serves as either a facilitator or barrier to good clinical care. *Peer counseling is an effective strategy for helping patients overcome some of those barriers.* [emphasis added]<sup>1</sup>

Peers often can accomplish things that nonpeers cannot.

Although many AIDS service organizations have incorporated peer volunteers into their services, this article focuses on HIV-positive peer employees because the issues involved in managing such employees are so different from those involved in managing most other workers. The article highlights successful human resources practices for recruiting, training, and supervising peers; it also reviews the literature and provides information gleaned from interviews with providers and peers working in Title IV-funded programs.

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—Alicia Beatty

### What Is a Peer?

A peer can be defined as “one who has equal standing with another or others, as in rank, class or age.”<sup>2</sup> In HIV/AIDS service delivery, the term often refers to people with similar serostatus, but it can also refer to people with shared demographic characteristics. To narrow the scope of inquiry, this article focuses on

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HIV-positive peers, who might not share other characteristics of the target population, such as age, race, or life experience (e.g., history of substance abuse or homelessness).

### Peers Are Effective

Most of the research on the impact of peers has focused on peer education—specifically, primary HIV/AIDS prevention education. But peer education is “an ill-defined, generic concept . . . this label conveys very little information about a programme’s important characteristics, methods, scope, content, and purpose, apart from the fact that persons considered to be ‘like’ members of the target population deliver some type of communication.”<sup>3</sup> A report by the United Nations Joint Programme on HIV/AIDS (UNAIDS) concurs: “In practice, peer education has taken on a range of definitions and interpretations concerning who is a peer and what is education (e.g., advocacy, counseling, facilitating discussions, drama, lecturing, distributing materials, making referrals to services, providing support, etc.).”<sup>4</sup>

Numerous studies have documented the effectiveness of peers providing HIV/AIDS education among a wide variety of populations, including commercial sex workers, factory workers, injection drug users, men who have sex with men, and youth.<sup>5</sup> Because peer education is a modality particularly favored for reaching youth, the short-term impact of HIV/AIDS peer education programs on young people has been studied in depth: Studies have demonstrated statistically significant peer intervention effects on youths’

virus-related knowledge, attitudes about risky sexual behavior, self-efficacy, and resistance to negative peer pressure about condom use.<sup>6</sup>

Much less research has been published about the effectiveness of peers in providing or facilitating access to care for people living with HIV/AIDS (PLWHA). Although some of these studies involve people who are not HIV positive, they nonetheless confirm the effectiveness of peers. Three studies, however, suggest that they can be effective. In one study,<sup>7</sup> women with HIV living in Baltimore were successfully trained in a theory-based counseling intervention. During the study period, they counseled other HIV-positive women about reproductive health, including condom use; they modified the counseling materials as necessary to best meet the needs of their clients.

In another study, teams of HIV-positive and HIV-negative peer counselors in San Francisco were trained to provide interactive health education groups to men. The groups focused on HIV disease self-management skills and information. The results showed that men who participated in the peer-led educational groups had significantly fewer symptoms of moderate or greater severity and better self-efficacy for controlling symptoms than did control group participants.<sup>8</sup>

The third study involved “near-peers” (who are not defined and thus might not be HIV positive) who were trained to provide directly observed therapy (DOT) with highly active antiretroviral therapy (HAART) to people with substance abuse disorders and a history of failure to adhere to HAART. The results were

promising, because most of the participants felt favorably about the intervention and simultaneously achieved measurable suppression of the virus.<sup>9</sup>

### Theory Base

Peer education is based on the notion that members of a peer group can influence others in the group. It draws upon several behavioral change theories, notably Social Learning Theory, the Theory of Reasoned Action, and the Diffusion of Innovation Theory. As explained in a UNAIDS report:

- Social Learning Theory asserts that people serve as models of human behaviour and that some people (significant others) are capable of eliciting behavioural change in certain individuals, based on the individual’s value and interpretation system.
- The Theory of Reasoned Action states that one of the influential elements for behavioural change is an individual’s perception of social norms or beliefs about what people who are important to the individual do or think about a particular behaviour.
- The Diffusion of Innovation Theory posits that certain individuals (opinion leaders) from a given population act as agents of behavioural change by disseminating information and influencing group norms in their community.<sup>10</sup>

Another pillar upon which peer involvement stands is derived from the client empowerment movement:

In the past 20 years, health and social service delivery programs have often

## What Peers Can Do

Peers can help clients by providing the following services:

- Provide general health information
- Help people understand specific aspects of their individual disease processes and management plans
- Counsel clients about HIV testing, treatment and transmission, sex and drug use behaviors, and contraception
- Identify barriers to care
- Facilitate access to substance abuse treatment
- Negotiate housing assistance
- Act as a patient advocate in specific situations, such as a gynecologic exam or discussion with other health care providers
- Foster trust in the health care system and promote treatment compliance
- Provide social support and enhancement of self-esteem.

From Anderson JR. Peer counseling for HIV-infected women. *The Hopkins HIV Report*. 1996;8(22). Available at: [www.thebody.com/jh/hivrept/jul96/anderson.htm](http://www.thebody.com/jh/hivrept/jul96/anderson.htm)

attempted to engage clients in the delivery of services. In fact, most community-based services for traditionally marginalized or powerless populations include a philosophy of empowerment . . . designed to encourage self-development, to improve group and individual decision-making skills, to establish and reinforce a sense of community, and to proactively enhance social justice.<sup>11</sup>

The self-empowerment movement among PLWHA was codified in 1983 in the "Denver Principles" written by the advisory committee of the People with AIDS Coalition. The principles do not specifically address peer provision of services, but they do affirm that PLWHA have the right "to full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives."<sup>12</sup> In all of these areas, PLWHA need information from trusted sources. It has been argued that peers living with HIV

disease "can more readily establish a connection with clients based on shared experiences [and/or] common backgrounds."<sup>13</sup>

### "We Can Relate"

Debbie DeRosalia, peer advocate at the Albany Medical College AIDS Program, explains the special connection she has with clients: "We can relate to one another; we walk in the same pair of shoes, so to speak. The patients might tell me more than they may tell a doctor or case manager because I am just like they are, I am one of them. When I tell them I'm also infected, it seems to close a door and open a window. The patient feels comfortable to know we have this connection; it allows us to bond."

DeRosalia works with patients who have just received their diagnosis. She observes,

With the newly diagnosed, I let them know there is life after an HIV/AIDS diagnosis. The virus is no longer a death sentence, and they can survive

this chronic illness. I help them to understand the definition of T cells and viral load and the importance of taking their meds consistently, why they need to be adherent and the danger of resistance. Together we try to come up with a plan to help them figure out what behaviors they possess and what behaviors they need to change in order to have a good quality of life.

DeRosalia also works with clients who are "no-shows," noting, "I try to connect with them and to help figure out what barriers are keeping them from accessing medical care and treatment."

Some PLWHA turn naturally to peers. In one study, researchers focused on HIV/AIDS patient involvement in antiretroviral treatment decisions and noted, "Patients who want to be involved in their antiretroviral decisions with their providers tend to have a strong desire for HIV-related information [and gather] information about drug treatments from a variety of sources,

including HIV-positive peers.”<sup>14</sup> The researchers conducted four focus groups with a total of 39 HIV-positive participants and learned that for many, “a network of those infected with HIV functions to provide direct information about antiretroviral treatments.”

A comprehensive list of what youth peers can do is included in *Youth-to-Youth—Peer Workers in HIV/AIDS Youth Programs: A Peer Development Guide*, a report on a CARE Act-funded Special Projects of National Significance (SPNS) project. As described in the report, peer staff are responsible for various project tasks, including the following:

- *HIV Testing.* Facilitate discussion of uncomfortable topics and support clients through the process from initial risk assessment to posttest counseling.
- *Recreational Outlets.* Show clients the benefits of life without drugs and alcohol through regular social outings.
- *Case Management.* Coordinate services and benefits to meet the individual needs of each client (e.g., housing, health care, long-term options).
- *Logistical Support.* Provide supportive services, such as transportation to appointments.
- *Development of Life Skills.* Help cultivate the life skills (e.g., resumes, job skills, training) of clients who have grown up outside the mainstream but need the skills to reintegrate themselves into society.
- *Outreach.* Familiarize agency staff with the target population and familiarize the target population with available services.
- *Advocacy.* Serve as a liaison between young clients and nonpeer staff (i.e., voice the needs of young people).

- *Decision Making.* Participate actively in all decision making regarding clients.
- *Peer Empowerment.* Serve as positive role models to empower youth and peer staff at other agencies.<sup>15</sup>

### Benefits of Peer Involvement

The benefits of peer involvement in HIV/AIDS service delivery manifest at the client, peer, and organizational levels. A Canadian study of PLWHA demonstrates the benefit for clients:

Respondents indicated that people living with HIV/AIDS can relate to service users and offer peer support, which helps clients to feel that they are not so alone in their struggles. By having HIV-positive peer counselors, many clients believe they will not be judged and can talk more freely.<sup>16</sup>

Another important benefit to clients is retention in care. The SPNS projects found, “Youth involvement was strongly linked to clients’ ability to utilize care and increased likelihood of program retention. This success is in large part due to the fact that project staff are the same age as the young people they are targeting.”<sup>17</sup>

Aside from the obvious financial benefits of a job, many benefits accrue to the peer workers themselves, including “increased self-esteem, self-assurance, and comfort and familiarity with the health care system”<sup>18</sup> and learning how to read laboratory test results or accessing online medical databases for current information about treatment.<sup>19</sup> In general, it has long been known that peer educators (regardless of serostatus) gain tremendously through their involvement in primary prevention activities. For exam-

ple, in a study of youth peer leaders, “repeat peer leaders had significantly higher mean scores on knowledge of HIV/AIDS, knowledge of planning and presenting skills, self-efficacy, and perception of self as a change agent.”<sup>20</sup>

Interviews with Title IV service providers echoed these themes. Alicia Beatty, director, The Circle of Care Program of the Family Planning Council of Southeastern Pennsylvania, states, “The women gain self-esteem! They feel they are making a difference, giving back, and they wouldn’t trade that for the world.” Commenting on the HIV-positive peers working at Larkin Street Youth Services, Sherilyn Adams, director of special services, observes, “They gain a sense of productivity in something that feels important and purposeful. They are helping others, giving back. They gain a sense of accomplishment: ‘Maybe things weren’t perfect for me, but now I can help this organization change to improve service provision for others.’”

The AIDS service organizations themselves receive many benefits, including consumer insight and perspective. SPNS projects<sup>21</sup> reported using those perspectives “to develop effective programs and program materials, as well as to better identify and address program barriers and the needs and desires of youth served.” In addition, “projects employing youth as outreach workers . . . were successful in reaching HIV-positive and high-risk youth and linking them to age appropriate care.” Other projects noted, “employing paraprofessionals from the community enables service providers to . . . tailor prevention services more

effectively and sensitively to the needs of the community."<sup>22</sup> The involvement of people living with HIV/AIDS also serves to legitimize AIDS service organizations: "Agencies have found that the involvement of PLWHA is an essential part of their acceptance and success in meeting the needs of the community."<sup>23</sup>

### Challenges

To implement a peer program successfully, program managers must plan for and overcome certain challenges.

**Health Concerns.** Managers need to help peers pay attention to their health: Maintaining one's physical, mental, emotional, and spiritual health is a full-time job for many people living with HIV/AIDS. Accommodating such needs can be particularly difficult in small and poorly resourced community organizations. AIDS organizations can be very demanding workplaces. The health of PLWHA can be challenged by working in such demanding environments."

Circle of Care's Beatty observes,

It's a challenge sometimes for the women to find a balance between working and taking care of themselves. They don't always want to acknowledge their own health status because they love what they do. That puts me and my staff in the position of giving "truth therapy" to help them understand that in order to role model, they have to take care of themselves.

**Role Model Issues.** It can be difficult to live up to the expectations that come with being a role model. The pressure to

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—Debbie DeRosalia

be the "perfect" PLWHA comes from all segments of the organization and applies to all aspects of the person's life. In the most extreme examples, PLWHA who are peer counselors feel they cannot show signs of depression and educators cannot admit to taking any degree of risk in their sexual practices.<sup>24</sup>

An ethnographic study of youth peer educators living with HIV revealed that some "are unable to 'practice what they preach' and feel guilty as a result."<sup>25</sup>

**Risk of Losing Own Support System.** Many PLWHA receive their own medical and case management services somewhere other than where they are employed. Some peers, however, perhaps particularly youth who have aged out of client status, face the danger of losing their own support system while providing support to others.<sup>26</sup> The case study of "Jose," a 23-year-old gay Latino sheds some light:

Because of his employment, Jose did not feel comfortable talking to the counseling staff at the agency when he was having problems. He had long been dependent upon staff at the agency for emotional support. The agency staff now had job-related expectations of him as their employee that were separate from his personal and emotional needs as their former client and a youth living with HIV.<sup>27</sup>

**Reinforcement of Stigma.** Young people and adults living with HIV "who become peer educators often become identified with their disease and begin to lead a life of an 'HIV+ person,'" which is still a stigmatized identity in the larger society. In addition, peers "are commonly asked to testify in public forums about their life experiences," an activity that can take an emotional toll.<sup>28</sup>

Larkin Street's Adams warns:

Watch out for exploitation of peers. We get a lot of requests for youth speakers to come tell their story. I

want to balance the need for these young people's voices to be heard, their need to tell their story, and the difficulty of doing this over and over. I want to be sure we are providing enough support to young people who are on the speaking circuit.

### **Need for Substantial Supervision and Support.**

Beyond the usual supervision needed by any employee, peers require "extensive support, supervision, time and resources," especially if they—youth or adult—need to develop basic workplace skills.<sup>29</sup> Program managers must be ready to provide support to peers in maintaining healthy boundaries between themselves and their clients and in dealing with their feelings if clients (or other peers) sicken and die.

### **Personal Growth and Program Evaluation.**

A welcome byproduct of empowering PLWHA is that they gain the knowledge and skills to advocate for themselves and others. This process can be a double-edged sword for organizations that are unable to respond as immediately and completely to peer requests for program changes.

### **Helper/Helped Paradox: The Transition From Client to Staff Member.**

One of the key challenges in incorporating peers into a program is helping peers navigate the transition from "helped" to "helper," from client to staff member. Those issues must be addressed directly in clinical consultation.

**Loss of Public Benefits.** Eligibility for publicly funded benefits programs may be based on income levels. Therefore, PLWHAs who work even part-time might

jeopardize their access to those programs. PLWHAs seeking paid work and employers should work carefully to ensure that employment does not have a negative effect on PLWHA's financial status.

### **How to Manage Peer Paraprofessionals**

Proper program planning (which should involve peers from the ground up), coupled with supervisors' commitment to providing a respectful and supportive work environment attuned to the special needs of HIV-positive peer workers, will go a long way in addressing these—and other—challenges. Many HIV/AIDS programs have been successfully including peers for a long time. By building on their experiences with recruitment, hiring, supervision, training, accountability, and support, other organizations can establish—or improve—peer programs.

**Recruitment.** Recruit peers from a broad base of candidates from both internal and external sources. Adams emphasizes, "Try to manage the process well and think about the subtle difference between making clients *aware* of job openings and *encouraging* them to apply."

**Hiring Criteria.** There is unanimity in the field: "Never hire a candidate based solely on specific demographic characteristics, such as ethnicity, gender, HIV status or sexual background."<sup>30</sup> Those interviewed for this article reported the following list of desirable traits in peers: commitment to the population and passion for the work; ability to learn; ability to build rapport and handle difficult situations well; skill at developing and maintaining personal and professional

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—Sherilyn Adams

boundaries; strong history of recovery from substance abuse (if relevant); and ability to work as a team. Jacquelyn Wilkerson, consumer involvement coordinator of the Family Connections program at Children's National Medical Center, adds, "It's crucial that they never give medical advice based solely on their personal experiences."

**Supervision.** Peers need at least weekly supervision from a clinical supervisor, and they benefit from group supervision sessions as well. Supervision can help peers understand their roles and responsibilities, which should be clearly

defined from the outset. Supervision should focus on long-term personal and professional growth as well as deal with issues that arise in day-to-day work with clients. Stacey Agnello, manager of Albany Medical College's HIV External Relations, points out, "Supervision is very time consuming, especially with new or inexperienced staff. You must think of it as an investment. Many people have never had any training to do this kind of work."

**Training.** All peers need tools to help them do their jobs. Some programs require that their peers receive peer leadership training (offered in the community) even before being hired. Other training topics include HIV 101 (it would be a mistake to assume that all people living with HIV know all the facts about the disease), diversity and cultural competence, and substance abuse. Peers should receive a thorough orientation to the workplace and have opportunities to take advantage of free or low-cost trainings offered by other agencies.

**Accountability.** "Some administrators and program managers are guilty of treating peer educators with kid gloves. . . . Agencies that employ peer educators should hold them to the standards that apply to [other] employees."<sup>31</sup> In interviews, program managers made that point repeatedly. For example, Adams says, "The staff needs to hold expectations of peers and treat them as equal employees. They have to hold them accountable, while being respectful and appropriate, and not minimizing their issues."

**Support System.** Peers require additional emotional support because they can so clearly identify with clients. Beatty states, "Never hire just one peer; they need each other for support." Gail Russell, a peer in that program, concurs: "The things you feel every day, it would be hard to have to hold that in and not have someone to talk to." It is crucial for supervisors to be savvy about the particular stressors on peers. As Children's National Medical Center's Wilkerson explains, "It can be hard on the peers, watching clients go through the progression of the disease. Maybe a client is experiencing an opportunistic infection that the peer had a year ago. It reminds her of how bad it was, like a flashback. It's absolutely stressful." Peers appreciate the extra understanding afforded by staff.

**Maintaining Boundaries.** It is essential that peers maintain personal and professional boundaries. Peers Joyce Hamilton and Russell have found several strategies to be helpful. Hamilton says, "I deal with pregnant women and women in their addictions. I don't take my work home with me. I focus on me and what I have to do. I will listen to a client if she calls, but that's as far as I go." Russell adds, "They can't call me at home; they can call me the next day in the office. I don't give out my home number." Albany Medical Center's DeRosalia tries to take it a step further: "Our goal is in empowering the patients to take control of their own lives, to take a firm stand on their destiny. We encourage, we try our best not to enable."

## Conclusion

HIV-positive peer workers can bring enormous amounts of passion, expertise, and dedication to their jobs, providing significant benefits for clients, the organization, and themselves. Program managers who can walk the fine line between supporting the peers while not being overprotective will be doing the peers—and, ultimately, the clients—a great service.

Because of the unique nature of the bond of shared serostatus, peers can often reach clients in ways that HIV-negative staff cannot. As Agnello puts it:

They share their life stories and in doing so, often identify issues that a case manager misses. By having similar experiences, peer staff identify behaviors that may not be evident to other staff, especially around substance abuse issues. They can confront behaviors such as active substance use, unprotected sex, or nonadherence. They relate to their clients on a different level than staff who are not living with HIV/AIDS, because they've 'been there.' They often have a unique insight that tells them when someone is not being truthful. Clients are much more apt to open up to peer staff than professional staff about risky behaviors. The most important benefit of utilizing peer staff is to give hope and extra support to others living with this disease.

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