

New Tactics

Volunteer Programs Adapt to Meet Changing Needs of People with AIDS

By Susan M. Chambré

In the summer of 1996, scientists announced that protease inhibitors, a new class of drugs, promised to lengthen the lives of people with HIV illness. One year later, federal Centers for Disease Control statistics showed that there were fewer AIDS deaths in 1996 than in 1995. These are important milestones in a changing epidemic. For many, HIV has become a chronic, long-term illness with periods of relatively good health. Although protease inhibitors combined with antiviral drugs are not a "cure" for AIDS, they are a quantum leap in treatment; they also represent the continuation of a decade-long trend during which doctors became more able to treat the opportunistic infections that beset people with AIDS. These changes have altered the role of volunteers in the epidemic. Staff in AIDS programs throughout the country have responded by reexamining and modifying the roles of volunteers.

The overall purpose of AIDS volunteering is far different than it once was. At first, volunteers were called on to work with the dying: to show concern and support, to help people to navigate an unresponsive and often uncaring human service system, to bear witness to their pain and suffering as they faced death

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Chicken Soup Brigade volunteer delivers groceries to client.

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and to help them to die in comfort and in dignity. Many volunteers saw their work as a privilege and commented that they "got more than they gave" from the courageous and exceptional people they met. The AIDS community started to rethink the nature of the disease in the mid-eighties as people throughout the country affirmed that they were living with AIDS, not dying. Gradually, survival time began to increase and today, volunteers work with people who live many more years after an HIV or an AIDS diagnosis. During much of this time, they can be independent and productive despite knowing that they are living in the shadow of death.

The most noticeable change has taken place in the nature of the relationship between people with HIV/AIDS and "buddies." The buddy role was created by the founders of the Gay Men's Health Crisis (GMHC) in 1982 to help people in crisis because they had a new, untreatable and stigmatized illness and would die quickly. A study done in the mid-eighties by Dr. Philip Kayal of Seton Hall University found that volunteers at GMHC thought that the buddy program was one of the agency's most important services. The companionship and practical help that buddies offered was crucial during the early years when many AIDS patients were isolated and abandoned by their families and friends. Today, the nature of the relationship is



Chicken Soup Brigade volunteers prepare meatballs in agency kitchen.

different. Many volunteer directors, like Brigid Lang of Housing Works in New York City, are rethinking the nature of the buddy relationship and reexamining the kinds of qualifications that are needed to do the job in light of the fact that people are living longer. John Sallot of AIDS Project Los Angeles (APLA) thinks that some people still have a "heroic image" of the buddy but notes, "These relationships that were based in illness and crisis now go on for several years." His agency has continually redesigned its training so that volunteers understand that the clients they work with may be relatively healthy. Staff at APLA more often are called upon to help people figure out how to sustain, change or voluntarily end a relationship that used to end much more quickly with the client's death.

Representatives of several agencies have pointed out that fewer people with AIDS are requesting buddies. Courtney Reid estimates that the Howard Brown Health Center in Chicago had 80 buddies two years ago and now has 12. In Seattle, during the first half of 1997, the number of clients receiving Chicken Soup Brigade's Home Chore service dropped from 165 to 142. Yet, at the same time, nearly one-third more clients required transportation, a service where volunteers drive clients to and from doctors' appointments.

The quality of much volunteering is also changing. Volunteers working in HIV prevention face different challenges since people might be more willing to engage in risky sexual or drug use practices if they believe that protease inhibitors will prolong their lives

or that a vaccine or another "cure" will soon be found. God's Love We Deliver in New York City has provided high quality home-delivered meals to homebound people with AIDS five days a week since 1985. At first, these meals were donated by restaurants; after 1987, they began to be prepared by volunteers in the organization's kitchen. Initially, the organization served people who were dying. Now, it is serving people who need the meals during a period of recovery from a serious illness that might be followed by a time of relative good health. Similar changes are affecting the Chicken Soup Brigade which opened a meal distribution site last July so that its clients could pick up the prepared

foods and groceries rather than waiting for a once-a-week delivery.

More and more people living with HIV or AIDS continue to work or return to work. Kathleen Reynolds is director of the Bronx Episcopal AIDS Ministry in New York City, a group that draws its volunteers from 21 parishes and services some of the most impoverished sections of the city. She says the group now provides more and more people with clothing for job interviews. The group's focus on providing "the things that will make life a little bit better" for clients more often involves helping them live with AIDS. The group is called upon to arrange fewer funerals.

Another important trend is that the demographics of the population living with HIV is changing. In 1990, 46 percent of God's Love We Deliver's clients were white and 62 percent of them were gay or bisexual men. Seven years later, 17 percent were white and 27 percent were gay or bisexual men. The changing face of AIDS, where a larger proportions of new cases are due to injecting drug use, has meant that some volunteers need to learn how to work with people whose life experiences were quite different from their own. Many more of those with AIDS have histories of substance use, homelessness, mental illness and more acute family problems than the original gay white men for whom buddy programs were originally designed.

Several volunteers I met when I did a study at Cityview, a long-term care hospital in New York City, were surprised to learn that some patients sold the Christmas gifts volunteers gave them if they felt that

they couldn't use them. When God's Love We Deliver and Momentum began to serve meals to a more varied and geographically dispersed group of clients, they recruited volunteers by forming partnerships with local organizations which provide space and volunteers who might be attracted by the chance to help their neighbors.

With the rise in the number of cases, AIDS volunteers came to represent a broad cross-section of people. While gay men continue to represent the backbone of many organizations, lesbians and heterosexual women have come to be a more and more important

source of assistance. Agencies in varied parts of the country are also attracting more volunteers from large corporations as well as college students and older people. Many AIDS volunteers also are clients. With improved health, people living with AIDS are able to volunteer on a regular basis and sometimes move into paid staff jobs. Carol Vogt of the Chicken Soup Brigade points out that people living with HIV "are the best volunteers because they take it seriously. It really matters to them. They show up on time. They treat it like a job." The role of clients is especially critical in agencies serving communities of color. Socrates Caba, the Volunteer Director at Bronx AIDS Services in New York, points out that clients derive two important benefits from their work: they are able to "give back" to the community and they can attend the agency's staff training programs. Their involvement places them in a setting where they have access to new and changing information and helps them to be informed health care consumers. Hopefully, the information they obtain can help them to enhance the quality and even the length of their lives.

Housing Works in New York City has a strong commitment to client participation. Clients serve on the agency's board, attend job interviews of prospective employees, and work in all of its departments. This high level of participation strengthens the agency's links to the community it serves. All of its clients have been homeless and many have histories of substance abuse and mental illness. Volunteer director Brigid Lang points out that clients' involvement provides the



Chicken Soup Brigade driver Tommy Martin and client.

agency with a "way to connect to the community" and gives clients the opportunity to be in a structured work situation. In this way, volunteering serves as an important prelude to entering the agency's job training program which has produced nearly one-fifth of the agency's current staff. Lang also speculates that with relatively better health, clients might broaden their interests in the future and be less concentrated in HIV organizations than they are today.

Even though the sense of urgency about the epidemic has decreased and many people with HIV are healthier, the epidemic is far from over. Lisa Carlson, of God's Love We Deliver points out that "Volunteers see they are needed." Carol Vogt notes, "The food is more important than ever." As the epidemic continues and changes course, volunteers remain an important source of labor and support for organizations throughout the country. At the same time, staff in a broad array of positions need to recognize that the roles they play will continue to change until a cure is found. Many patients are not benefiting from protease inhibitors because of their high cost, the complicated treatment regimen they require, or because they are physically unable to tolerate them.

As the early optimistic reports are followed by more sobering information on the long-term impact of these treatments, volunteers will continue to be needed to fight AIDS but in different ways than in the past. At the same time, they still will be needed to pack grocery bags, serve and deliver meals, provide support, educate the living and comfort the dying. ■