

PATIENT NOTES

Speaking Out: A Message from a Black Woman AIDS Activist

Janice Jirau, Vice President, Board of Directors, LifeLink, Inc., PWA Coalition of Washington, DC.

Editor's Note:

When Janice Jirau's husband was hospitalized with a stroke in November 1988, he was also diagnosed with AIDS. He died of AIDS-related complications in May 1989. From Janice's own life experience and her contact with those whose lives are now being impacted by HIV infection, she has come to realize that there are many people living in crisis due to poverty, isolation, lack of self-esteem, and lack of reliable support systems. She is now dedicated to working for "more than short-term solutions" to the issues of AIDS, drug abuse, and poverty. She is working to "change the systems which created and perpetuated them". She was a featured guest on the AIDS Satellite Television Network's March 14 telecast on Women and HIV Infection. As she waited for her segment in the studio that day, she expressed her concerns on the effects of HIV in the black community — concerns which, she pointed out, hold true for any disenfranchised community in our nation.

I am concerned about rejection, because I see people dying for lack of spirit due to that rejection. The black community is in a crisis due to the stigma (or homophobia) that is attached to AIDS and HIV infection. AIDS is associated with immorality, and black religious leaders have not taken a stand to educate the community that it's O.K. to love people with AIDS. The stigma has caused families to 'throw away' PWAs (persons with AIDS). Not having a support system — human touch, or a connection to their families — alot of PWAs are giving up,

and alot of them are dying. I know of families who cannot share their feelings about losing a loved one to AIDS, who do not feel comfortable sharing with their minister that they have sons and daughters affected by this disease, and that they, as a family, need support from the community. We are not getting the message of compassion.

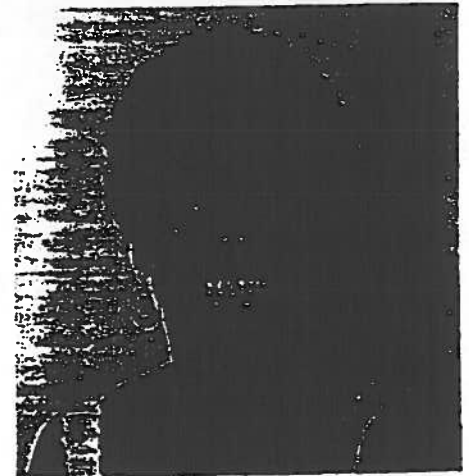
We are also not getting the message of empowerment. There have been attempts to address the issues of the black community in this crisis from a distance. Because of that distance and language barriers there have been communication problems. Many poor people are not hearing about the high-powered conferences that educate on AIDS and empowerment. The few grass-roots organizations are scrambling to compete in a massive effort to get their share of funding for community projects — funding which is greatly controlled by other ethnic groups.

There needs to be a recommitment to help black grass-roots organizations achieve their goals of education and empowerment, and these organizations need a specific approach to reaching their community. We have limited our efforts in going into the community thus far. I am concerned about the people who don't come to community groups, who don't come to workshops, who don't have any idea of what's going on in education about this disease. We need to find innovative ways of tapping into resources to get to the people we can help. Perhaps a specially produced TV documentary with call-in lines could identify the communities in need, and

get an accurate account of the types of needs they have. Counseling and service organizations could be available and ready to assist them.

The black community needs to hear from blacks who have been where they are, and who can understand the life and obstacles (social, economic) that are very real and unique to their community. They need to hear from people who are sensitive to their experience, not from people coming in from outside trying to dictate. Black people need to empower other black people.

When I speak to community groups I come out of my own experience. I've been through welfare lines. I've been through spousal abuse. I've been through child abuse. I've been through all of that. As I share, I see tears in the eyes of people who did not think another human being shared their experience. I give them hope. I let them know I care, and that there are other people out there who care and want to help.



Janice Jirau