Race, AIDS & ECONOMICS

By Shirley L. Smith

As the number of minorities infected with AIDS continues to increase at an alarming rate, there is a growing concern over the funding disparities that have existed since the epidemic was first noted in 1981.

Funding disparities can be found on every level -- from AIDS prevention and education to services, minority AIDS workers and physicians say. But nowhere is the disparity more evident than in the area of research.

There are very few minorities involved in research, particularly in the area of clinical trials. In 1993, clinical trials in humans cost at least $170 million, or 38 percent of the National Institute of Allergy and Infectious Diseases’ (NIAID) $459 million research budget.

NIAID, the lead governmental agency for AIDS research, has three extranational programs that use trials to test new drugs and evaluate experimental therapies for AIDS and AIDS-related opportunistic infections and cancer. The largest of these trials are conducted under the AIDS Clinical Trials Group, a national network of AIDS Clinical Trial Units (ACTUs) established at major academic institutions.

African-Americans have historically been underrepresented in such trials, both as active participants and as leaders in research. Of the 5,250 ACTUs, only four are at minority institutions: Howard University, Meharry Medical College, University of Puerto Rico and the University of Hawaii.

Minorities were also poorly represented in early studies of AZT, DDI and DDC – the only licensed drugs used to fight HIV infection from 1987 to 1992. Another AIDS drug, D4T, was approved by the Food and Drug Administration in June. But, as with its predecessors, the test trial (privately sponsored by Bristol-Myers Squibb) that led to D4T’s approval included few minorities.

Although the government admits there have been some clear disparities in minority participation in clinical research, officials at NIAID say progress is being made. “We are by no means where we would like to be,” says Dr. George W. Counts, who heads up the agency’s Clinical Research Management Branch for five years. But, he says, NIAID is making more of an effort to reach out to minorities.

Of the 14,499 people who participated in clinical trials for new AIDS drugs in 1993, African-Americans and Hispanics accounted for 42 percent of the patients. This is a marked improvement from 1987, when the trials began with only 18.7 percent minority participants, 7.4 percent of whom were African-Americans.

Dr. Counts believes the relative lack of minority participation in the ‘80s reflected the demographics of AIDS at the time. “In 1985, 86 and 87, we were falling off the legacy that this was a gay disease.” Hence, the trials consisted mostly of gay white men.

But some AIDS treatment advocates and physicians contend that there were reports early in the epidemic that AIDS was spreading in black populations, but the government did not respond to those reports.

“AIDS was misidentified early in the epidemic as somehow related to homosexuality, and funding decisions were made to funnel all the money in that direction,” says Dr. Abdul Alim Muhammad, director of the Abundant Life Clinic in Washington, D.C.

As a result, he points out, minorities were not included in critical studies and very little money was pumped into our communities for prevention and AIDS-related services.

If minorities had been informed of their risks from the beginning, we would have been able to mobilize and organize early in the epidemic like the white gay community, says Alonzo Fair, president of D.C.’s United Response to Black America’s Needs (URBAN), a research and technical assistance firm that focuses on health care and social issues affecting people in the inner city.

The global demographics of AIDS was never characterized by homosexuality, Dr. Muhammad asserts. “The whole public health policy surrounding AIDS has been flawed from the beginning. It’s a very clear pattern of racial discrimination that has existed.”

As early as 1983, African-Americans and Hispanics were reported as making up 40 percent of the AIDS cases, according to data compiled by the Centers for Disease Control and Prevention in Atlanta. The majority of these were homosexual and bisexual men.

Current CDC statistics reveal that homosexual contact is still the main mode of transmission for HIV infection in the United States, but the highest rate of increase in AIDS cases reported in 1993 was among heterosexuals. In this group, African-American and Hispanic numbers represented 55 percent of the men infected and 50 percent of the women.

African-Americans and Hispanics are also disproportionately represented in the total number of U.S. AIDS cases. Of the 339,250 cases reported to the CDC as of October, 1993, African-Americans accounted for 31 percent, even though we make up only 12 percent of the population. The numbers for Hispanics are just as alarming. People of Hispanic origin make up about 9 percent of the population, yet they account for almost 17 percent of reported cases.

One of the major obstacles health officials say they encounter when trying to treat minorities infected with HIV or recruit minorities into clinical trials is the deep-rooted mistrust of medical research and the government. “We have a long history that has to be overcome,” Dr. Counts says.

“The legacy of the Tuskegee experiment is still present, and people view research with a jaundiced eye,” says Dr. Wayne Greaves, referring to the Tuskegee Syphilis Experiment, a government study conducted from 1932 to 1972 in which hundreds of rural black men with syphilis were monitored -- but never treated.

Dr. Greaves, who runs the AIDS Clinical Trial Unit at Howard University, is the only black person leading an ACTU study. Even though Howard is a black institution, it has experienced difficulties recruiting minorities because of the legacy of the Tuskegee study, he says.

Another big obstacle that hinders recruitment efforts is eco-

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nomics. The majority of the university’s trial patients are African-Americans who fall in the low-income bracket, he says.

“People here live in rat-infested environments and they can’t pay rent and we’re talking about getting involved in clinical tri-

als,” Dr. Greaves says.

AIDS is often one of many problems facing African-Americans who live in urban areas. “In addition to being in a medical facility, we find ourselves in a social-service capacity,” says Viktoria Trimmer, research coordinator of the ACTU at Howard. “Our patients don’t have any money. We find ourselves trying to access money to pay for rent, buy groceries.”

The desperate need for health care in these communities has forced Howard and other minority institutions to put their empha-

sis over the years on care rather than research, Dr. Greaves says. Because the commitment was not there for research, the facili-

ties don’t exist and the schools did not attract minority researchers. Consequently, minority institutions often don’t have the infra-
structure they need to compete for federal dollars to do research.

Things have got to change, Dr. Greaves says. “All the things we know about black folks, about this disease, have been written by white researchers and white institutions. It’s time that we now move to the next rung of the ladder. Because the disease affects us a lot, we need to be players and policymakers in the field.”

Prior to the enrollment of the four minority schools into the ACTU program in 1993, white establishments monopolized all the research funds.

“Not one of the black schools, with the exception of Howard, has the resources to carry out a program独立ely,” explains Dr. Rudolph Jackson, a professor at Morehouse School of Medicine and director of the Association of Minority Health Professionals Schools AIDS Research Consortium.

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In 1990, over a year after he was diagnosed with having HIV, the virus that causes AIDS, Gregory Hutchings enrolled himself into a clinical trial.

"The way the propranolol is with AIDS, you are going to die," the 38-year-old says, "I can imagine something that could possibly prolong my life or someone else's, it empowers me."

Unfortunately, Hutchings' perspective is somewhat unique. A lot of African-Americans stay away from clinical trials for fear that the past will repeat itself.

People have vivid memories of the infamous 40-year Tukey Sphagnum Experiment, which used hundreds of poor black men in Alabama as guinea pigs for a government study on syphilis. The researchers studied the men, many of whom were illiterate, to monitor the long-term effects of the venereal disease. Hutchings says, "I don’t know why, but I was appointed as an effective treatment during the course of the study, the men were denied treatment."

The experiment ended in 1972 in a wave of controversy, but it is still talked about, and stories — some of them distasteful — are passed on from generation to generation. Education and health officials say when it comes to AIDS, they have to continuously deal with the Tukey question. It has become a major obstacle not only in recruiting minorities for studies but in getting them to take much-needed drugs to treat the disease. It has also given credence to the belief by some African-Americans that HIV was developed by white scientists as part of a government plan.

As the number of AIDS cases within minority communities continues to increase at a disproportionate rate, minority participation in clinical trials is crucial, says Dr. Wayne Greaves, a professor at Howard University and the only African-American running an AIDS Clinical Trial Unit (ACTU). Clinical trials are necessary for the development of new drugs and therapies to fight HIV infection and the opportunistic diseases that accompany the disease. It also is the first step in developing prevention vaccines.

Although the number of minorities involved in clinical trials has improved to better reflect the demographics of the disease, much of the new data has not been analyzed yet, says Victoria Trimmer, research coordinator of the ACTU at Howard University.

There is no evidence of biological differences between the races that makes it necessary to include different ethnic groups in trials, but previous studies have shown that certain drugs used to treat other ailments have not worked as well for black people as they have for whites.

For example, Trimmer says, "The drug enalapril, an anti-hypertensive [used to lower high blood pressure], was studied for years in white males, and they found that the drug was not as effective in blacks." The inclusion of minorities in studies is necessary to detect such differences, she says.

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