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ABSTRACT

The Tuskegee study of untreated syphilis in the Negro male is the longest nontherapeutic experiment on human beings in medical history. The strategies used to recruit and retain participants were quite similar to those being advocated for HIV/AIDS prevention programs today. Almost 60 years after the study began, there remains a trail of distrust and suspicion that hampers HIV education efforts in Black communities.

The AIDS epidemic has exposed the Tuskegee study as a historical marker for the legitimate discontent of Blacks with the public health system. The belief that AIDS is a form of genocide is rooted in a social context in which Black Americans, faced with persistent inequality, believe in conspiracy theories about Whites against Blacks. These theories range from the belief that the government promotes drug abuse in Black communities to the belief that HIV is a manmade weapon of racial warfare.

An open and honest discussion of the Tuskegee Syphilis Study can facilitate the process of rebuilding trust between the Black community and public health authorities. This dialogue can contribute to the development of HIV education programs that are scientifically sound, culturally sensitive, and ethnically acceptable. (Am J Public Health, 1991;81:1498– 1504)

Public Health Then and Now

The Tuskegee Syphilis Study, 1932 to 1972: Implications for HIV Education and AIDS Risk Education Programs in the Black Community

Stephen B. Thomas, PhD, and Sandra Crouse Quinn, MEd

Background

AIDS Among Black Americans

Since acquired immunodeficiency syndrome (AIDS) was first recognized and reported in 1981, more than 179 000 persons with AIDS have been reported to the Centers for Disease Control (CDC). Of these, more than 63% have died. Infection with the human immunodeficiency virus (HIV) has emerged as a leading cause of death among men and women under 45 years of age and children 1 to 5 years of age.¹

By May 1991, there were 179 136 cases of AIDS reported in the United States. Of the reported cases, 97 329 (54%) were White and 51 190 (29%) were Black. Thus, although Whites still constitute a majority of the AIDS cases, Blacks are contracting AIDS in numbers far greater than their relative percentage in the population (Blacks constitute 12% of the US population). In addition, 52% of all children (under age 13 at time of diagnosis) and 52% of all women with AIDS are Black.¹ The best data available demonstrate that in the United States, HIV infection is spreading more rapidly among Blacks than among other population groups.

Because of the disproportionate impact of AIDS among Blacks, special emphasis must be placed on reaching this population with effective HIV education and AIDS risk reduction programs. To plan and evaluate these programs effectively, it is crucial to have an understanding of the behavioral risk factors and AIDS knowledge deficiencies in the Black community.

Public health professionals must recognize that the history of slavery and racism in the United States has contributed to the present social environment, in which those Blacks, whose behavior places them at greater risk for HIV infection, are also among the most disadvantaged members of our society. As we enter the last decade of the 20th century, the promises of opportunity and equality envisioned by the civil rights movement have failed to be realized for the vast majority of American Blacks. Blacks' consequent anger and despair in the face of persistent inequality have contributed to the development of conspiracy theories about Whites (the government) against Blacks. These conspiracy theories range from the belief that the government promotes drug abuse in Black communities to the belief that HIV is a manmade weapon of racial warfare.

For example, The Nation of Islam has disseminated literature that describes AIDS as a form of genocide, an attempt by White society to eliminate the Negro race.² The mainstream Black media have also contributed to the discussion. "Tony

Requests for reprints should be sent to Stephen B. Thomas, PhD, Department of Health Education. Minority Health Research Laboratory, University of Maryland, College Park, MD 20742.

Editor's Note. Elizabeth Fee, PhD, and Robert K. Korstad. PhD, are coeditors of the journal's Public Health Then and Now department. Contributions for this department should be addressed to Dr. Fee as follows: Elizabeth Fee, PhD, The Johns Hopkins University, School of Hygiene and Public Health, 624 North Broadway, Baltimore, MD 21205.

Editor's Note. See related editorial by Des Jarlais and Stepherson on page 1393.

Stephen B. Thomas and Sandra Crouse Quinn are with the Minority Health Research Laboratory, Department of Health Education, University of Maryland.

Brown's Journal," a popular Public Broadcast System television show, aired a series of programs debating the issue of AIDS as a form of genocide. The Los Angeles Sentinel, the largest Black newspaper on the West Coast, ran a series of stories beginning March 9, 1989, suggesting that Blacks had been intentionally infected with HIV. Essence also ran a story titled "AIDS: Is It Genocide?"3 In that article, Barbara J. Justice, MD, a New York City physician, asserted that "there is a possibility that the virus was produced to limit the number of African people and people of color in the world who are no longer needed" (p. 78). James Small, PhD, a Black studies instructor at City College of New York, was quoted as saying:

Our whole relationship to Whites has been that of their practicing genocidal conspiratorial behavior on us from the whole slave encounter up to the Tuskegee Study. People make it sound nice by saying the Tuskegee "Study." But do you know how many thousands and thousands of our people died of syphilis because of that?³

The history of the Tuskegee Syphilis Study, with its failure to educate the participants and treat them adequately, helped to lay the foundation for Blacks' pervasive sense of distrust of public health authorities today. Fears about genocide have been reported by public health professionals and community-basedorganization staff who work in Black communities. During his 1990 testimony before the National Commission on AIDS, Mark Smith, MD, from the School of Medicine at Johns Hopkins University in Baltimore, described the African American community as "already alienated from the health care system and the government and . . . somewhat cynical about the motives of those who arrive in their communities to help them" (p. 19).4 Smith said that the Tuskegee Syphilis Study "provides validation for common suspicions about the ethical even-handedness in the medical research establishment and in the federal government, in particular, when it comes to Black people" (p. 20).4

Harlon Dalton, associate professor of law at Yale University and member of the National Commission on AIDS, eloquently describes the social basis for genocidal theories in his much quoted essay, "AIDS in Blackface."⁵ Dalton believes that the Tuskegee Syphilis Study is a reflection of society's historical disregard for the lives of Black people. He accepts the commonly repeated distortion that "the government purposefully exposed Black men to syphilis so as to study the natural course of the disease."⁵

The continuing legacy of the Tuskegee Syphilis Study has contributed to Blacks' belief that genocide is possible and that public health authorities cannot be trusted. These fears and attitudes must be assessed in order to develop AIDS education programs for the Black community. For example, the Southern Christian Leadership Conference (SCLC), a leading civil rights organization founded by Dr Martin Luther King, Jr, received funding from the CDC to provide HIV education through a national program titled RACE (Reducing AIDS through Community Education). In 1990, the SCLC conducted a survey to determine HIV education needs among 1056 Black church members in five cities (Atlanta, Ga; Charlotte, NC; Detroit, Mich; Kansas City, Mo; and Tuscaloosa, Ala). While 35% of the respondents believed that AIDS is a form of genocide, another 30% were unsure. Additionally, 44% believed that the government is not telling the truth about AIDS, while 35% were unsure. Furthermore, 34% believed that AIDS is a manmade virus, while 44% were unsure.20

The results of the SCLC survey strongly suggest that Blacks' belief in AIDS as a form of genocide and their mistrust of the government should be cause for serious concern among public health officials. Within this context, the health professionals responsible for HIV education must be made aware of the history of the Tuskegee Syphilis Study and its implications for HIV education and AIDS risk reduction programs in Black communities. Unfortunately, the details of the Tuskegee study are not well known. Therefore, we utilize the work of historian James Jones, who provides the most comprehensive description of the Tuskegee study in his book, Bad Blood: The Tuskegee Syphilis Experiment—a Tragedy of Race and Medicine.6

Factors Leading to the Tuskegee Syphilis Study

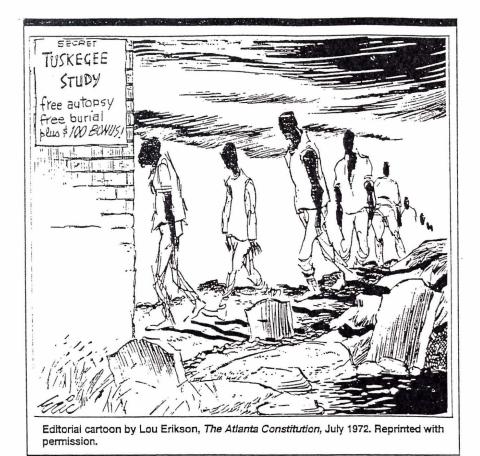
The Julius Rosenwald Fund, a philanthropic organization in Chicago, Ill, was dedicated to the promotion of the health, education, and welfare of Black Americans. In 1928, the fund's director of medical service approached the United States Public Health Service (PHS) in an effort to expand activities to improve the health status of Blacks in the rural South. At that time the PHS had successfully completed a study of the prevalence of syphilis in over 2000 Blacks employed by the Delta Pine and Land Company in Mississippi. Twenty-five percent of the sample had tested positive for syphilis. The PHS collaborated with the Rosenwald Fund to provide treatment to these people. It was the success of this collaboration that led the PHS to submit a proposal to the Rosenwald Fund for expansion of syphilis control demonstration programs into five counties in the rural South. The Rosenwald Fund approved the proposal with the condition that a Black public health nurse be employed on the project.^{6,7}

From 1929 to 1931, the Rosenwald Fund sponsored syphilis control demonstration projects in Albemarle County, Virginia; Glynn County, Georgia; Pitt County, North Carolina; Macon County, Alabama; and Tipton County, Tennessee. The primary goal was to demonstrate that rural Blacks could be tested and treated for syphilis. During the testing phase of the study, it was found that in Macon County, Alabama, 35% to 40% of all age groups tested were positive for syphilis.^{6,7} Before the treatment phase of the project could begin, two things happened that led to the Tuskegee Syphilis Study.

First, there was much speculation in the scientific literature on racial differences in the natural history of syphilis. Although some theories suggested that syphilis affected the neurological functioning of whites, there was speculation that latent syphilis had an impact on the cardiovascular systems of Blacks. However, Dr Bruusgaard in Oslo, Norway, conducted a retrospective study of white men with untreated syphilis which found that cardiovascular damage was common and neurological involvement was rare. This finding, published in 1929, was contrary to the prevailing scientific view in the United States.6

Second, the start of the Depression in 1929 devastated the Rosenwald Fund's financial resources, which were needed for the treatment component of the demonstration project. Without financial support from the Rosenwald Fund, the PHS simply did not have the resources to develop treatment programs in all five counties. It was thought that the best chance of salvaging anything of value from the project lay in the conduct of a scientific experiment.

Conflict between findings from the Oslo study and the prevailing scientific view in the U.S. on racial differences led Taliaferro Clark, M.D., of the PHS, to propose that a major improvement on pre-



vious syphilis research could be obtained by conducting a prospective study of living patients. Consequently, in 1932, Dr Clark stated that "the Alabama community offered an unparalleled opportunity for the study of the effect of untreated syphilis" (p. 94).⁶

The original study population consisted of 399 Black men with syphilis and 201 controls. The study was intended to last for 6 to 9 months. However, as Jones demonstrates, the drive to satisfy scientific curiosity resulted in a 40-year experiment that followed these men to "end point" (autopsy). Jones eloquently describes the irony of the Tuskegee Syphilis Study:

[The] study would be an expression of concern for Negro health problems, keeping the PHS involved as a vital force in promoting medical attention to Blacks. The more damaging the disease was shown to be, the more pressure would build on Southern legislators to fund treatment programs. The study would also permit the PHS to maintain the momentum of public health work in Alabama by continuing the close working relationships with state and local health officials, not to mention Black leaders at the Tuskegee Institute (p. 94).⁶

The Tuskegee Syphilis Study

Strategies Used to Recruit and Track Participants

The 40-year continuation of the Tuskegee Syphilis Study can be attributed to extensive collaboration among government agencies, along with an unprecedented community-based approach that demonstrated a degree of cultural sensitivity toward the poor Black target population in Macon County. The strategies used to recruit and retain participants in the study were quite similar to those being advocated for HIV education and AIDS risk reduction programs today. In addition to the PHS, which served as the lead agency, there was an impressive group of cooperating agencies from state and local levels:

- Macon County Medical Society
- Tuskegee Institute
- Alabama State and Macon County Boards of Health
- · The Milbank Memorial Fund
- local Black churches and public schools
- · local plantation owners

During the early phase of the project, the PHS decided to ask Tuskegee Institute to participate in the study. It was felt that because Tuskegee Institute had a history of service to Blacks in Macon County, its participation would not threaten white physicians in the county. Furthermore, the PHS felt that the use of Black physicians was necessary to facilitate the cooperation of subjects.⁶ Tuskegee Institute benefited from this collaboration by receiving funds, training opportunities for interns, and employment for its nurses. Jones describes the complex political maneuvers involved in setting up the study:

[By persuading the Tuskegee Institute physicians to cooperate], the old syphilis control demonstration team of [PHS] clinicians would be reunited and the study would have the appearance of a revival of syphilis control work. The true purpose of the experiment would be totally obscured, leaving investigators free to trade upon the goodwill and trust that the Rosenwald Fund's syphilis control demonstration had generated among the Black people of the county and their white employers. Dr. Clark was not the least bit embarrassed by the deceit. (p. 100)⁶

The study included culturally sensitive grassroots approaches to ensure the involvement and continued participation of the men. The study employed Eunice Rivers, a Black public health nurse from Macon County, throughout the entire 40 years. As the primary contact person, she provided transportation, organized the men for examinations by the visiting PHS physicians, provided reassurance, and formed trusting relationships with the men and their families.⁸

The PHS was extremely successful in enlisting Black church leaders, elders in the community, and plantation owners to encourage participation. The plantation owners had an economic incentive to maintain the health of their employees. Often they would give permission for medical examinations while workers toiled in the fields.7 In addition, physical examinations, including the taking of blood samples, were conducted in Black churches and schools. Jones describes the process through which subjects were recruited: "First the health officials won over local leaders. Then, they used schoolhouses and churches as makeshift clinics, with local schoolteachers and ministers serving as 'advance people' who spread the word about where and when the 'government doctors' would be in the area" (p. 69).6

In addition, the fact that Whites ruled Blacks in Macon County, coupled with the Black men's extreme poverty and almost total lack of access to health care, made the men willing subjects. As Dr Frost, a Black physician from the Rosenwald Fund, stated, "as a group, they were susceptible to kindness."⁶

Lack of medical care in Macon County meant that many of the study participants had never been treated by a physician. The PHS physicians, believing that their patients would not understand clinical terms, did not even attempt to educate them about syphilis. Participants were not informed that they suffered from a specific, definable disease that was contagious and transmitted through sexual intercourse. Nor were they told that the disease could be transmitted from mother to fetus. The PHS clinicians translated medical terms into local language. Syphilis became "bad blood," a phrase that Black people of the rural South used to describe a variety of ailments.9 Consequently, when the PHS physicians announced that they had come to test for "bad blood," people turned out in droves. The PHS also used incentives including free physical examinations, food, and transportation.8 Burial stipends, provided by the Milbank Memorial Fund, were used to gain permission from family members for autopsies to be performed on study participants who reached "end point."6

From the historical and social perspective of the rural South in the early 1930s, the PHS strategies represented a high degree of understanding about the cultural milieu in which the study was being conducted. There is no doubt the approach was a sophisticated demonstration of cultural sensitivity coupled with political savvy and an impressive commitment by collaborating agencies. However, the tragedy was that a project originally intended to meet real health needs ended in a mere attempt to salvage scientific data.

How Did It Go on for so Long?

The Tuskegee study of untreated syphilis in the Negro male is the longest nontherapeutic experiment on human beings in medical history.⁶ Numerous factors contributed to the continuation of this experiment over a period of 40 years. However, almost from the outset, its scientific merit was questionable.

The Alabama state health officer and the Macon County Board of Health extracted a promise from the PHS that all who were tested and found to be positive for syphilis, including those selected for the study, would receive treatment. It was understood by all, except the subjects, that the treatment given was less than the amount recommended by the PHS to cure syphilis. By the late 1930s some physicians began to raise concerns regarding the scientific merit of a study about untreated syphilis when it was clear that some subjects had received some form of treatment. In 1938, removal of these men from the experiment was briefly considered, but it was decided that in the interest of maintaining esprit de corps among the participants and in order to avoid suspicion, those men who had received minimal treatment would remain in the experimental group.⁶

The ultimate tragedy of the Tuskegee experiment was exemplified by the extraordinary measures taken to ensure that subjects in the experimental group did not receive effective treatment. During World War II, approximately 50 of the syphilitic cases received letters from the local draft board ordering them to take treatment. At the request of the PHS, the draft board agreed to exclude the men in the study from its list of draftees needing treatment.⁶ According to Jones,

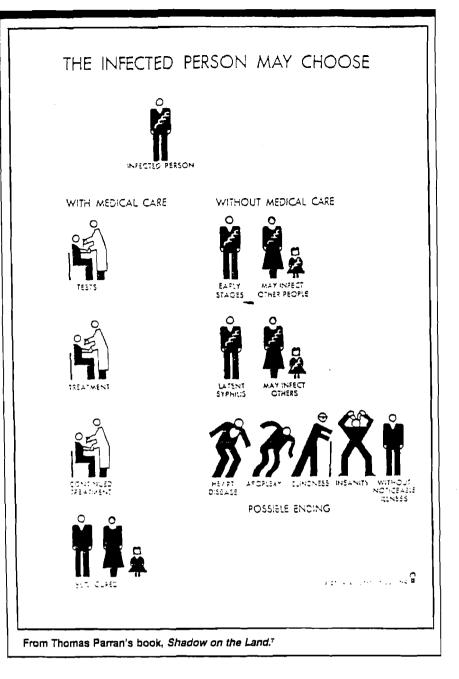
[Preventing] the men from receiving treatment had always been a violation of Alabama's public health starutes requiring public reporting and prompt treatment of venereal diseases . . . Under the auspices of the law health officials conducted the largest state-level testing and treatment program in the history of the nation [but] state and local health officials continued to cooperate with the study (p. 178).⁶

In 1943, the PHS began to administer penicillin to syphilitic patients in selected treatment clinics across the nation. The men of the Tuskegee Syphilis Study were excluded from this treatment for the same reason other drugs had been withheld since the beginning of the study in 1932 treatment would end the study. Once penicillin became the standard of treatment for syphilis in 1951, the PHS insisted that it was all the more urgent for the Tuskegee study to continue because "it made the experiment a never-again-to-be-repeated opportunity (p. 179).⁶

In 1952, in an effort to reach subjects who had moved out of Macon County, the PHS utilized its entire national network of state and local health departments for the first time in its history in order to bring subjects in for examination. Over the next 20 years, state and local health departments cooperated in keeping the men in the study, yet denying treatment. According to Jones, the ultimate reason why the Tuskegee Syphilis Study went on for 40 years was a minimal sense of personal responsibility and ethical concern among the small group of men within the PHS who controlled the study. This attitude was reflected in a 1976 interview conducted by Jones with Dr John Heller, Director of Venereal Diseases at the PHS from 1943 to 1948, who stated, "The men's status did not warrant ethical debate. They were subjects, not patients; clinical material, not sick people" (p. 179).⁶

Jones details the following chronology of events leading to the end of the Tuskegee Syphilis Study:

- November 1966. Peter Buxtun, a venereal disease interviewer and investigator with the PHS in San Francisco, sent a letter to Dr William Brown, Director of the Division of Venereal Diseases, to express his moral concerns about the experiment. He inquired whether any of the men had been treated properly and whether any had been told the nature of the study.
- November 1968. Buxtun wrote Dr Brown a second letter, in which he described the current racial unrest prevalent in the nation. Buxtun made the point that "the racial composition of the study group [100% Negro] supported the thinking of Negro militants that Negroes have long been used for medical experiments and teaching cases in the emergency wards of county hospitals. . ." (p. 193).6 Dr Brown showed this letter to the Director of the Centers for Disease Control. For the first time, health officials saw the experiment as a public relations problem that could have severe political repercussions.
- February 1969. The CDC convened a blue-ribbon panel to discuss the Tuskegee study. The group reviewed all aspects of the experiment and decided against treating the men. This decision ended debate on the Tuskegee study's future: It would continue until "end point." The committee also recommended that a major thrust be made to upgrade the study scientifically.
- In the final analysis, it was Peter Buxtun who stopped the Tuskegee Syphilis Study by telling his story to a reporter with the Associated Press. On July 25, 1972, the Washington Star ran a front-page story



about the experiment. It is important to note that the PHS was still conducting the experiment on the day when the story broke.

The story was picked up off the wire service and became front-page news and the subject of editorials in major newspapers across the nation. It did not take long for officials in the Department of Health, Education, and Welfare (HEW) and the PHS to form a chorus of denunciation in concert with the public outcry condemning the study. Little effort was made directly to defend or justify the experiment. For example, Dr Donald Printz, an official in the Venereal Disease Branch of the CDC, publicly stated that the experiment was "aimost like genocide ... a literal death sentence was passed on some of those people" (p. 207).⁶

Implications for HIV/AIDS Risk Reduction Programs in the Black Community

The historic 1972 disclosure of the Tuskegee study in the national press led to congressional subcommittee hearings held in February and March of 1973 by Senator Edward Kennedy. The result was a complete revamping of HEW regulations on protection of human subjects in experimentation. On July 23, 1973 a \$1.8 billion class-action law suit was filed in the U.S. District Court for the Middle District of Alabama on behalf of the men in the study. In December 1974, the government agreed to pay \$10 million in an out-ofcourt settlement. Jones provides a detailed description of the law suit consequences.⁶

There has been relatively little discussion of the Tuskegee Experiment within the public health professional literature since the historic 1972 disclosure of the study in the national press. For example, Cutler and Arnold's 1988 article titled "Venereal Disease Control by Health Departments in the Past: Lessons for the Present"¹⁰ failed to make any mention of the Tuskegee study yet called upon readers of this journal to honor Surgeon General Parran who at one point directed the study. Silver described this omission as evidence of the continued inability to confront our racist past. Silver went on to state that

... the behavior of the PHS officers was no more than representative of the sentiments and prejudices of the times. But not to remember is to forget, and to forget is a disservice to those who suffered the indignities. .. [In] calling upon us to honor [Parran], one of the participants, we should also mention the context in which the meritorious service was earned.¹¹

Both Brandt¹² and Fee¹³ emphasize the importance of history in the cultural meaning of disease. Therefore, as the pattern of HIV infection shifts and increasing numbers of Blacks are affected, it will be crucial to understand the historical context in which Black Americans will interpret the disease. The failure of public health professionals to comprehensively discuss the Tuskegee experiment contributes to its use as a source of misinformation and helps to maintain a barrier between the Black community and health care service providers. In presentations at public health professional meetings and interactions with Black communitybased-organization staff members, the authors have consistently observed how the Tuskegee Study is used to undermine trust and justify AIDS conspiracy theories. Although there is no evidence to support Dalton's assertion that the men were intentionally infected with syphilis,5 this distortion continues to be disseminated through community discussions and the popular media. There is no need to misrepresent the facts of the study to recognize how it contributes to fears of genocide. Given that the conduct of the study demonstrated little regard for the lives of the men who participated, it is no surprise that Blacks today do not readily dismiss assertions that HIV is a manmade virus intentionally allowed to run rampant in their communities.

Now, almost 60 years after the experiment began, the Tuskegee Syphilis Study's legacy is a trail of distrust and suspicion that hampers HIV education efforts in Black communities. During testimony delivered before the National Commission on AIDS in December 1990, Alpha Thomas, a health educator with the Dallas Urban League, stated: "So many African American people that I work with do not trust hospitals or any of the other community health care service providers because of that Tuskegee Experiment. It is like . . . if they did it then they will do it again" (p. 43).⁴

Public health professionals must recognize that Blacks' belief in AIDS as a form of genocide is a legitimate attitudinal barrier rooted in the history of the Tuskegee Syphilis Study. Many public health authorities who work with Black communities are uncomfortable responding to the issue of genocide and the Tuskegee study. The common response is to ignore these issues. This approach may result in a loss of believability and further alienation. One culturally sensitive response would be for public health professionals to discuss the fear of genocide evoked by the AIDS epidemic. They must be willing to listen respectfully to community fears, share the facts of the Tuskegee study when it arises as a justification of those fears, and admit to the limitations of science when they do not have all the answers. This approach may help public health authorities to regain the credibility and the public trust they need to successfully implement HIV risk reduction strategies in the Black community.

The necessary public health science technology and experience exist for the development and implementation of effective community-based HIV education programs that are ethnically acceptable and culturally sensitive. Strategies such as (1) the use of program staff indigenous to the community, (2) the use of incentives, and (3) the delivery of health services within the target community were used to recruit participants in the Tuskegee Syphilis Study. These techniques are being implemented by AIDS risk reduction programs today. The value of these community-based strategies should not be diminished by their association with the Tuskegee study. The impact of HIV infection and AIDS in Black communities is exacerbated by the presence of other



Unidentified subject and nurse Rivers in cotton field. (Source: Centers for Disease Control, Atlanta, Ga.)

sources of poor health status and social inequities. Therefore, AIDS risk reduction programs must be built on solid assessments of community perceptions and needs, and must include ongoing involvement of community members in program planning and evaluation efforts.¹⁴

Successful HIV education and AIDS risk reduction will require a long-term commitment from and collaboration among federal agencies, state and local health departments, community-based organizations, private industry, philanthropies, and institutions of higher learning. Such collaboration must be based on trust between the agencies and the Black community. Given the legacy of Tuskegee, the credibility of public health service providers from outside the Black community is severely limited. Consequently, CDC's program to provide direct funding to Black community-based organizations (CBOs) to deliver HIV education represents a significant development in the effort to overcome distrust. However, while CBOs may have ready access to a community and may have established credibility with the target population, they often lack the infrastructure necessary for long-term success.14 Consequently, CBOs will require consistent technical assistance and long-range funding from government and private agencies. To ensure that the specter of Tuskegee will not impede progress, it is crucial that decision-making power be distributed in such a manner that collaborating agencies allow CBOs to maintain control over program integrity.

Distrust of and resistance to involvement with public health programs have a legitimate basis in history; to overcome these feelings will require cultural sensitivity. In testimony before the National Commission on AIDS, Dr Smith stated:

[The Black] communities' perspective on medical research has a historical basis which sometimes outweighs the demonstrable integrity and commitment of individual investigators. . . In light of the historical basis of the suspicion of being guinea pigs, it is particularly ironic to hear the cries for more access to experimental medicines. [This resistance] will only be overcome, frankly, with a more long-range effort to reassure African Americans that they will not be the victims of more Tuskegees.⁴ (p. 31)

Public health professionals must support Blacks' increased access to clinical trials so that the AIDS knowledge base can be expanded and the benefits of potential treatments can be realized. The successful inclusion of Blacks in clinical trials will require researchers to conduct their investigations in convenient settings trusted by the Black community. In addition, investigators must recognize that simple compliance with protection of human subjects procedures is not sufficient. The researchers who conducted the Tuskegee study made a conscious decision to withhold information about syphilis from participants. Consequently, Blacks today may not believe that they are being told the whole truth about HIV. To overcome the distrust of community members, researchers must see that they are fully informed about research procedures, costs, and benefits, and that they have representation on research advisory committees. Investigators should conduct their work with an attitude of respect for the humanity of study participants, regardless of the social and cultural gulf that may exist between investigators and subjects. Ultimately, cultural sensitivity can best be manifested through the professional obligation to advocate AIDS policies that provide for the protection of civil rights and access to health care services.¹⁵

It must be acknowledged that public health research and practice operate in an environment influenced by societal values and political ideology. For example, needle distribution programs for intravenous drug users, along with HTV testing policies and counseling of HIV-infected women, are frequently the subject of political debate. Efforts to develop needle distribution programs have been stymied by political controversy, moral questions, and outraged claims that such programs have a genocidal impact on Black communities. In many communities where drug abuse is epidemic, needle distribution programs are perceived as contributing to the drug problem, particularly when such programs are promulgated in the absence of access to adequate drug treatment services. The image of Black intravenous drug users reaching out for treatment, only to receive clean needles from public health authorities, provides additional fuel for the genocide theory. The emphasis on HIV testing and counseling without adequate access to clinical trials and appropriate therapy for AIDS evokes memories of the deliberate withholding of treatment by the researchers in the Tuskegee study. Public health professionals must ensure that HIV testing and counseling are accompanied by specific informed consent, full discussion of treatment options, and appropriate referrals for primary care and clinical trials.

The reproductive rights of HIV-infected women cannot be separated from societal values, political ideology, moral issues, and concern over access to primary health care. In an effort to prevent perinatal transmission, the CDC and state health departments advocate HIV testing programs and counsel HIV-infected women to avoid pregnancy.¹⁶ However, implementation of these public health policies in the Black community is potentially volatile and disastrous. The promotion of condoms as a means of preventing HIV infection is viewed with suspicion by Blacks. Levine and Dubler state that "many African Americans view any attempt to interfere with or discourage reproduction as part of a plan for genocide" (p. 333).¹⁶ If health care providers demonstrate a lack of sensitivity to these views and continue to advocate HIV testing, contraception, and abortion, the fears of Blacks—who are already alienated from health care providers—will be reinforced.

AIDS in the Black community must be understood within the broader context of other leading causes of preventable death that may result in decreased population growth and decreased lifespan. The failure to close the gap in health status between White and Black Americans can be directly attributed to social inequities and Blacks' lack of access to health care. George Lundberg, editor of the Journal of the American Medical Association, attributes this lack of access to long-standing, institutionalized racial discrimination.17 Although the PHS officials who conducted the Tuskegee study were clearly influenced by the racial prejudice of their time, it was their use of institutional power and resources that transformed prejudice into racism. We must guard against prejudicial assumptions about the race, class status, and lifestyle of people at risk for HIV infection. As Allan Brandt states, "the notion that science is a value free discipline must be rejected. The need for greater vigilance in assessing the specific ways in which social values and attitudes affect professional behavior is clearly indicated" (p. 27).18 A failure to eliminate prejudice aggressively today could lead to repressive AIDS policies, cloaked as traditional public health practices designed to control the epidemic.

As the American public becomes increasingly aware of AIDS as a significant health problem in the Black community, there will be both opportunity and danger. The opportunity is to deal comprehensively rather than haphazardly with the problem as a whole: to see it as a social catastrophe brought on by years of economic deprivation and to meet it as other disasters are met, with adequate resources. The danger is that AIDS will be attributed to some innate weakness of Black people and used to justify further neglect and to rationalize continued deprivation. We must be mindful that the AIDS epidemic has uncovered the harsh reality of diminished economic resources, the limits of medical science, and confusion over how best to attribute responsibility for the prevention of HIV infection It is within this context that public healt must be used as a means for social ju: tice.¹⁹

The AIDS epidemic has exposed th Tuskegee Syphilis Study as a historic: marker for the legitimate discontent c Blacks with the public health system. I the absence of a cure for AIDS, educatio remains our best chance to stop the spreaof HIV infection. We must discuss the feeling within the Black community tha AIDS is a form of genocide, a feeling jus tified by the history of the Tuskegee study This dialogue can contribute to a bette understanding of how to develop and im plement HIV education programs that are scientifically sound, culturally sensitive and ethnically acceptable.

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