

The Foundation and AIDS: Behind the Curve but Leading the Way

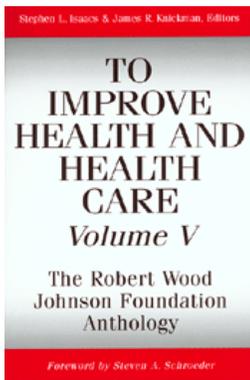
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Robert Wood Johnson Foundation

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Editor's Introduction

The emergence of AIDS in the early 1980s challenged many of the tenets of grantmaking that characterized the Foundation's approach of that period, particularly its reluctance to focus on specific diseases. By the mid-1980s, the dimensions of the AIDS crisis, the lack of leadership from government and the philanthropic community, the potential impact of the disease on the nation's hospitals, and the urging of leading public health experts across the country led the Foundation to rethink its position. In 1986, the Foundation announced the first of its programs aimed at mobilizing resources and public opinion to combat AIDS.

The initial program followed a preferred Foundation approach to grantmaking: find a model of service delivery that looked promising—in this case it was the San Francisco model—and then test it at a number of other locations in the hope that the federal government would adopt and expand it. The Foundation subsequently funded an open-ended nationwide program seeking innovative ways of preventing HIV/AIDS (especially in low-income communities, where most AIDS patients contracted the disease through substance abuse), a public television series, and many individual projects.

Despite its initial reluctance to enter the field, the Robert Wood Johnson Foundation became the largest source of philanthropic funds devoted to AIDS prevention during the late 1980s, and became known for its work on AIDS. The Foundation's first president, David Rogers, was named vice-chairman of the National Commission on AIDS in 1989 after leaving the Foundation.

In this chapter, Ethan Bronner, the education editor of *The New York Times*, chronicles the way in which the Foundation responded to the AIDS crisis. It is a story of how one foundation dealt with an area of high sensitivity and, in the author's words, "how AIDS changed the Robert Wood Johnson Foundation [and] also, in an important sense, how AIDS changed the country."

The patient is a 30-year-old black man with daunting medical and social problems. He is thin, and suffers from nausea, chronic fatigue, and pain in his feet and hands. He walks with difficulty. He is on a cocktail of medications that he obtains from several different providers, telling each a different story. He is seeing a psychiatrist but misses appointments. His t-cell count is low, his viral load high. He lives with his parents but they are throwing him out. He has AIDS.

On an oppressively hot Tuesday afternoon in August, 2000, Carla Gray, a case coordinator at AIDS Arms, in Dallas, enters a large meeting room at the Cathedral of Hope in the city's Oak Lawn section. She needs the kind of coordinated help for this patient that cannot be had through a phone call or two. It is at this weekly meeting—and only at this meeting—that such help is available to Dallas's AIDS patients. Seated there are representatives from several dozen community service groups, among them the AIDS Resource Center, HOPWA (Housing Opportunity for Persons with AIDS), and Parkland Hospital's Amelia Court Clinic, which has the largest number of AIDS cases of any area hospital. Gray presents the case, starting with the medical and moving to the social. Then she lays out what must be done. Her patient needs food and housing. His medicines (both psychiatric and for HIV) need to be straightened out and to come from a single source. He could also use clothing and transportation. Before the hour is out, she finds him a room to share, secures a commitment from a food pantry, and settles on a clinic and a social worker. He will be picked up for his psychiatric sessions. Later the same day, she will speak to her patient's physician and psychiatrist.

Such AIDS case management meetings have taken place every Tuesday afternoon in Dallas since 1986, when, with a grant from the Robert Wood Johnson Foundation, the Community Council of Greater Dallas set the program in motion. At first, of course, the meeting was much smaller. Fewer groups were represented, and fewer cases were discussed. It was held not in a large room at the Cathedral of Hope but in a small one at St. Thomas Episcopal church. Two other differences are especially noteworthy. The cases then under consideration contained virtually no African-Americans or women. The cases were those of gay white men. And perhaps most significant of all, the goal was different. Today, AIDS case management involves medical treatment using protease inhibitors and retroviral agents that help patients to live. Then the aim was the much grimmer one of helping patients to die.

In the year 2000, some 5.3 million people around the world, including 600,000 children under the age of 15, became infected with the HIV virus that causes AIDS, according to the World Health Organization.

It has killed about 22 million people, including 3 million in 2000. And the number of women dying from it exceeded the number of men in 2000. The epidemic has been especially fierce in sub-Saharan Africa, home to 10 percent of the world's population and 72 percent of new AIDS infections.¹

In the United States, AIDS has gone from a disease of largely gay men to one affecting the poor and intravenous drug users. And it has turned from an unambiguous death sentence to a chronic condition that can be managed. About 1 million people in the United States and Canada are living with the virus, with approximately 45,000 new cases of AIDS in the year 2000.

Despite those changes, the kind of community-based case management launched in 1986 with Foundation grants totaling \$17.2 million in Dallas and 10 other communities around the country has held up remarkably well, and continues without significant structural or conceptual shift. Although more and different kinds of organizations are involved, the typical patient has changed, the Foundation has moved on, and the programs are paid for today with federal and state funds, the community-based case management approach remains an integral part of scores of urban and rural health networks.

"The Robert Wood Johnson Foundation played a key role," remarked Philip Lee, a former assistant secretary of health in Democratic administrations who was instrumental in getting the Foundation involved from his position at the University of California at San Francisco. "Here we saw this thing going on with what appeared to be very serious implications, and we were appalled that the government and foundations were doing nothing."

What the Robert Wood Johnson Foundation did was this: noting that San Francisco, through community-based groups, had found a way to care for AIDS patients more effectively and humanely outside hospitals, it paid to create similar four-year demonstration projects in 11 communities through a project called the AIDS Health Services Program. The sites were Atlanta, Dallas, Fort Lauderdale, Jersey City, Miami, Nassau County, Newark, New Orleans, New York City, Seattle, and West Palm Beach. The idea was to get others (either foundations or the state and federal governments) to match the grants and take over the programs. That, by and large, happened. Shortly after the first Foundation grants were made, they were matched by federal emergency funds set aside for AIDS, and in 1990 Congress passed the Ryan White Comprehensive AIDS Resources Emergency Act, which authorized funds for programs based on the Robert Wood Johnson model.

In 1988, the Foundation's involvement in AIDS took two more turns. As the nation was gripped by the spreading epidemic, with tens of thousands dead and dying, the Foundation invited proposals from anyone for anything related to AIDS care. The response was overwhelming. More than 1,000 proposals came in from organizations in 48 states, the District of Columbia, and two territories, with requests ranging from \$1,000 to \$10 million. Almost the entire staff of the Foundation spent weeks sifting through the proposals. More than 80 percent of the requests came from communities outside the major epicenters of HIV infection—Los Angeles, New York, and San Francisco. Leighton Cluff, then the Foundation's president, issued a statement at the time to Congress and the public saying, "We knew that few community-based AIDS projects qualified for existing federal, state, or private funding, particularly those located in low-prevalence areas. Now we've documented the extent of that funding gap and the nature of the problems these communities are confronting." Dozens of groups were funded, including those engaged in educating runaway youths in the Southeast, union members, and a network of interfaith volunteers coordinated by Associated Catholic Charities of New Orleans.

In the same year, some \$4 million went to a four-part PBS series called "AIDS Quarterly," hosted by Peter Jennings. The idea was to reach millions of viewers with a reliable broadcast focusing on scientific, public policy, legislative, and community elements of AIDS. The series was produced by WGBH in Boston, which is responsible for the NOVA and Frontline programs.

With all these projects funded—and several others, including a pediatric AIDS program at Yeshiva University in New York—the involvement of the Robert Wood Johnson Foundation in AIDS had become enormous. Indeed, a paper published in August, 1990, by senior Foundation staff members declared, "The Robert Wood Johnson Foundation has awarded over 100 AIDS-related grants totaling more than \$45 million, making it the single largest source of private philanthropic funding for AIDS to date."²

One year later, the Foundation largely withdrew from the business of funding new AIDS projects, both because it worried that it was getting involved too deeply with a single disease and because federal funding for AIDS had finally taken off, allowing for a graceful exit.

While it may seem self-evident today that what was then the nation's largest health care philanthropy would take on the nation's largest epidemic, this was far from a certainty at the time. After the disease was first identified, four years went by without the involvement of Robert Wood Johnson or, for that matter,

any other national foundation. And once the Robert Wood Johnson Foundation did decide to play a role, many were surprised. As Frank Karel, a Foundation vice-president, put it, "I was frankly astounded—pleased but astounded—when we went into AIDS. It represented a sharp departure and carried so much baggage." The story of how the Foundation made the decision to enter the AIDS maelstrom, and was changed by it, is a complex one. It is partly the story of how the Foundation grasped what was still an unarticulated precept: that to make a difference in health, it would often have to consider social issues far from medicine per se. It would also have to be willing to take a risk. How AIDS changed the Robert Wood Johnson Foundation is also, in an important sense, how AIDS changed the country.

THE EPIDEMIC EMERGES

Epidemics often begin surreptitiously. On June 5th, 1981, the *Morbidity and Mortality Weekly Report* of the Centers for Disease Control, gave the first published notice of a new syndrome by describing five homosexuals afflicted with pneumonia at three different California hospitals. "The fact that these patients were all homosexuals suggests an association between some aspect of a homosexual lifestyle or disease acquired through sexual contact and pneumocystis pneumonia in this population," the report noted. Over the next few years, that pneumonia and Kaposi's Sarcoma, a previously rare skin cancer, became achingly familiar manifestations in thousands of gay men of what was named Acquired Immune Deficiency Syndrome.

Homosexuality may not yet be fully accepted in American society, but it is such a widely recognized phenomenon today that prime-time television shows, whole areas of study, and even some college scholarships revolve around it. Vermont now legally sanctions civil union between two men or two women. Few can be unaware today that there is an active gay community in the United States; it is an increasingly mainstream viewpoint that homosexuals should have the same rights as heterosexuals. Yet when AIDS broke out, homosexuality was still a sufficiently taboo topic that the disease was largely ignored. It made everyone uncomfortable. As Randy Shilts wrote in *And the Band Played On*, his classic account of the early AIDS years, "From 1980, when the first isolated gay men began falling ill from strange and exotic ailments, nearly five years passed before all these institutions—medicine, public health, the federal and private scientific research establishments, the mass media, and the gay community's leadership—mobilized the way they should in a time of threat. The story of those first five years of AIDS in America is a drama of national failure played out against a backdrop of needless death."³

There were three reasons not to expect the Robert Wood Johnson Foundation to jump into AIDS care. First, the Foundation, which began its work as a national philanthropy in 1972, had decided from the outset not to focus on any single disease. It viewed single diseases as the province of the National Institutes of Health and of disease-specific voluntary agencies like the American Cancer Society and the American Heart Association.

Second, having chosen to focus on health service delivery, the Foundation saw no obvious role for itself in an epidemic that seemed primarily to require biomedical and clinical research, epidemiological surveillance, and public education.

And finally, for a conservative board of directors that was still entirely male and white, there was the specter of controversy. It can be hard to remember today, in a country that has heard public discussions of oral sex in the Oval Office, but throughout the first part of the 1980s, with President Ronald Reagan in office, public dialogue was not open to issues of sexuality, let alone homosexuality. Edward N. Brandt, Jr., assistant secretary for health in the Department of Health and Human Services in the first Reagan administration, recalled talk among fellow federal officials that AIDS was "God's vengeance" for immoral behavior.

"The room would have cleared if someone said they had AIDS," he added. "On television, I couldn't use certain phrases to describe how the virus is transmitted, because that might offend the American public, and we had whole meetings about how to refer to sexual intercourse."⁴

Many complained at the time that Reagan and his aides rarely spoke publicly about AIDS, thereby adding to the public's tendency to ignore the spreading epidemic. But Brandt says he takes partial responsibility for the silence and, in retrospect, believes that it was the right path. "My sense was that if Reagan and those around him had spoken about AIDS, it would not have been helpful. I figured the best thing to do was to depoliticize it by telling them we should leave it to the doctors and scientists."

As late as 1985, the CDC had stopped spending money on AIDS education because the White House had worried that the government ought not to be funding what, in its view, amounted to instructions in male anal intercourse. According to Shilts, the CDC director, James Mason, was heard to complain that he had suddenly found himself talking with complete strangers "about sexual acts that he would not discuss with his wife even in the privacy of his own home."⁵

Steven Schroeder, president of the Robert Wood Johnson Foundation, said it was no surprise to him that the board had not jumped in earlier. "When I came on as president, in July of 1990, I was the youngest of 18 white men on the board," he said, noting that today four members are female and black or Hispanic. "Foundations tend to be conservative and not to take risks. And the population with AIDS was a population that the Foundation's board was not very familiar with."

Robert Blendon, a professor of health policy at Harvard University, who was the Foundation's senior vice-president in the mid-80s added, "We went through 10 years convincing people we were not a single disease foundation. We used to have to explain this to board members who had concerns of their own like prostate cancer or heart disease. So how do we explain that this one is different? Older Americans were the last ones to worry about AIDS. This was not a disease that affected them or their friends. And they were less likely to be open to other ways of life. So although the Foundation's staff wanted to get involved, it seemed impossible at first."

By the summer of 1985, however, the epidemic had forced its way into the national consciousness. More than 20,000 Americans were either dead or dying of AIDS. And one of those, it turned out, was Rock Hudson, the square-jawed leading man in scores of films like "Pillow Talk" and "Magnificent Obsession." The news that the actor who played the quintessentially American romantic man had "the homosexual disease" produced a groundswell of attention. President Reagan, a former actor, suddenly connected to this disease. He called Hudson in his Paris hotel room to wish him well (Hudson, ashamed of his condition, had gone to Paris for treatment) and Ed Brandt, who had been a Reagan administration official, said colleagues told him this was a big turning point in the federal government. Hudson became the hook for numerous media organizations to focus on AIDS in a serious way for the first time. The disease was front-page news in virtually every major newspaper on Sunday, July 28th. That week, both *Time* and *Newsweek* produced large stories on Rock Hudson and AIDS.⁶

All of the public discussion of AIDS increased the sense among Foundation staff members that they could no longer sit this one out. Other pressures to act had been building as well. Ruby Hearn, a senior Foundation vice-president, recalls a talk to Foundation staff members in 1984 by the Princeton sociologist Paul Starr after the publication of his book, *The Social Transformation of American Medicine*. Starr said that the public response to AIDS was shamefully lax, and urged the Foundation to do something about it.

Starr noted that the response of others elsewhere to his view on AIDS was indicative of the era. "In a speech to a group of health care executives, I spoke with some passion about the need for a concerted response to the AIDS epidemic," he recalled. "Someone from the audience asked me, 'Are you married?' I was. The questioner assumed that anyone who cared about AIDS was gay. One of the huge barriers to an effective response was precisely that many people didn't think AIDS was a matter of 'public health.' They thought it involved the health of a 'special interest,' and of course they blamed the epidemic on moral conduct they disapproved of."

But beyond the growing urgency and public attention, something significant took place that gave the Foundation the opening its staff sought. A new study showed that the way the San Francisco gay community had organized itself to cope with AIDS was making a big difference for the city's overtaxed hospitals and for the patients themselves.

THE AIDS HEALTH SERVICES PROGRAM

As early as 1982, a multidisciplinary outpatient AIDS clinic was set up at San Francisco General Hospital, and by 1985, the concept of community-based services for people with AIDS had emerged in the form of a locally organized collaborative network of hospitals, outpatient clinics, and volunteer-driven community-based groups. Care was coordinated by case management, which included emotional support, counseling and advocacy in obtaining home care, hospices, and public health education. According to studies carried out then and later, those factors were primarily responsible for dramatically reducing the average length of a hospital stay for AIDS patients. That stay was 11.7 days in San Francisco compared with 25.4 days in New York City, where outpatient community-based care did not exist.

Such coordination of care was not entirely new or unique. It had been used successfully in San Francisco and elsewhere for the mentally ill after the de-institutionalization wave of the 1970s, and for the elderly. But urban hospitals, already overtaxed by the crack epidemic and still-rising crime, were faced with an acute burden as AIDS patients started to fill their wards. AIDS patients often lost their jobs and their insurance and became dependent on Medicaid. The hospitals were threatened with becoming their homes. Here Foundation staff members saw a way to bridge their concerns about AIDS with the traditional ones of their board.

Drew Altman, president of the Henry J. Kaiser Family Foundation in California, was at the time a vice

president of the Robert Wood Johnson Foundation and recalls being goaded by his wife to find a way for the Foundation to get involved.

"I discovered that in San Francisco they had developed a model that could be applied to the rest of the country," he recalled. "The way the Foundation worked was to find a model, replicate it, and evaluate it. David Rogers was president of the Robert Wood Johnson Foundation at the time, and he was nervous about this because of the single disease question. But when he saw how the San Francisco model could be used to help save teaching hospitals, he saw a way to sell this to the board. He understood that we could say, 'Hey, Hopkins and others could go down the tubes. So we need to help the teaching hospitals, not just gay people.'"

Patricia Franks, director of the AIDS Resource Program at the University of California, San Francisco under Philip Lee, remembers Lee, accompanied by Mervyn Silverman, director of public health for San Francisco, approaching David Rogers. They told him that the government was doing nothing, there was no funding for this epidemic, and Robert Wood Johnson could play a key role. They were armed with a study they had commissioned showing that AIDS patient care in San Francisco was significantly less expensive than elsewhere because of its community-based approach.

The key meeting to bring the Foundation into AIDS care occurred in the fall of 1985, when Lee and Silverman came to the Foundation's Princeton headquarters. Silverman and Lee made their case well. They had data, and they had a plan that could be replicated. And those items were what Rogers and his staff needed. It was not hard to make the case decisively at the next board meeting, where the plan was approved. As John Gagnon, a sociologist and an expert in the fields of sexuality and AIDS put it, "The Robert Wood Johnson Foundation was as slow to respond as everyone else but it was on the cutting edge of that slow response."

In the following year, cities with heavy AIDS caseloads worked to put together proposals based on the San Francisco model. In late 1986 and early 1987, the successful proposals were selected, and the grants were distributed. From the start, it was clear that San Francisco offered a model, but only in the most general sense. Other cities had AIDS, but they did not have the highly organized and professional gay community of San Francisco. In fact, by the time the Foundation's work began, the disease had already peaked and started to subside in San Francisco. Sexual practices that spread the disease, including

indiscriminate partnering at bathhouses, had declined markedly. And politically San Francisco was extremely well organized. So to use it as a model was fine as a start, but far from perfect.

In the two-city project of Newark and Jersey City in New Jersey, for example, AIDS was never a gay epidemic but—foreshadowing a nationwide pattern that would emerge 5 to 10 years later—a disease of intravenous drug users and their sexual partners, including many non-whites. Steven Young is today deputy director of the Office of Science and Epidemiology at the HIV/AIDS bureau of the Health Resources and Services Administration, or HRSA, in the U.S. Department of Health and Human Services. In 1986, as a state employee, he served as project director for the Foundation-funded project for the two New Jersey cities. Young said recently, "When I came to the federal government in 1990 and people were starting to talk about the changing demographics of the epidemic, I said, 'What are these people talking about?' The AIDS patients in the city where I come from were 75 percent intravenous drug users."

New Jersey set up case management meetings in a dozen different medical care settings to discuss coordination and efficiency, as Dallas had done. Newark was already facing an AIDS epidemic among children, he recalled. But the biggest challenge was organizing the various elements of the community.

"It was not an easy sell," Young said. "We primarily addressed issues from the perspective of medical care—establishing clinics to deal with the throngs knocking on the doors of the ERs—and working through substance abuse centers. We had a very difficult time getting the more traditional black community-based groups and churches to really recognize the issue."

Not having that community base was not exclusively a bad thing. It meant less public support, of course, but it also allowed for greater direction from the top. "When people are not as well organized, there is less political opposition to each step," Young said. "You could simply create things because they were needed and then bring people along."

Young sees the Foundation-supported work in New Jersey as largely successful but not entirely so. "I don't think we ever proved that we were able to reduce hospital use in New Jersey," he said. "The idea was that by setting up an individual care plan, patients wouldn't use the hospital as much. In fact, we found the cost overall going up because we gained access to services for people who had been outside the system. Not surprisingly, if you include more people, it costs more."

Cost aside, community-based case management can be a tricky business, as other communities discovered. Robert Blendon, the Harvard University health policy researcher and former Robert Wood Johnson Foundation senior vice president, said that the organization of care was challenging. "In a hospital you are lying in your bed and hundreds of things are given to you," he said. When patients are in a community setting instead of a hospital, he explained, there are a series of independent organizations providing care, and a central group to coordinate services is needed. "And don't forget that in many of these cases we were talking about a population that feels discriminated against, so you had to include them in the decision making. There was a constant feeling on their part of being experimented on, the way African-Americans in the South used to feel," Blendon said.

Yet how to include intravenous drug users? This was not a notably well-organized community, nor was it easy to serve them. As Merv Silverman put it, "It is easier to put gay men in housing than someone who is shooting up."

Relations between and within groups were delicate. Warren W. Buckingham, known to all as Buck, works today on AIDS as a senior technical adviser in the Africa bureau of the United States Agency for International Development. He began his long career in AIDS when he started the Dallas AIDS ARMS program ("ARMS" is an acronym for "Accessing Resources to Mobilize Support") in 1986.

"In the gay community in Dallas, there had been almost no cooperation between men and women," Buckingham said. "A lot of gay men were sexist. Eventually, they got over that, because lesbians with nothing to gain saw their brothers dying and stepped up and provided the care."

In some projects, there were uneasy relations between the administrators and sectors of the affected population. Many recall, for example, that in a major Southern city, a society woman ran the AIDS outreach program. She worked well with gay men but not with poor African-Americans. And in Dade County, Florida, the heavily affected Haitian community vigorously opposed listing Haitians as "high-risk."

Many of the community-based organizations that got involved in AIDS case management were born specifically for that purpose, often starting with nothing more than a telephone in someone's living room. They sometimes failed to mature into real organizations, making care somewhat sketchy. As John Gagnon, the sociologist who studies AIDS, described the situation, "There were lots of fake community

organizations, a kind of pseudo-grass-rootsism." But he acknowledged that it was not clear what the alternatives might have been.

Indeed, evaluating the effectiveness of a program aimed at a crisis is difficult, because when one asks if something worked, the reply must begin with "Compared with what?" Vincent Mor of Brown University's Department of Community Health was commissioned by the Foundation to lead a team of evaluators after the AIDS Health Services Program was under way. They reported, "High caseloads limited case managers to providing what amounted to information and referral services to many clients, and prevented case managers from monitoring their clients as frequently as desired. Case managers were forced into a mode of responding to crises and 'putting out fires': Opportunities for proactive—rather than reactive—intervention were thereby restricted. In this respect, the AIDS Health Services Program did not provide a strong test of case management for people with AIDS because in many locations the intervention was not implemented in an optimal manner."⁷

In conclusion, the Mor team pointed to the tensions between minority and non-minority community groups, the attention that needed to be paid to keeping tense consortia together instead of treating patients, and the gap between plans and reality.

"The broad goals of all the AIDS Health Services Program consortia as articulated in 1986 were lofty, ambitious, and unattainable—and reminiscent of earlier efforts at social reform," the evaluators said.⁸ They added that it might make sense, over the long term, for consortia responsibility to be assumed by a lead agency, but that the agency should not become a new bureaucracy.

But Mor and his colleagues did note that the Ryan White Comprehensive AIDS Resources Emergency Act of 1990, named for an Indiana boy who struggled heroically with AIDS, was modeled directly on the Foundation-sponsored projects. The Ryan White Act drew on the project's approach in a number of ways. This included the use of a case-management, community-based model of care intended to relieve hospitals, the use of representative community planning groups and development of local political leadership, the use of volunteer/ buddy support and community-based organizations for a variety of health and supportive services, and the focus on maximizing the availability of all local, state, and federal funds to develop a comprehensive continuum of care.

Yet another important contribution of the AIDS Health Services Program was in personnel. Many of the key players in federal AIDS care—Pat Franks, Buck Buckingham, Steven Young, Andy Kruzich of Seattle—gained vital experience in the field with the Foundation's projects.

The Robert Wood Johnson Foundation, in keeping with its policy of creating a demonstration project and then getting out so that others may take it over, built its exit into AIDS Health Services after four years. It funded only those projects which could demonstrate that they had found other sources of support for the following years, and Foundation officers also urged the federal government to supplement and extend its funds. In 1986, partly in response to the Foundation's efforts, Congress appropriated and the Health Resources and Services Administration, or HRSA, funded four cities—Los Angeles, Miami, New York, and San Francisco—for a total of \$15.3 million. Over the next few years, the federal government added more, some of them also served by the Foundation. By 1989, HRSA funding covered 25 communities, including all the Foundation-funded sites.

Many of the projects around the country were chagrined when the Foundation kept its word and declined to renew them. Pat Franks at the University of California at San Francisco was one of them. She recalls in 1988 trying hard, in conjunction with Philip Lee, to persuade the Foundation to renew its grant. When that failed, the two of them wrote a long letter of thanks detailing how the money had been useful.

"I was disappointed, but they did a good thing because the government needed to see that this couldn't be done by a foundation," Franks said. "They also felt that if they continued to put huge amounts of money in, nobody else would get into the game. The Ford Foundation got involved in a limited way and so did local and regional foundations. But the real point was to get the federal government involved, and that is what happened."

THE AIDS PREVENTION AND SERVICES PROGRAM

Part way through the AIDS Health Services Program, Foundation staff members saw a growing need for additional AIDS-related activities. As time went by, it became clear that there were multiple causes of AIDS and that it was not unique to the gay community. In March, 1988, the Foundation issued an unprecedented Call for Proposals. Unlike any of its previous Calls for Proposals, this one set no overall funding level and had no time or dollar limit for individual grants. Foundation vice-president Ruby Hearn recalled, "For the first time in our history, we put out word that said, 'Give us your good ideas on how to deal with this.' We were inundated with requests."

The Foundation gave applicants just under four months, until July 1, to apply. As Leighton Cluff, then the Foundation's president, put it in a special memorandum to congressmen and state officials, the Call for Proposals had two purposes: to generate imaginative ideas for the Foundation to consider, and to provide a measure of the nation's unmet demand for help in fighting the epidemic.

The response was 1,026 proposals totaling more than \$537 million over periods ranging from three months to six years. Especially noteworthy was the fact that many proposals came from places not traditionally associated with AIDS—like Fargo, North Dakota, and Cheyenne, Wyoming. Proposals came from churches, schools, and the Girl Scouts. Nearly a third of the proposals targeted minority groups. One of the applications was written in Spanish; others proposed producing bilingual and culturally sensitive materials. And just under half of the applications sought funds for efforts to prevent the further spread of HIV infection.

The Foundation awarded \$16.7 million to 54 projects together called the AIDS Prevention and Services Program. The projects included an AIDS prevention program for primary and secondary school students in Anchorage, Alaska, that used native puppets and familiar role models in Alaska Native culture; a prevention program for migrant farm workers in Delaware, Maryland, and Virginia; an education and outreach program for homeless people in Los Angeles; and a service, referral, and day care program for infected mothers and their children in Boston.

Project Street Beat, sponsored by Planned Parenthood of New York City, sent mobile medical vans to reach out to teenage prostitutes, young intravenous drug users, and homeless young people in the South Bronx and Brooklyn. Its director, Jeanne Kalinoski, said, "We know they aren't going to come in and ask for help, so we go out to them." Another project provided AIDS education to working prostitutes in Denver and San Francisco. Still another offered dental care for HIV-infected people and another free bedside legal information. Yet another offered information and referrals to AIDS patients who had lost their sight, a fairly common but unnoted problem.

One of the enormous shifts in American society produced by AIDS was that, because of the necessity to educate the public on the spread of the disease, discussions of sexual practices had become nearly commonplace. Merv Silverman, the director of public health in San Francisco at the start of the AIDS epidemic, remembers designing the first anti-AIDS poster in 1982. It was viewed as scandalous at the time. It simply urged gay men to reduce the number of their partners and not to take drugs. Six years

later, in a sign of the changed times, as part of the AIDS Prevention and Services Program the Foundation was sponsoring projects in which teenagers lectured one another on the use of condoms by spreading them over fruits and vegetables.

Some of the projects were good and successful; others were less so. There developed a sense in the Foundation that this kind of approach—funding that is broad but thin—has limited impact. But the experience of trying to plug holes in the care and education provided to those with AIDS gave the Foundation's staff members a sense of how to move forward as a philanthropy. They noted that irrespective of the kind of physical or mental disorder suffered, the impediments encountered were pretty much the same—uncommunicative bureaucracies, uncoordinated services, insurance benefits that were poorly designed for people with chronic conditions, and case managers being funded only rarely, even though they are often the glue in the system.

By the 1990s, the Foundation had changed its grantmaking approach with respect to chronic conditions and was tackling systemic problems in the way services were organized and provided to people with chronic disorders.

AIDS QUARTERLY

One other significant project of the late 1980s was "AIDS Quarterly," the PBS series hosted by Peter Jennings. The project's four broadcasts were widely described as among the most powerful and frank discussions of the epidemic on American television. When Jennings introduced the first installment, in the winter of 1989, he laid out the grim statistics: "45,000 people are dead so far and 1.5 million of our fellow citizens have the AIDS virus." He added, "Every minute, someone on our planet gets the AIDS virus."

One of the broadcast's main tasks was to dispel prejudices and myths, to make clear that AIDS is a disease, not a providential plague, and to fill a hole left by the delinquent media. "Let's get one thing clear at the outset," Jennings said. "AIDS is a virus. It is not a moral issue. And another thing. We in the media have not always been very helpful to you in understanding AIDS." He then laid out some of the frequent misconceptions about the disease that had been repeated on major news broadcasts—for example, that AIDS can be transmitted by mosquitoes or kissing.

"AIDS Quarterly" offered a mixture of longer documentary pieces and shorter, snappier moments of scientific and political update, like the controversy over whether to make the experimental drug AZT

more available despite the concerns of the Food and Drug Administration. Among the more powerful segments was one that followed Admiral James Watkins, chairman of a committee appointed by President Reagan to make recommendations on AIDS. Called "The Education of Admiral Watkins," the segment showed a churchgoing, straight-laced admiral who had never before met an AIDS patient or thought much about the disease traveling to AIDS clinics and parts of the inner cities like New York's Hell's Kitchen.

"We had our own biases unrelated to reality," the admiral acknowledges of his committee and himself partway into the documentary. The segment showed the admiral learning that hemophiliac children who had contracted AIDS through blood transfusions faced fear and prejudice in their own communities because of the unfounded belief that other children could be infected simply by playing with them. In Anderson County, Tennessee, for example, a 12-year-old boy was banned from school. "This was in the Bible Belt," Admiral Watkins says in sad wonderment. "Where are our pastors? Where are our religious leaders?"

Another segment showed the Pacer family of Salt Lake City, a large Mormon family of seven grown children and 35 grandchildren. Joe Pacer, the family's head, was a doctor and a highly respected community member. His fourth child, Malcolm, 39 years old, was gay and had contracted AIDS. The segment showed the family obliged to reconcile its own feelings toward homosexuality, forbidden in the Mormon church, and its love for Malcolm, who died at the segment's conclusion. As Jennings said after that segment, the broadcast's aims were, in part, to "dispel myths and allay irrational fears."

While many agreed that the broadcasts were first-rate, others raised the question of how effective they were on a network that tends to draw largely educated viewers. Others countered that informing and winning over the elite is a vital task in any campaign. No one sought to measure the program's impact. Given the difficulty of measuring the effectiveness of educational broadcasts such as the "AIDS Quarterly," its impact remains unclear.

LOOKING BACK: THE FOUNDATION'S ROLE IN THE AIDS CRISIS

The Foundation largely ended its direct support for AIDS care with the end of the AIDS Health Services Program in 1991. By then, federal programs ran into the billions, and there was no longer a clear need for a trail-blazing effort on the Foundation's part.

"I didn't feel any push from anyone to go forward with AIDS funding," Steven Schroeder says of his arrival as the new president in July of 1990. "No one came up with a version 2.0 of it. There was lots of federal funding for it by that time, and the role of a foundation like ours is not to pile on."

The Robert Wood Johnson Foundation still plays an indirect role in AIDS through its programs on drug abuse and the homeless. Its Faith in Action program supports local coalitions of congregations providing volunteer aid to those who are homebound. About 10 percent of those are HIV-positive, according to Schroeder.

Paul Jellinek, the Foundation vice-president who helped to begin the Foundation's first AIDS project, recalls well the difficulties caused by religious objections to homosexuality. Lessons from those early days are applied today in many programs, including Faith in Action. Among other things, Jellinek said, there is special value in getting churches to help those with AIDS: "It helps debunk the 'wrath of God' argument. If churches are stepping up to the plate, it sends a different message. That's one of the things you learn with experience."

There were other lessons as well. Foundation officials understood at the outset that San Francisco's AIDS health care model could not be replicated precisely because of the unique circumstances of that city and its well-organized gay community. But using it as a model still offered lessons about the difficulty of taking an approach to one kind of community and bringing it to entirely different circumstances. Community-based care models were far more complicated in Newark and Jersey City, because where there were so few gay AIDS patients and so many intravenous drug abusers, a very different kind of "community" existed. It also turned out that creating community-based organizations in loose-knit communities was more easily said than done.

The AIDS Health Services Program brought the Foundation into an area where it could make a difference. For a variety of reasons, the federal government was staying out; other foundations were nervous about getting in. The Robert Wood Johnson Foundation saw an opportunity and seized it. It offered a model for helping patients and relieving hospitals that the federal government adopted, setting the stage for the Ryan White Act. At the same time, the Foundation saw the opportune moment to leave the scene and devote its energies to other areas. Finally, in examining the AIDS Health Prevention and Services Program, officials of the Foundation saw the limits of making grants to many groups dealing

with different elements of the disease. It refocused its efforts afterward to try to have more systemic impact, an approach that has been the dominant one in recent years.

Notes

¹ "AIDS Infections Rise Globally, but Sub-Saharan Cases Stabilize," *New York Times*, November 25, 2000, p. A5.

² P. S. Jellinek, R. P. Hearn, and L. E. Cluff. "Responding to AIDS: The Robert Wood Johnson Foundation's Experience." *AIDS and Public Policy Journal*, August, 1990, p. 212.

³ R. Shilts. *And the Band Played On* (New York: St. Martin's Press, 1987), p. xxii.

⁴ "Proceedings of AIDS Prevention and Services Workshop," unpublished report of the Robert Wood Johnson Foundation, February 15–16, 1990, p. 36.

⁵ R. Shilts. *And the Band Played On* (New York: St. Martin's Press, 1987), p. 586.

⁶ *Ibid*, p. 578.

⁷ V. Mor, J. A. Fleishman, S. M. Allen, and J. D. Piette. *Networking AIDS Services* (Ann Arbor, Michigan: Health Administration Press, 1994), pp. 89–90.

⁸ *Ibid* p. 208.