Taking it to the streets
Minority AIDS organizations battle the epidemic  page 4
Sincce its inception in 1968, the Health Policy Advisory Center—also known as Health/PAC—has served as a unique progressive voice for changing consciousness on domestic and international health priorities. Through the Health/PAC Bulletin and the books Prognosis Negative and The American Health Empire, and in its outreach to a national network of grassroots activist groups, Health/PAC continues to challenge a “medical-industrial complex” which has yet to provide decent, affordable care.

IN THIS ISSUE

Against All Odds
Health/PAC examines the response of community-based organizations to the AIDS crisis among minority groups ........................................... 4

“The Other Half I Got To Live”
An interview with Edgundo Cruz, a man with AIDS-related complex and no place of his own to live .................................................... 12

From the AIDS Unit: A Social Work Story
Social worker Rhys McMartin writes of his encounter with a mother who is losing her second son to AIDS ............................................. 14

Historical Omissions: A Critique of And the Band Played On
Nick Freudenberg reviews Randy Shilts’ history of the AIDS epidemic as a basis for future strategy ...................................................... 16

Health Care for All And Not a Penny More: A Proposal
Alan Sager proposes a comprehensive plan to provide universal health care—without an increase in spending ........................................... 21

HMOs Come to Britain
Geoff Rayner reports on the latest weapon against Britain’s National Health Service—imported from the USA .......................................... 27

Vital Signs
News reports on PRO statistics, hospital overcrowding, an AIDS hotline, and more .............................................................. 29

Speaking of Health and Medicine
Quentin Young takes aim at some of the small-minded reactions to AIDS around the country ......................................................... 31

Watching Washington
Barbara Berney draws lessons from the establishment of state programs for worker education in health and safety ................................. 32

Index to Volume 17 ................................................................. 33

Health Policy Advisory Center
17 Murray Street New York, New York 10007 212/267-8890
Health/PAC Bulletin
Volume 18, Number 1 Spring 1988


Executive Editor Joe Gordon
Assistant Editor William Deresiewicz
Staff Editor Ellen Bilofsky
Volunteer Loreta Wavra

Interns Anne McDonough, Caren Teitelbaum

Design Maggie Block, Three to Make Ready Graphics
Typography First Galley Typography
Printing Print-Rite Press
Illustrations Frances jitter

Front Cover Photo James Shellington of Baltimore's Health Education Resource Organization speaks with worker about AIDS. David Harp/Baltimore Sun.

Back Cover Photo Demonstrators rally for universal health coverage at State House in Boston last fall. Phyllis Graber Jensen/Boston Herald.
Everyone’s Epidemic

It is now well-known that AIDS is taking a disproportionate toll on people of color in this country. The cruel abandonment of the health-care, housing, and other needs and basic rights of our minority population during the Reagan years has, of course, deepened the threat of AIDS and made the job of combatting the epidemic all the more daunting.

In the face of lingering federal inaction—and despite enormous obstacles within minority communities themselves—private, minority-run organizations are responding to the growing threat of AIDS in our inner cities. Born out of blood, sweat, and tears, these mostly small organizations lead a fragile existence, relying heavily on volunteers and in-kind support. But what they accomplish on such scant resources is remarkable and inspiring.

Their organizers are well aware that without an unprecedented, comprehensive national response to AIDS, there can be no hope of narrowing this epidemic’s lethal wake. Now, eight years into the epidemic, while federal policymakers are just beginning to recommend a full-fledged response, groups like the ones described in our cover story are providing desperately needed support, education, planning, and organization. Multiplying their activities even ten-fold will not be enough to stem the spread of AIDS, yet these fledgling support systems are ameliorating suffering and saving lives. They also offer up important lessons in how to best prevent the spread of infection within our culturally diverse communities. These are vital, monumental gains which deserve the support of everyone who recognizes that AIDS is a disease of all of us.

-Joe Gordon, Executive Editor
Against All Odds
Grassroots Minority Groups Fight AIDS

One day three years ago, Curtis Wadlington learned that a close friend had AIDS. The friend was in a hospital, and his family didn't want him home. "His family was dysfunctional," Wadlington says. "A lot of IV drug use. So I brought him home with me and took care of him for the last ten months that he lived." Remembering that time now, Wadlington speaks softly, almost monotonously, his face impassive, his eyes burning.

"I ended up leaving my work—taking care of him was a full-time job," he says. His friend was in and out of the hospital until he died. "The nurses weren't doing what they should be doing. The workers wouldn't clean his room. A lot of days it was just me and him."

So for ten months Curtis Wadlington took the place, for his dying friend, of the entire social welfare system of their city, Philadelphia, of much of the public health system, and even of the AIDS service network, since the Philadelphia AIDS Task Force, the city's local private AIDS organization, all but refused to help him.

Wadlington's experience as a social worker taught him how to get what he needed—"who to holler at"—but, he thought, what about all the people who were going through the same thing and didn't know the system?

Curtis Wadlington's friend was black, a part of the "other" AIDS epidemic—the one that gets scant notice in the media, the one that has found virtually no place in the nation's consciousness, the one that receives the smallest crumbs from the crust that the federal government throws to AIDS education and counseling. Forty percent of the 52,000 people with AIDS (as defined by the Centers for Disease Control) are black, Hispanic, Asian, or Native American; among women and children, the proportion is twice as high. In large cities, over half the people with AIDS are members of minority communities. In some of New York City's largest black and Hispanic neighborhoods, more than 2 percent of all infants are born with AIDS-infected blood.

By the end of 1981, the first year of the epidemic, the AIDS surveillance reports published by the CDC showed that 20 to 25 percent of those with the disease were black or Hispanic. Epidemiologists saw by the following year that those numbers would steadily grow, that, like hepatitis, another disease that passes through blood and semen, AIDS would invade the black and Hispanic communities through the sharing of needles among intravenous drug users, through intercourse among homosexual and bisexual men, and through sex between women and drug-using and bisexual men. Their prognosis was correct: the proportion of AIDS cases found among blacks and Hispanics has grown steadily, and everything now known indicates that those two groups will bear ever-greater shares of the epidemic.

The federal response to the crisis of AIDS in minority communities has been criminally slow. The CDC held its first conference on minority AIDS in August 1987, and established a minority section of its National AIDS Information and Education Program last December. Not until February did the President's AIDS Commission release a draft report acknowledging the severity of the epidemic among blacks and Hispanics. Federal money earmarked for minority AIDS is only now being released; none has yet reached its target.

Minority communities were left to combat AIDS on their own, without the wealthy donors and sensitivity to sexual issues that allowed the white gay community to organize in the face of prejudice and neglect. Within the last three years, dozens of minority AIDS groups have come into being, all relying overwhelmingly or exclusively on the volunteer efforts of poor and working-class people.

This is the story of such groups, and of one in particular: BEBASHI of Philadelphia—Blacks Educating Blacks About Sexual Health Issues—the organization

This article is based on reporting by Bulletin editors William Deresiewicz and Joe Gordon, and was written by Deresiewicz. Health/PAC board members Robert Cohen, Arthur Levin, Ann Umemoto and Richard Younge provided research assistance.
Curtis Wadlington joined in order to help other blacks avoid the pain and frustration he went through for his dying friend.

BEBASHI was organized three years ago by Rashida Hassan, an infection-control nurse and longtime activist within the city's black community. At the time, 98 black Philadelphians had been diagnosed with the disease. Hassan's first task was to convince people that AIDS is actually a black problem. Resistance came from two sources: white gay men and blacks themselves.

"Although the gay community was saying it's not a gay white disease," Hassan recalled during a conversation earlier this year, "AIDS brought about a tremendous gay community empowerment. They said, 'No, we don't want AIDS to be classified as a gay disease, but on the other hand it's given us an opportunity to speak out in ways we haven't been able to before.'"

In fact, Hassan worked at the Philadelphia AIDS Task Force until frustration with the group's lack of response to black concerns led her to organize BEBASHI. "I came into a climate," she recalled, "where I had to say: 'Like everything else in our society, people of color are disproportionately affected, and I'm not going to let my community be the last one to be dealt with again.'"

Hassan spoke with the patience of a teacher and the understated irony of someone who's had to put up with a lot of idiocy.

That same perception of AIDS as a gay white disease thwarted Hassan's efforts to mobilize black leaders. "The last thing they wanted to know was that there was some kind of deadly disease, primarily associated with gay men, affecting their community," she said. "As many leaders told me: 'We've got enough stigma, we don't need to add AIDS to it.'"

But Hassan wasn't daunted. "I knew about the incubation period," she said, "and I thought if we start now, we might have a chance to beat the numbers." She gathered several of her colleagues in health care—nurses, health educators, social workers—to form BEBASHI. At first the group operated out of the living room of Hassan's apartment. She and her colleagues would meet weekly to discuss the issues and plan their activities. They would distribute information and provide support to people who were infected with AIDS.

James Shellington of Baltimore's Health Education Resource Organization distributes AIDS information at city's Lexington Market last spring. A former IV drug user, Shellington is part of HERO's Street Outreach AIDS Prevention Program.
room of one of its members, but BEBASHI's contacts within health care led to an informal arrangement with District 1199C, the Philadelphia local of the National Union of Hospital and Health Care Employees. Since 1986, the union has provided BEBASHI with free office space and covered its operational expenses. The group, with a staff of four and 30 regular volunteers, works out of a single room crowded with pamphlets and festooned with public-health posters; the door is always open and the phones ring constantly.

While BEBASHI seeks to educate all members of the black community, it focuses on gay men, IV drug users, and young people. Targeting programs to the first group has proved difficult. Unlike gay white men, gay blacks don't have a network of political and self-help organizations, because to identify with one another in this way would expose them to double discrimination from white heterosexuals. Nor do gay blacks live in separate neighborhoods. As Hassan said, "People in the black community are not ostracized because of sexual orientation. They live next door, because where else are you going to live?"

BEBASHI distributes condoms and literature in the city's few black gay bars and organizes "home parties"—safer-sex Tupperware parties. "We talk about basic AIDS transmission," Hassan said. "We have a visual aid that we use to show you how to use a condom. We talk about erotic behavior, that sex isn't dead because you have to use a condom."

Like other cities, Philadelphia faces a critical shortage of drug-treatment programs, so protective measures for IV drug users must be implemented within the context of addiction. "IV drug users will tell you that they're very careful who they share their needles with," Hassan said. "That means that at least they're thinking about it." Other AIDS workers have found many addicts to be hostile to AIDS education, resentful of being told, essentially, that they should modify their sexual or drug behavior for the sake of a society that has abandoned them.

Curtis Wadlington talked about his work as coordinator of BEBASHI's youth programs. Sitting across from Hassan at his cluttered desk in the back of the office, he explained that educating young people about AIDS means counseling them about life. "When you start to talk about AIDS," he said, "you end up talking about relationships, school, stress, being yourself, physical and mental health, caring about other people."
Hassan also stressed work with youth: "The younger your audience is," she said, "the more likely you are to reach someone who hasn't had sexual activity. We tell them that part of being an adult is accepting responsibility. We talk to them about self-empowerment, getting them to see that there is actually a reason to save themselves."

Much of BEBASHI's work addresses the black community at large. The group believes the best way of educating people to reduce their risk of contracting AIDS is by talking with them directly. Last year, BEBASHI gave over 750 presentations at schools, community centers, and churches, and sent volunteers out five days a week to talk to people and distribute condoms in gay bars, drug-treatment centers, and the city's commercial sex district. Forty percent of Philadelphia's blacks are illiterate; what brochures BEBASHI does publish present information as briefly as possible, and are understandable to people with second-grade reading levels. The group also appears regularly on Philadelphia's two black radio stations, its best source of publicity, and runs workshops for health professionals, workers in social welfare organizations, and black journalists.

It is often said that AIDS is a magnifying glass for our society, revealing the worst and best in ourselves and our nation. The worst is well-known: homophobia, racism, extreme poverty. BEBASHI is part of what's best, as are dozens of other organizations working in black, Hispanic, Asian, and Native American communities around the country. These include the New York Minority AIDS Task Force, the Hispanic AIDS Forum of New York, the San Francisco Black Coalition on AIDS, the Minority AIDS Project of Los Angeles, the Kupona Network of Chicago (the name means "to get well" in Swahili), HERO (Health Education Resource Organization) of Baltimore, Portland's People of Color United Against AIDS, and the National Native American Prevention Center on AIDS, based in Oakland.

While the history and activities of these groups have been shaped by the politics of their cities and the needs of the particular communities they serve, they have much in common. Many have expanded their activities beyond providing education and information on AIDS to include programs in support of those who have contracted the disease. The New York Minority AIDS Task Force runs group counseling for people with AIDS, people with AIDS-related complex, and families of infected individuals, and has set up an AIDS buddy program. HERO provides legal services and housing, albeit in small numbers, for people with AIDS who have lost their homes. Ron Rowell of the National Native American Prevention Center says he devotes a great deal of time to educating nurses and other health professionals about AIDS within his community.

The Kupona Network, which also provides housing and recently opened a drop-in center for people with AIDS, has been unusual in receiving support from local Chicago officials. "The city health department recognized the importance of what we wanted to do," says its director, Tim Offut. "They encouraged us to form and are doing whatever they can to assist us."

The younger groups—those in cities where AIDS emerged relatively recently—are learning from the older ones. Portland's People of Color United Against AIDS has developed a systematic strategy for disseminating information, first developing a cadre of educators, then going out into the community at large. Amani Jabari, the group's director, has also learned to discuss AIDS infection not in terms of risk groups, but of risk behaviors, to make clear that being gay or taking drugs intravenously does not in itself make one more vulnerable to contracting the disease or pass a death sentence. Talking to gay men, IV drug users, and others about what they can do to reduce their risk lessens their feelings of helplessness and avoids stigmatizing them.

Organizers of nearly all these groups have had to overcome resistance and even hostility from white AIDS organizations, who, they say, resented minorities asking for a piece of the small pie the gay groups had
The city health department recognized the importance of what we wanted to do. They encouraged us to form and are doing whatever they can to assist us' fought so hard to win. Minority-run organizations were disdained as "Johnny-come-latelies," and were told they would have to refight the same battles white organizations were already beginning to win. "There are people within white male communities," says Amanda Houston-Hamilton, a physician with the San Francisco Black Coalition on AIDS, "who, no matter what their sexuality, are racist."

Even when white AIDS organizations conceded the need for education and counseling among blacks and Hispanics, they insisted on remaining in charge, on "owning AIDS," as several activists put it. Suki Ports, former director of the New York Minority AIDS Task Force, says that organizations like the Gay Men's Health Crisis were loathe to surrender their reputation as the experts on AIDS even though the programs they had developed for mostly middle-class white men were inappropriate for people of different status, educational level, and ethnicity.

Nor have minority AIDS organizations received much encouragement from existing institutions within their communities. The most influential and all-pervading institution in black and Hispanic communities is the church, and most churches have been very slow in confronting the epidemic. Never before having dealt with issues of sexuality in any but the most dogmatic way, they have neither the framework nor the appetite for discussions of homosexuality, adolescent sexuality, or safer sex. But there are ways for churches to help even without confronting these issues — by counseling families of people with AIDS, running programs for drug users, and stressing the importance of AIDS prevention for the preservation of the family. A growing number of churches have begun such programs, often in response to pressure from minority AIDS groups.

While the churches' reluctance to confront the epidemic stems from religious taboos, it also reflects the stigma that many in minority communities attach to homosexuality. Many blacks and Hispanics with AIDS, Suki Ports says, find that revealing their condition cuts them off from friends, family, and community.

In addition to this, Hassan and other grassroots organizers point out that the major national black organizations — the NAACP, the Southern Christian Leadership Conference, the Urban League — have so far done very little in the fight against AIDS.

Yet the obstacles white AIDS groups and the black and Hispanic leadership have placed in the way of minority AIDS organizations are like pebbles compared to the monumental public health problems in whose shadow these communities have lived for generations: inadequate health services, medical indigency, malnutrition, unemployment, a dearth of decent housing. "People walk in with AIDS, but they also walk in with poverty," says the Rev. Carl Bean of the Minority AIDS Project in Los Angeles, a group he founded in 1985 upon discovering that no one in his city was addressing the problems of black people with AIDS. "We're dealing with mothers who have to grease the crib legs and place them in cans of oil to keep the rats off the crib, kids who still hunt down soda bottles to buy potato chips for a meal."

"People of color with AIDS," Hassan says, "come with all the social problems that you can think of: they're unemployed, they're probably going to be homeless if they're not already, they don't have health insurance." They are thrown at the mercy of overburdened social welfare systems that often do everything in their power to deny them help. AIDS, she explains, has become an excuse to deny public housing, health care, and psychiatric services to people in need.

What resources do minority AIDS organizations have to educate their vast communities about AIDS prevention and offer help and comfort to the thousands who have contracted the disease? Private contributions and volunteers — "peanuts and love," as one activist put it. This may resemble the situation white AIDS groups faced until several years ago, but, black organizations point out, it's even worse. Minority communities can't draw on the kind of wealth that can generate a million dollars in a single evening; Rashida Hassan tells of col-
lecting five and ten dollars at a time from neighbors. And volunteers, as Suki Ports explains, are much harder to recruit in places where people need every minute for survival.

Yet even today, the most well-funded groups run primarily on volunteer effort. And, as Curtis Wadlington says, "When we say 'volunteer' we should say 'crazy people,' because they volunteer an eight-hour day." BEBASHI, like other groups, has been able to stay afloat with small city service contracts, enough to pay for Hassan's salary, at least. The group was recently awarded a $100,000 grant from the City of Philadelphia, which brings its total operating budget to a quarter of a million dollars, about a tenth of what Curtis Wadlington estimates is needed to educate Philadelphia's 600,000 blacks effectively. Still, that's way ahead of the $100,000 budget of the New York Minority AIDS Task Force, one of the major minority AIDS service organizations in a city of over three million blacks and Hispanics.

Only tax dollars can provide the sums needed to turn the rising tide of AIDS in minority communities. Yet as of this writing, Congress has allotted only $10 million for AIDS education and information programs in minority communities. Of that total, $7 million went first to states, which then issued requests for proposals (RFP's)—invitations to community-based groups to apply for grants for specific projects. The states are evaluating the responses they have received. There are several problems with RFP's. Each embodies certain values, which, according to Paul Moore, head of the AIDS Initiative of New York City's Health and Hospitals Corporation, tend to be those of the white middle class. Advances in our understanding of AIDS tend to be long in reaching the bureaucrats who draft them. "San Francisco to this day is writing RFP's that say that AIDS is a gay white disease," Amanda Houston-Hamilton says.

The RFP system, as Amani Jabari points out, is based on the idea that organizations should fight with one another for funds. The name of his group, in fact—People of Color United Against AIDS—reflects the attempt of minority AIDS groups in Portland to cooperate with each other despite the efforts of the state health department to force them into competition. The biggest problem with applying the RFP system to AIDS funding is the time it takes. The $7 million allocated to states will not reach the streets until June, more than nine months after it was appropriated.

An additional $3 million has been appropriated for national minority AIDS organizations like the National Minority AIDS Council [see sidebar]. This money, too, will go through a system of RFP's, and will finally be dispensed in September. The $10 million total, taken out of the roughly $100 million Congress has appropriated to AIDS education and information overall, comes in the eighth year of an epidemic that from its very beginning had at least a 20 percent minority component.

Paula Van Ness, head of the CDC's Office of AIDS Education and Information, points out that much of the money already allocated to fight the epidemic has gone to services—programs for children, for IV drug users—

---

Organizations Fighting AIDS

Readers interested in finding out more about minority AIDS organizations can contact the National Minority AIDS Council (NMAC), a new organization under the direction of Don Edwards. NMAC is organizing a conference to develop a national strategic plan to combat the epidemic in the minority community. Many of the groups mentioned in this article are Council members. Write: NMAC, 714 G St. S.E., Washington, DC 20005.

The National AIDS Network also does important work on minority AIDS issues. Its monthly newsletter for members, Multicultural Notes on AIDS Education and Service, provides useful information on minority AIDS initiatives. NAN's Minority Affairs Director is Gilberto Gerald. Write: 1012 14th N.W., Suite 601, Washington, DC 20005.

A listing of the other organizations mentioned in the article follows:

Hispanic AIDS Forum
140 W. 22 St., Suite 301
New York, NY 10011

BEBASHI
1319 Locust St.
Philadelphia, PA 19107

Minority Task Force on AIDS
92 St. Nicholas Ave., Suite 1B
New York, NY 10026

The Kupona Network
4611 S. Ellis
Chicago, IL 60653

HERO
101 W. Read St., Suite 812
Baltimore, MD 21201

National Native American
Prevention Center on AIDS
5266 Boyd Ave.
Oakland, CA 94618

San Francisco Black Coalition
on AIDS
URSA Institute
185 Berry St., #6600
San Francisco, CA 94107

Minority AIDS Project
5882 W. Pico Blvd., Suite 210
Los Angeles, CA 90019

People of Color
United Against AIDS
2813 SE Colt Drive #432
Portland, OR 97202

Spring 1988

Health/PAC Bulletin
Rev. Carl Bean, executive director, the Minority AIDS Project, Los Angeles.

We're dealing with mothers who have to grease the crib legs and place them in cans of oil to keep the rats off!

that, while not specifically targeted to minority communities, serve members of those groups. She also maintains that decisions about AIDS funding are made by Congress, not by the CDC. "If I had my way," she says, "I'd be spending a billion dollars on education alone. But no one cares what I want."

AIDS has been and is still perceived as a disease that has yet to affect the "general population." Large segments of the public and the media continue to see it as a disease confined to certain outgroups who brought it on themselves. Rather than leading the country towards an acknowledgement of the scope of the epidemic, Congress has pandered to popular prejudice and distrust. "We're in an election year," Van Ness says. "Some people think AIDS has been overplayed." Every day that's wasted means more lives lost; the federal and state response to AIDS so far amounts to negligent homicide on a vast scale.

When will AIDS get the money it needs? "It won't be until case numbers nationally reach a million," Rashida Hassan says. "People will literally be dying in the streets."

Until then, the Rashida Hassans and Curtis Wadlington's will continue to fight for the survival of their communities. Wadlington learned a long time ago that no one else will fight for them, and that ordinary commitment isn't enough. "We tell people in training" he says, "that it's down to the real stuff now—either we sink or swim. Because a lot of people are going to die in the next five years, and we're going to need that mentality just to save the few." □
Q:
With virtually no advertising, no large donors, or foundation grants, how does Health/PAC keep going?

A:
READERS.

To keep going—and to continue growing—Health/PAC needs your help in reaching out to new readers. We're 20 years old this year and deeply committed to continuing our tradition of independent health care journalism.

We've come this far by bringing you vital reporting and analysis of critical health care issues in a magazine that also offers hope and encouragement for the future of health care.

As the massive need for care continues to go unmet... as the AIDS epidemic grows without an adequate federal response... as our decaying public hospital system is strained to new limits, and as fragile health and civil rights remain under attack, the Bulletin will continue to speak out as a voice of conscience and concern.

Help Health/PAC by recommending the Bulletin to others, giving a gift of membership to a friend or colleague, or by sending a contribution.

Yes, I want to become a member of the Health Policy Advisory Center and receive the Health/PAC Bulletin.
☐ Individuals $35.00  ☐ Institutional subscription $45  ☐ Students/low income $22.50
☐ I'd like to send the Bulletin as a gift to the person(s) at the address below. My payment is enclosed. Please notify them of my gift.
☐ I want to help Health/PAC support the fight for health care. Enclosed is my tax deductible contribution of $15 $25 $50 $100 other.

Name
________________________________________________________________________

City ___________________________ State _______ Zip ___________________________

Charge:  ☐ Visa  ☐ Mastercard No. ________________________________

Exp. Date ___________ Signature ___________

Send your check or money order to:
Health/PAC Bulletin, 17 Murray St., New York, N.Y. 10007
Edguardo Cruz is 33 years old and has AIDS-related complex (ARC). He shares a variety of hardships with other poor Puerto Rican New Yorkers whose lives have been interrupted by illness and the strong social stigma of AIDS.

A veteran and former postal worker, he was treated for pneumonia at Manhattan's Veterans Administration Medical Center in February. He had just been turned away from a Brooklyn hospital after telling an emergency room physician that he has ARC. "They made me wait six hours and then they threw me out," he said recently.

Cruz had a high fever and chills when a friend drove him to the V.A. hospital. There he joined 16 other patients in the new AIDS unit; the hospital treats more than 100 AIDS outpatients, 70 percent of whom are black and Hispanic. As he sat near a picture window facing the East River, he spoke about having two lives: before and after he tested HIV-positive in 1985. He separated from his wife and young son a year later. His brother knows he has ARC, but not his mother nor his closest aunt. She lost her son to AIDS last year. The death of Edguardo's 31-year-old cousin affected him deeply. They had shared needles. Both his mother and aunt believe that he is ill because of a preexisting medical problem, which affects the muscle and nerve functions of Edguardo's hands and legs.

One of his hopes is to return to Puerto Rico, where he spent his childhood with his grandmother. He likes to skim the island's newspapers for real estate ads. "You could live good and cheap there," he told me during our two-hour meeting. His poor health, low income, and lack of family and community supports leave Edguardo with few options. He's on a waiting list for public housing, and he's also appealing the rejection of his request for a V.A. pension increase. When he left the hospital in February, he had no place of his own to go to. He was feeling stronger and eagerly awaited a visit with his son. Staff members at the AIDS unit were pursuing housing leads for him and following up on his benefits appeal. Despite his wish to keep his illness from his close relatives, Edguardo generously consented to this interview. He was encouraged that his words would be read by people who want to help fight AIDS.

—Joe Gordon

"The Other Half I Got to Live"

Life with AIDS-Related Complex

As soon as the bomb exploded on me, everything went like a blackout. There was nothing else there. The first thing I thought about was did I give my wife the virus? I started sweating drops and everything. She took the test and praise God she came out negative. A year after, we started getting more and more separated. Her family was scared, and I could understand them being scared. They saw these things on TV, people dying, and they used to pressure her. She used to come home from her mother's, crying, and I knew what she was crying about. I came to the conclusion that it was better we got separated than have her go through all the things that, you know—she was getting disgusted, our sex life was all different. She wasn't comfortable any more, and I wasn't feeling comfortable. And we used to look at each other and we couldn't, we didn't know how to, you know, bring our closeness back together again.

That happened. That's the way it is now. Everything is brought down because of the sickness. And the hard thing about it is that I was "clean" a whole year before this happened. When I was in high school, I used to see girls and guys shooting up right in the auditorium. I used to see that all the time, and I'd say, I couldn't never do that. I mean I saw junkies, man, like my uncle. I used to see him get sick, and I said I would never do that. I saw what it did to other people, but I still did it.

We had plans, me and my wife. We had a great relationship. And since we already had one son, we wanted to see if we could get the girl, right? But then it was this bomb. I moved out of the house. My son is 10.
When you come to think of it, it hurts. I didn't want her to come to see me like she hated me, or that she was being with me because she had to, because I was sick. We're great friends and everything, but we're just not together.

I'll tell you the truth, I gave up a lot, cause I was living good in my house. I had my meals. I was sleeping warm, had my big bathroom. I used to just be able to lay there, to stay with my wife and son. Help him with his homework. "Pappy, help me!" "No, after you do it, then I check it." And I would be working in the post office. That's what I'd be doing.

But I'm having difficulty now. Because now that I moved out, I be staying in, like, my aunt's house, and it's hard to get housing. The apartments are expensive and my income each month is only $425, and I've been fighting for my V.A. benefits increase for a year and a half already. All the rents are being raised. Forget it. Where I used to live they're asking 600 bucks. Where am I going to get 600 bucks to pay for an apartment? It's gonna be more murders and killings, because I'm telling you the rent is too high. I could stay at my mother's house a couple a nights, but not constant. Especially if I get sick. She don't have a big house. If I ever get real, real sick and I need care in the house, that's gonna be the hard part. That's gonna be the question. I hope that never comes up.

If I tell my mother, she'll get mad. She'll start crying. She'll start saying, "Ooh, my baby!" She's gonna say, "It happened because you don't care for yourself." But she'll also feel bad, she'll feel like any other natural mother. When my cousin died of AIDS he was sick, he was bad, man. He couldn't breathe, he couldn't talk, he couldn't eat. He was real bad. A lot of my friends have died. A lot of guys got AIDS and they don't want to even talk to you, to look at you. They're ashamed. You know, my pastor wanted me to step up on top of the pulpit and give my testimony that I got AIDS and Jesus is taking care of me. But I don't want people to be looking at me, like, you know, some leper. No matter what you say, people are gonna put up a wall. It's a little better now because people are getting to see it and understand it. Especially the poor folks. The "us," you know, what they call the minorities. We see it so much.

People could help you when you talk to them, but that's it. You got the last decision. You are alone. That's why I hurt, cause a lot of people tell you, "Oh, we understand." But you don't understand nothing, cause you ain't going through it. Like, when I go dancing and I see a pretty girl, I can't tell this girl anything that would try to get her closer to me. And that's hard, but we have to deal with that. I can't have no relationships. I can't do anything. That's why I say I'm usually laughing about it, because if I wasn't laughing about it, I wouldn't be here today. But this is the thing, you can't do anything about it. You just keep doing what you're supposed to do, like eat and feel good. Taking care of myself and doing what the doctor tells me to... But if I could get me a place, with my own kitchen, my own bathroom, and my own room, I'll be great. I feel like I could make a good life with whatever I got left.

Edguardo Cruz, who has AIDS-related complex, is trying to lead an independent life, despite his poverty and poor health.
From the AIDS Unit: A Social Work Story

RHYS McMARTIN

Just as I was trying to complete some paperwork before calling it a day at the hospital I work at, a male nurse entered my office and asked in a quietly demanding manner, “What are you doing for the family members of AIDS patients?” I explained that I’m only here part-time and haven’t had the opportunity to set up any support groups, but that I hoped to do so in the near future. Even though the tone of his question annoyed me, I controlled my voice to try to honor the unwritten policy of decorum on the new AIDS unit. What I said didn’t seem to temper him, and he continued to tell me the facts of a case I already knew. He said that Mrs. Rivera, the mother of a patient currently on our ward, lost the youngest of her sons to AIDS a year ago, has not had the time to mourn his loss, and is in need of some kind of counseling.

Mrs. Rivera was well-known for running down the halls. She would rush by, en route to her son’s room, slipping her hands into rubber gloves like a doctor speeding to emergency surgery. She was often frantic, always loud, and frequently took it upon herself to perform the most personal nursing duties for her middle-aged son, whom she called “baby.” All this passed through my mind as the nurse asked, “Is there anything you can do for her now?”

He was annoyed by my efforts to finish up my paperwork and remained standing at the door. He wasn’t going away, so I put down my social work summary and asked him to show me to Mrs. Rivera.

Mrs. Rivera was with her son in the TV room at the end of the hall. There she sat, talking loudly, taking up the space of two chairs, and emptying out a flight bag filled with two bottles of disinfectant, rubber gloves, paper towels, and cherry-flavored cough drops for her son’s cold. In the flurry, I saw her pop what appeared to be a Valium into her mouth. As her voice drowned out the six o’clock news, patients and their visitors gradually made their way out of the room.

To my left in the TV room sat her son, Pepe, who was trying to move his wheelchair toward me. He was being fed three IV medications and was faintly repeating something that sounded like “meth...meth...meth...methadone.” I took a deep breath and asked Mrs. Rivera if I could speak privately with her in her son’s room. In rapid response she asked, “Did I do something wrong? Is there bad news?” I assured her that nothing was wrong and that there was no bad news.

Mrs. Rivera is in her early sixties and comes from a large family. She wears slacks, no makeup, and has her hair pulled back into a small ponytail. She comes to visit armed with her large vinyl flight bag, purse, and always with food for other patients on the ward. Her son has been living with her since he was first diagnosed with AIDS. He is now a patient in the new AIDS unit here. She tells me that Pepe began taking drugs at the age of 13, stealing from friends and neighbors to support his habit. On various occasions, she and everyone else in her family have been roughed up by neighborhood thugs as a way of settling old scores. One year ago she lost her youngest “baby” to AIDS, and now wonders what will happen to her once this son dies. Caring for her grown sons has become a way of life for her.

“How do other mothers cope with burying their own flesh and blood?”

She told me that because of her own health problems she is unable to visit as frequently as she would like. She is on Medicaid and has a home-health aide. For the next 15 minutes she described her hypertension, headaches, high cholesterol, and hemorrhoids. She told me a little story of how her home attendant can find meat with absolutely no fat, and is prepared to get into fights with butchers, if necessary. When I tried to focus the conversation by asking her when she had last seen her doctor, she gave me a long, hard stare and continued to list her ailments.

Her speech was loud and tense. One minute she was crying, and the next minute she was raising up her fist as if raging out against someone. She said she would “get even” with everyone who had given her son drugs. “I’m gonna get them,” she said, lunging forward in her chair, her tired eyes squinting with rage. I gave what I hoped would sound like a sigh of support, but I was really feeling hopeless and lost. I wondered whether

Rhys McMARTIN, MSW, is a social worker who has elected to work specifically with people with AIDS.
this was the way Mrs. Rivera felt all of the time. After catching her breath she asked me if she could smoke and, in an attempt to calm her, I said sure. As she held her unlit cigarette, I kept thinking about how much I wanted to prove myself to the staff, particularly to the male nurse; I hoped that when Mrs. Rivera left the room she would appear more relaxed after her "therapy." Noticing the oxygen tank in the room, she again asked if it was okay to smoke, and I again consented. But with her eye on the tank, she stopped short before striking the match. "I don't care about myself," she said, "but I don't want anything to happen to you." With tears in her eyes she discussed her son's illness. As she spoke, her words triggered another angry outburst, this time directed at her son-in-law, who, she said, slandered Pepe's reputation over the Christmas holiday. She said she wished "he should suffer half of what Pepe is going through," and again raised her clenched hand upwards. She was like an exhausted boxer in the midst of a long fight. Her words flailed the air like tired fists. Then she asked me, "How do other mothers feel? How do they cope with burying their own flesh and blood?" All I could think of was an old movie I had seen about a family during the Second World War. Every one of their sons had been lost in battle; then a law was passed that prohibited drafting all of a family's children. Now, even though we are not at war, some mothers are still losing all their children.

As Mrs. Rivera resumed her angry outburst at her son-in-law, I had the feeling that what was taking place before me was not of the real world. I wanted to pretend that I was sitting in some small, dark Off-Off-Broadway theater. I felt that I dared not leave, for fear that something might happen to me. Again her anger and frustration mounted as she spoke. But when she heard her son yelling, "Mama! Mama!" off she went, bolting from her chair and running down the hall of the AIDS unit as I sat there wondering just where I was.

Back in my office, I thought over what I might have done differently. I wondered why I was unable to feel more empathy for her. How much was she hurting? How much was a stage performance? Looking at Mrs. Rivera I saw my father's face—he could also laugh and rage all in the same breath. But before I could dismiss Mrs. Rivera because of this memory, another one flashed before me. Many years ago, when I first moved here from the Midwest, I had lost someone whom I loved very much. I remember having gone through the same kind of hysterics and doing anything I could to dull my senses. I would visit friends and become a "management problem," just as Mrs. Rivera is a "management problem." But wasn't I in pain and asking for help? Didn't people help me? Didn't I really want to help Mrs. Rivera?

I returned to the TV room and scheduled another appointment with her. ☐
The AIDS epidemic is inseparably entwined in the social and political fabric of this country. As with all epidemics, AIDS offers our society the opportunity to address underlying problems that have contributed to its rapid spread: sharp cutbacks in primary and preventive care, the refusal to make a serious effort to solve this country's drug crisis, a lack of any systematic attempt to provide people with comprehensive health and sex education, and discrimination against homosexuals, women, and minorities.

So far, the social movements that erupted in the 1960's and early 1970's have not been very successful in offering an alternative vision of how to respond to the AIDS epidemic. At best, they have reacted defensively to the moralistic and punitive view of AIDS coming from the Reagan administration and its supporters. While the gay movement has made impressive strides in educating gay men about AIDS, in reducing high-risk behavior, and in forcing the government to allocate more resources for treatment, research, and prevention, it has not yet been able to forge a broader coalition united around a concrete political agenda.

Such an agenda would call for dramatic new efforts in drug prevention and treatment, increased access to primary care (including health counseling), intensive community and school-based health education, and stronger and more vigorously enforced protection against discrimination for gays, women, and minorities. It would seek to link ongoing struggles for better living conditions and increased social justice to concrete demands for services needed to stop the spread of AIDS.

There is no more urgent political and public health task in the coming years than to mobilize blacks, Latinos, women, health workers, labor unions, and others to put AIDS prevention high on their agendas. Such an effort could result in both much wider support for preventive action and a more comprehensive view of what needs to be done to stop the spread of AIDS.

To accomplish these goals, the political forces that need to act must thoroughly understand the history of the epidemic's early years. Why did the gay community respond as it did? How did the country's social and political environment determine how minorities or women or middle-class Americans responded to AIDS? How did the federal government's role influence the political dialogue on AIDS? What role did the media play?

Answers to these questions could lay the foundation for a political strategy for AIDS prevention. The questions also establish a critical point of departure for judging the growing collection of books on AIDS. And the Band Played On: Politics, People, and the AIDS Epidemic, by Randy Shilts, has been widely recognized as the most comprehensive history of the epidemic's first five years, 1980 to 1985. I intend in this review to examine just how well Shilts' book gives us the insights needed to respond to the next phase of the epidemic.

The central thesis of And the Band Played On is that the United States missed the opportunity to stop this epidemic. "The bitter truth," writes Shilts "was that AIDS did not just happen to America—it was allowed to happen by an array of institutions, all of which failed to perform their appropriate tasks to safeguard the public health... The story of these first five years of AIDS in America is a drama of national failure, played out against a backdrop of needless death."

Shilts blames the Reagan administration, the scientific community, public health authorities, local political leaders, gay community leaders, and the mass media for refusing to take the necessary steps to contain the epidemic. Ultimately, he concludes, the early history of the AIDS epidemic is a morality play, "a tale of courage as well as cowardice, compassion as well as bigotry, inspiration as well as venality, and redemption as well as despair."

Nick Freudenberg is director of the Program in Community Health Education at Hunter College School of Health Sciences/CUNY.
scientists. He is willing to ask questions, challenge authorities, and investigate the claims of scientists and public officials.

Shilts describes in detail the Reagan administration's consistent rejection of requests for more resources for AIDS and the reluctance of political leaders in New York City and San Francisco to take strong action early in the epidemic. He demonstrates clearly that the control of AIDS depends as much on what happens in politicians' offices as on what happens in research laboratories or hospital wards. A broader understanding of this insight would provide a useful antidote to the media's constant focus on the search for a technological fix, such as an effective vaccine or a new drug.

Shilts also makes clear that while the origin of the epidemic may have been beyond human control, its spread was not. It was decisions made by the Reagan administration, local politicians, public health officials, and some infected individuals that allowed the human immunodeficiency virus to become endemic in certain populations and localities. In his novel, *The Plague*, Albert Camus described the sense of inevitability and passivity that deepened as his fictional epidemic widened. Today many fear that AIDS is beyond our control, a message that Shilts contradicts by directly linking each rise in the epidemic's toll to specific opportunities missed or actions not taken.

The book also helps to give AIDS a human face by describing how several people have experienced the disease from pre-diagnosis to death. AIDS educators have found that people with AIDS can often quickly break through public fears and misconceptions, and Shilts' portraits provide a vivid picture of such struggles. This compassionate response to real people facing death with dignity and courage reminds us of the important role people with AIDS will continue to play in challenging society to respond to the epidemic with humanity rather than hysteria.

Any chronicle of a condition as complex as AIDS will inevitably leave out certain important details. Is it fair to fault Shilts for his omissions? Yes. A journalist covering a story as major as this one is obligated to communicate its significant elements. If she or he fails to do so, readers are entitled to protest. For an engaged journalist like Shilts, the obligations are even greater. Shilts wrote this book "so that [an epidemic such as AIDS] will never happen again, to any people, anywhere." As readers who are public health advocates, we must judge whether his presentation helps to achieve his stated goal.

Among the most glaring deficiencies is the negligible attention Shilts gives to the tragic experience of AIDS among minorities, intravenous drug users, and women. While the story of Gaetan Dugas, the homosexual airline steward who is believed to have infected
scores of men on the East and West Coasts, is described in lurid detail (he is mentioned 39 times in the book), there is not a single description of a black man with AIDS. Only brief passages describe how IV drug users or women lived and died with the disease. Belle Glade, a Florida town with a large black population and one of the highest prevalences of AIDS in the country, gets no mention. The Haitian connection with AIDS, a remarkable political and scientific controversy, receives scant attention and gets none of the investigative reporting that Shilts offers elsewhere in the book.

In his book, *AIDS in the Mind of America* (1986), Dennis Altman observed that “the central dilemma in thinking about AIDS is that while it is medical nonsense to think of it as a ‘gay disease,’ it is the gay experience of AIDS, rather than, say, that of drug users, hemophiliacs, or Zairians, that has shaped the perceptions and politics of the epidemic.” Changing this perception is a crucial public health task if we are to break the false and dangerous sense of invulnerability to AIDS felt by so many groups. It is also a crucial political task in generating broader support for prevention.

In reality, by the end of 1987, 38 percent of people with AIDS in the United States were black or Latino, more than 16 percent were intravenous drug users, and 7 percent were women. In New York City, 56 percent of people with AIDS are black or Hispanic, 31 percent are IV drug users, and nearly 11 percent are women.

**Is it fair to fault Shilts for his omissions? Yes.**

Any progressive political response to the AIDS epidemic must take into account these groups’ experiences with AIDS, as well as those of gay men. There is no doubt that gay men (including blacks and Hispanics) have borne the brunt of the epidemic and that the gay community has more fully mobilized against AIDS than any other group. But gay, minority, ex-drug users’, health workers’, and women’s organizations must forge a common stand on what is needed to control the epidemic. Otherwise, the right-wing agenda on AIDS—massive and mandatory testing, moralistic preaching of traditional values of chastity and monogamy, and isolation of people with AIDS—will lose its most committed and politically sophisticated opponents.

Weaving these disparate groups into a viable coalition poses a formidable political challenge. Their different class, political, and historical experiences are linked only through their common oppression by the dominant society. Shilts’ account of the epidemic makes this unifying task more difficult by leaving out some crucial chapters of its history.

Shilts seeks to explain why gay men failed to heed the early warnings that AIDS was spread by anal intercourse with an infected partner. He attributes this reluctance to an unwillingness to give up the seemingly unlimited sexual freedoms won in the late 1960’s and 1970’s, to an ideological position that puts “political dogma ahead of the preservation of human life,” and to the greed of gay entrepreneurs who profited from sexual license.

Another explanation, mentioned but not sufficiently examined, is the profound distrust of government, media, and medical authorities felt by gay men as well as by minorities and IV drug users. It was the government itself, after all, that made homosexuality illegal. And until the early 1970’s, the American Psychiatric Association had defined homosexuality as a mental illness.

More broadly speaking, the government that brought us the infamous Tuskegee experiment, the Love Canal coverup, Three Mile Island, and sterilization abuse gives disenfranchised groups ample reason to be distrustful. Is it surprising that the belief remains widespread in gay and minority communities that AIDS can be traced to an experiment in biological warfare conducted by the U.S. government? In view of this, is it plausible to expect these communities to trust information campaigns on drugs and sex that are sponsored or funded by this same government? By laying such heavy
responsibility for inaction on the gay community itself, Shilts ignores the political context and blames the victims of the epidemic for their condition.

Most AIDS organizations and activists have insisted that the federal government play a stronger role in educating the public about AIDS, a thrust that Shilts does not question. It is true that only the federal government has the resources that a comprehensive prevention campaign requires. But the unwillingness of many AIDS workers to challenge the content of federal efforts—or the government's control—seriously limits the effect of these programs because the target populations distrust both the messenger and the explicit conservatism of its message.

Perhaps the most effective AIDS educators are those with a history of challenging the government and protecting their communities against discrimination, yet these are precisely the groups least likely to get federal dollars. Cindy Patton, a former editor of Boston's Gay Community News, has described the transformation of many AIDS organizations from activist and advocacy groups into more established service providers, a metamorphosis sped up by government funding. By overlooking this central dilemma that AIDS organizations have grappled with for the past three or four years, Shilts misses an opportunity to examine the political pressures faced by AIDS programs that have received federal support.

There is not a single description of a black man with AIDS.

Similarly, his limited descriptions of the class and racial background of the gay community in New York City or San Francisco provides little understanding of the political potential of the gay movement. In her history of the creation of the Castro, San Francisco's gay community, Frances Fitzgerald notes in Cities on a Hill that by 1978, San Francisco gay society was pulling away from its origins in the counterculture. "It was doing so," she writes, "in part for reasons that had little to do with homosexuality and a great deal to do with the fact that its inhabitants were well-educated young white men. It had become a male preserve—and a society that more or less ignored gay women; it was now becoming a class preserve." These changes in the way gay men perceived their relationship to the dominant society during the late 1970's and early 1980's helped to define the stance they took towards AIDS and the government. In becoming an interest group, rather than a movement, their ability to pose a larger political vision was diminished. Without examining this political process it is difficult to assess why the gay leaders responded as they did. Shilts' explanation again blames the victims of the epidemic and trivializes the complexities of gay politics.

In truth, Shilts' political history of the AIDS epidemic is curiously apolitical. By framing the story as a morality play, his account often degenerates into a battle between the good guys and the bad guys. Anyone who called for decisive action early is a hero. Anyone who opposed such action is cowardly, opportunistic, or stupid.

Thus, President Reagan, San Francisco Director of Public Health Mervyn Silverman, New York City Health Commissioner David Sencer, and a variety of gay leaders, blood bank officials, and civil rights lawyers are all grouped together as the enemy. Conversely, Shilts casts Gay Men's Health Crisis founder Larry Kramer, CDC virologist Don Francis, and San Francisco epidemiologist Selma Dritz as heroes.

Shilts is correct when he writes that the epidemic has brought forth both admirable and reprehensible behavior, but readers need a framework for assessing the significance of these actions. His undifferentiated sense of
outrage obscures rather than clarifies who the real enemies are and how to unite to challenge them. This oversimplification extends into other areas. Shilts castigates Silverman for failing to shut San Francisco's gay bathhouses earlier and Sencer for not making HIV testing more widely available to New York City residents. But Silverman had an explicit strategy of seeking community approval for such action prior to imposing legal sanctions. Acting without such support, he argued, would reinforce gay men's distrust of health authorities, closing the door to further communication. One can disagree with this often-ignored public health principle, but it is neither cowardly nor stupid. Shilts frames the AIDS story as a morality play.

As for HIV testing, even by early 1988, there is not yet substantial evidence that HIV antibody screening by itself leads to significant reductions in risk behavior. There are clear indications that it can have negative psychological consequences for those who test positive and can lead to loss of health insurance, employment, and friends. Even now, few testing programs include the level of counseling and support needed to help those tested use the information to protect themselves and others. To have questioned widespread testing in 1984 and 1985 can be said to show thoughtful restraint, not callous indifference to public health.

Shilts' vitriolic attacks on Silverman, Sencer, and others are ill-informed, but most importantly, they dismiss the real debates that must continue on the most effective public health and political strategies for containing the epidemic. He accepts the conservative dogma that rigorous public health measures and strong protection of civil liberties are polar opposites. Shilts implicitly suggests that any opposition to any proposal for strong public health measures is motivated by cowardice or unwillingness to confront self-interested opposition. This view gives unintentional support to most efforts by the right wing to discredit opponents of its punitive approach to AIDS.

Finally, and perhaps most importantly, Shilts oversimplifies what needed to be done to contain this epidemic early on and what needs to be done now. Current evidence suggests that by 1982 or 1983, the virus believed to cause AIDS was already well established in certain sectors of gay men, intravenous drug users, and recipients of blood transfusions. More vigorous and explicit educational campaigns begun then could have helped prevent its further spread, and more systematic and coordinated research might have led to quicker clinical results, but it seems unlikely that these actions would have significantly lowered the mortality seen through 1987. After all, those who are dying of AIDS today were in all likelihood infected several years ago.

The real roots of the epidemic go deeper into our social structures and further back in history. We can only speculate about what measures might have prevented the rapid spread of HIV infection: a serious and nonpunitive response to the heroin epidemic of the 1960's and 1970's, one that offered treatment, jobs, and hope to the hundreds of thousands of addicted men and women; a climate in which gay men could have defined a sexuality for themselves free of police harassment, a repressed sexual ethic, and stereotyped gender roles; an educational system that provided young people with a usable understanding of health and sexuality; a culture in which women could obtain and use effective contraception and sexually transmitted disease protection without interference from the government or their sexual partners; a health care system that made primary and preventive care readily available.

Shilts' political history of AIDS is curiously apolitical.

Obviously, a better and more just society would have a very different pattern of health and disease, but it is not rhetorical to insist that we need both a public health and a political vision to inform and inspire our efforts to contain this epidemic. The AIDS epidemic provides an opportunity to mobilize the resources needed to address social defects that preceded and will follow this current crisis.

If we can use this crisis to ensure that the society that emerges is more just and more healthful, then our efforts to contain this epidemic will have lasting significance. And the Band Played On provides an important account of the epidemic's early years. It conveys a sense of urgency that can inspire us to work harder, but the history we need to move us forward in controlling the AIDS epidemic has yet to be written. □
Health Care for All
And Not a Penny More: A Proposal

ALAN SAGER

The United States spends more money to provide less health care to a smaller portion of citizens than any other industrial democracy. The care we do provide is less effective than that given elsewhere. Yet even this will cost us about $540 billion this year, or $1.5 billion a day.

Despite the escalation of military spending during the past eight years, we still spend 60 percent more on health than on defense.

How do other nations do better with less? Are they more adept at preventing illness? Probably not. Smoking and drinking are more common in Europe; intense industrialization there means more serious environmental threats to health.

Do other nations save money by keeping people out of the hospital? No. Patient-days per capita are far higher in Western Europe and Canada than in the United States.

The differences lie mainly in more intelligent use of resources. Because hospitals elsewhere operate under budgetary constraints, but have no constraints on their obligation to serve people, they and their physicians must make clinical trade-offs between care and cost. Their administrative costs are appreciably lower. In addition, Western Europeans and Canadians who are ill seek services sooner because they do not face financial barriers to care. Early diagnosis saves lives and money. The health systems in other democracies are far from perfect, but they have achieved great things.

While each European and Canadian system has been shaped by unique political, economic, and cultural conditions, they share at least one phenomenon. During periods of financial crisis, most of these nations established a program of national health insurance (NHI) or national health service (NHS) to achieve universal access at affordable costs. Hospitals faced bankruptcy, and only public money could save them. In return, the public sought equal access to care, affordable only if costs could be controlled. A bargain was struck: universal access and public support of hospitals in exchange for public regulation.

Three Routes to Equity

Controlling costs is central to the future of equal access to health care in the United States. The Health Care Financing Administration recently estimated that, if current trends continue, our expenditure on health care will reach 15 percent of the GNP by the year 2000—up from 11.2 percent now. Even this growth assumes no improvements in access. Our weakening economy will not bear such an increase.

Many of those eager to keep costs below 15 percent will not welcome improvements in access. Advocates of universal access should therefore fight for intelligent, appropriate cost controls whenever possible. Increased spending has usually been the lubricant of greater equity and the financier of reform in the United States, and has been the habitual companion of NHI and NHS elsewhere. We can't afford that. In this article, I propose a way to achieve universal access and reform the delivery of health care without spending more money.

There are at least three paths that lead—directly or indirectly—to a health care system that combines universal entitlement, simple and progressive financing, and reform of delivery systems.

One path is simple and comprehensive: a direct leap to a national health program embodying progressive principles. Regrettably, it is unlikely to attract the political constituency it deserves at any time in the near future.

Uninsured citizens would have access to integrated, one-class care.

A second path involves financing insurance coverage incrementally for progressively larger groups of uninsured citizens. This would require raising new money to pay premiums—a great deal of it. Premiums would be high because health care is expensive. Insurance entities individuals to all the care the system can give and doesn't encourage hospitals and physicians to spend money carefully. Once the patient's care is covered, physicians and hospitals have no reason to economize. Cost control under insurance typically uses high out-of-pocket expenses to deter patients from seeking care.

Many intelligent advocates of incremental insurance
recognize these problems. Still, they argue cogently that insurance is desirable because it provides entitlement up front and with dignity, and because it is recognized as the mainstream mode of coverage in the United States. They hope that universal insurance will somehow be endured long enough—both politically and financially—for its high cost to drive us to institute genuine reforms, including cost controls.

A third path exists, which we might call "linked incrementalism"—linked because it integrates universal access with cost controls and reform, and incremental because it slowly builds on evolving financing techniques and ways of providing care. The approach, which I detail below, draws upon a decade of (generally) progressive reforms in Massachusetts, and is designed for implementation at the state level. It would be easiest to implement in those states with historically high health costs that have begun regulating hospital payment, but can be modified to work in other states.

The Proposal
The plan has five features: (1) it offers equal access to one-class hospital and physician care; (2) it maintains our current level of spending; (3) it requires trade-offs—making care available according to need and clinical efficacy, not ability to pay; (4) it offers simple administration and democratic governance; and (5) it provides for equitable and progressive financing.

Access. All low-income uninsured citizens would be entitled to complete hospital and physician services, both inpatient and ambulatory. Eligibility would be based on income—perhaps up to 200-250 percent of the federal poverty line. There would be no co-payments or deductibles, since these deter use and are costly to administer. Up-front, dignified entitlement would be offered through an insurance card, issued to each individual or family. To promote genuine access, caregivers would be paid at Blue Cross rates and by Blue Cross methods. Caregivers are familiar with this arrangement, and usually find it adequate.

Hospitals would be subjected to a productivity squeeze.

While hospitals would have no financial reasons for objecting to providing care, since they would be paid for serving uninsured patients at Blue Cross rates, some might be reluctant for other reasons. Each would therefore be obliged, as a condition of licensure, to serve all eligible patients who live within its primary service area. To preclude gerrymandering, the area would be defined as the most geographically compact region in which 95 percent of the hospital's inpatients live. Most eligible patients would reside within the service areas of several hospitals, and would be free to choose care at any one.

How would hospitals be paid? A free-care pool would be funded through a proportionate assessment on each. Initially, the assessment would be set at the current average statewide percentage of total costs going to finance free care and bad debt. (These are the costs that hospitals now write off; together, they are called "free care" in this article.) If free care were 4 percent of costs in a given state, for example, every hospital in that state would pay a sum equal to 4 percent of its costs into the pool.

No financing system alone can induce hospitals to work in the public interest.

Hospitals, in turn, would raise this money through a surcharge on paying patients—merely a formal method of cost-shifting, their current way of financing free care. If Medicare and Medicaid were not paying for free care, Blue Cross and commercial insurers would be charged the entire burden. If Blue Cross and the commercials together covered half the patients in our hypothetical state, they would add an 8-percent surcharge onto their payments to each hospital. So would firms that self-insure. This would not, by itself, change total hospital spending or spending on free care; it would merely redistribute the latter so that each insurer and business would pay its fair share.

Each hospital would also pay its fair share. A hospital that provided more than the state-wide average in free care would not be placed at a competitive disadvantage. It would not have to raise its charges above those of other hospitals to subsidize uninsured patients. In the same way, hospitals that refused to serve uninsured citizens would no longer be rewarded by being able to charge lower prices. Hospitals that provided above-average amounts of free care would draw more money from the pool than they paid in; those that provided below-average amounts would lose money on the pool arrangement.

Gradually, the pool would be increased—over perhaps five years—until it grew large enough to finance all hospital and physician care needed by uninsured citizens. We could use a rule of thumb to estimate the required amount. If 10 percent of a state's population is uninsured, and if these citizens require about as much hospital care as the average person in the state, about 10 percent of hospital costs should flow through the pool. Nationally, physician costs are about half of hospital costs, so a sum equal to an additional 5 percent of hospital costs would be added to the pool. The pool would then need to equal 15 percent of hospital costs.

In our hypothetical state, only 4 percent of hospital

Physician and patient at Valentine Lane Family Practice, Yonkers, N.Y.
costs are currently devoted to free care. The remaining 11 percent would have to be squeezed out of existing spending and channeled to uninsured citizens through the pool.

Balancing the Scales

Spending controls. The most likely candidates for squeezing are the hospitals. A cap would be set on their total revenue from payers other than Medicare, which would continue to pay per admission. Each hospital's costs during a recent "base" year would serve as a benchmark. Maximum permitted revenue during the first year of the plan would be calculated by taking those base year costs and adjusting them to allow for medical inflation, volume, and case mix. The ceiling would then be recalculated yearly.

If a hospital provided a larger volume of care in a given year, this would be paid for only at marginal cost—the cost of actually providing more care. That is, fixed costs would be assumed to be covered at the previous year's volume, so hospitals would be paid only for the variable costs of providing more care—the costs of additional nurses, lab techs, supplies, meals. Similarly, hospitals that provided less care would suffer budget reductions equal only to the actual savings associated with providing less care. This would eliminate financial incentives to give any more or less care than is clinically appropriate.

To raise the additional money needed to bring the free-care pool to its proper level—11 percent of hospital costs in our hypothetical state—hospitals would be subjected to a productivity squeeze. That is, they would be required to operate more efficiently each year by having their revenues cut—after adjustment for inflation, volume, and case mix—by 2 percent a year for five and one-half years.

Trade-offs. Hospitals could adapt to the squeeze in several ways: by reducing the costs of individual services, by providing fewer services per admission or per outpatient visit, and by providing fewer admissions or visits to non-pool patients; in short, by making clinical trade-offs.

A hospital would be allowed to reduce care to non-pool patients by up to 2 percent annually without triggering an additional cut in its revenue. Similarly, the first 2 percent of increased volume annually, associated with care of pool-insured patients, would be paid for at 100 percent of average costs. This would strongly encourage hospitals to increase care for pool patients at the expense of traditionally insured patients until the two groups enjoyed the same level of service. Hospitals would then be providing the same amount of care as before, for the same money.

Hospitals would be obliged to deliver both inpatient and outpatient care to pool-insured patients, forcing them to make a commitment to ambulatory care. Because hospitals would need to organize ambulatory care as efficiently as possible, they might form consortia with health centers or groups of physicians to serve pool-insured patients.

Once hospitals made these trade-offs, they could begin to give care according to the only criteria that matter: equity, clinical need, and efficacy of treatment.

Simple administration and democratic governance. Under this plan, no new paperwork would be introduced since hospitals would be reimbursed for pool-eligible patients in the same way they are for Blue Cross patients. Since no out-of-pocket payments would be required of these patients, their care should be simpler to account for. Eligibility would be determined annually, either by hospitals or by government. Citizens would be encouraged to register with one hospital and to seek care there routinely, making medical records more easily available.

Democratic governance becomes increasingly important in this hospital-centered model. Hospitals are the focus of the plan because uninsured citizens are used to seeking care from them, because it is simplest to draw money from them to finance an enlarged pool, and because they exist as entities that can be legally obliged to serve pool-insured patients. The right financing method is important, but no financing system alone can provide the proper balance of incentives and penalties to induce hospitals (and physicians) to work in the public interest. To hope otherwise is to yearn for a self-regulating free market that will never exist.

Equitable and progressive financing. It would be unfair to finance the pool exclusively through private insurance contributions. Employers would complain that they are paying not only for their own workers, but also for the employees of companies that decline to provide insurance. Businesses that fail to offer health insurance, however, tend to be small, labor-intensive, and engaged in competitive industries with low wages and low profit margins. To mandate that these businesses provide coverage would be regressive; it could also cost jobs.

An alternative would be to require that each business pay a tax equal to some fixed percentage of wages if it fails to provide a minimum health insurance package. This would also deter any firm now providing coverage from dropping it and asking workers to swim in the pool.

A Beginning in Massachusetts

Many of the foundations for this plan have, in fact, already evolved in Massachusetts. These include prospective payment to hospitals, a productivity squeeze (though with the savings from it returned to insurers), a growing free-care pool—now equal to over 6.6 percent of hospital costs—and regulations governing the provision of care from that pool. The existing system is very complex, and unfair in many respects, but it is a step toward the type of system outlined here.

Any national reform must deal with great differences among states.
Social worker and client at Boston City Hospital.

Hospital spending in Massachusetts, in dollars per person, is about 40 percent above the national average. The surgery rate runs 20 percent higher. The number of physicians per person is the highest in the nation. If Massachusetts cannot afford hospital and physician care for all at current spending levels, what state can? But solutions in one state are not enough. Any national reform must deal with the great differences in costs, spending, and insurance coverage among the states.

Words of Caution

There are certainly problems with this proposal. It is fairly complex. It may appear to subsidize hospitals and to perpetuate an inefficient and demeaning free-care approach. Four important objections are considered here:

Dignity and entitlement. Many argue that traditional up-front insurance entitlement is more dignified than back-door pool financing of free-care costs. But, has Medicaid—a form of insurance—given dignity to those it serves? Would legislation that requires employers to provide their workers with third-class insurance benefits, laden with co-payments and deductibles, do so? The pool's insurance card would constitute up-front entitlement. Uninsured citizens would have access to integrated, one-class care—financed as generously and as promptly as that of any Blue Cross patient.

Fragmentation and cost. Many believe that only a combination of managed care and prepayment can increase access and contain costs. This proposal wouldn't limit the amount spent on individual patients, but would have hospitals assume an unlimited obligation to provide service while requiring them to do so with limited (but sufficient) financial resources. It would avoid the dangers to the health of low-income citizens posed by prepayment and managed care.

Hospitals that refused to deliver adequate services to pool-insured patients, and instead allocated disproportionate resources to other patients or to esoteric and costly services that benefited only a few, could be placed in receivership and new trustees given control. Receivership would provide opportunities for testing more democratic methods of governing hospitals. The new board could include representatives of the former trustees, administrators, medical staff, other employees, payers (including representatives of the pool), and patients.

Under the plan, hospitals would benefit by assuming responsibility for organizing care within financial limits. They would have the power to manage their affairs, but only as long as they met their obligations to all citizens.

Opposition from business. Employers will fear having to pay, indirectly, for the increased care the pool would provide. They might respond by supporting the gradual substitution of tax dollars for surcharge dollars. (Further, they might even support simple, progressive financing of all health services.) Failing this, though, they might be attracted to the plan by its provisions for containing hospital costs. If a state were willing to cap
physicians' revenues, part of the pool could be financed by squeezing these as well, enhancing the plan's desirability to business.

Business's support for the cost controls and reforms needed to accommodate universal access is unlikely today. Large employers are increasingly dedicated to controlling their own health care costs through HMO's and other plans that feature incentives to withhold care. These tend to exacerbate mistrust among hospitals, physicians, patients, and payers, and to irritate relations between employers and workers. They produce limited, one-time savings. Businesses will back publicly-coordinated containment of medical costs only after their own private schemes fail.

Can we trust caregivers? All systems of payment ultimately channel money to caregivers. What matters most is whether practitioners get money in a way that encourages and obliges them to serve all citizens equitably. Any attempt to reform the financing and delivery of health care must confront caregivers on precisely these issues—especially that of their willingness to welcome and serve all people in need, within budgets. This approach does so. It attempts to change the relations between uninsured patients and the very caregivers from whom they already seek health services. It avoids the potentially vicious lock-ins—and lock-outs—of managed care. And, most importantly, it aims to put in place a financing method that gives caregivers the opportunity to exercise their clinical judgment, and to do what's right. •

6. 141 Consolidated Massachusetts Regulations 30.00-30.11.
As did the gentlemen adventurers of centuries past, today's buccaneers of the British right wing view America as a storehouse of exotica. Whereas Sir Walter Raleigh valued the New World for its flora and fauna, his descendents covet its social and political ideas. Some of these, they feel, may be useful in their battle against "socialism," a force they see as endemic to British institutions and policies. Health Maintenance Organizations (HMO's), private corporations that provide primary care at fixed prices, are now being touted as the latest weapon.

Tories have long yearned to dismantle Britain's system of public medical care, the National Health Service, and the Thatcher government has already succeeded in damaging its facade, if not the actual skeleton. As in the United States, private firms now provide auxiliary services for many British hospitals, and such in-hospital tasks as housekeeping are handled by subcontractors. In fact, the government's direct control over Health Service policy has allowed it to make such subcontracting mandatory.

The Tories' ambitions are larger than this, though. In 1981, Thatcher's minister for health announced that he expected the private health care sector to grow to 25 percent of the size of the public sector. While the private sector has doubled in size since 1979 (with American corporations like Humana leading the way), it remains tiny compared to the NHS. The increase in membership in private health plans is stuck below five percent annually (compared to growth rates of 20 to 30 percent in the late 1970's) and, as in the United States, proprietary and charity hospitals are struggling to fill their beds.

The Media's Darling

This near-stagnation, after eight years of Tory rule, has left the government looking for new ways to privatize Britain's health care. Recently, HMO's have come to play a large part in the resuscitation of this cherished Conservative dream, aided by their increasing prominence in the media.

The visit to Britain, in 1984, of Alain Enthoven, the guru of competitive health care, helped give academic respectability to the idea of HMO's. Enthoven spoke to a seminar at the Royal Institute of Public Administration, and also wrote a proposal, well-received by some academics, for introducing competition into the NHS. In 1985, the British press gave front-page coverage to a report claiming that a forthcoming government study on primary medical care would contain proposals for the establishment of HMO's. Events since have advanced apace. HMO's have been featured in television news items, in editorials in the Economist and the Financial Times (the latter explicitly recommending their introduction into Britain), and in a report by the Adam Smith Institute, the influential right-wing policy group linked to the American Enterprise Institute. HMO's are riding the crest of this wave of publicity. The idea of their establishment in Britain has acquired appeal and acceptance despite its not having yet been the subject of even one scholarly study of any serious length.

Enter the Americans

The prospects for the development of private HMO's in Britain are sufficiently attractive for one California-based organization, Family Health Plan, to have taken the plunge. In 1986, FHP announced its intention of setting up four HMO's in Britain. No plans for these organizations have yet been completed, but if a private HMO is able to undercut the high-priced providers of private care, it may well be able to establish a viable operation. American health corporations have made mistakes in Britain before, however, and their vision of money-making HMO's may prove to be another mirage.

For British conservatives, the attraction of HMO's is clear. They offer a way both to introduce competition into health care and to limit government spending on medical services, while dressing both objectives in the robes of consumer protection. At particular issue is the primary care provided by the NHS. Spending on general practice is less tightly controlled than are expenditures for hospital services, and the way general care feeds into secondary and tertiary care leaves much to be desired. The most frequently heard argument claims that doctors too often use their position to dominate the primary health care team and engage in isolated, individual practice. (In fact, the Left has long been urging that general practitioners be extricated from their position as small state-supported businesses and brought into salaried service, preferably within health centers.)

The Mirage of Cost Savings

While the establishment of HMO's may appear to be a sensible method of containing health care costs and

Geoff Rayner is a health policy analyst in London, and a former employee of the National Health Service.

Spring 1988

Health/PAC Bulletin
reining in general practitioners, such benefits are illusory. The reduction in expenditures of 25 to 40 percent that many predict is based on the bloated costs of American health care, which generally involve fees double and triple those paid by users of the NHS. Furthermore, private medicine is an optional addition to care under the NHS, not a fully comprehensive alternative to it. Most people who have private medical insurance still go to their general practitioners as public patients, since no private insurance covers general practice. Hence, subscribers to an all-inclusive HMO would be paying for something they already get for free. Private patients do not have access to subsidized medication, and neither would members of HMO's.

Absent clear financial benefits, it's hard to imagine patients forsaking public primary care. Ninety-seven percent of the population is still covered under the NHS's general practice. The demand for such services remains high (they still make house calls!), and international opinion rates primary health care as “a Great British success.”

In its review of primary care services mentioned above, the Thatcher government, while praising HMO's, backed off from making an explicit recommendation for their establishment. Now that the Tories have won a third term, they are likely to be less timid. Yet with obvious drawbacks to their creation in Britain and absent any compelling argument on their behalf, HMO's remain valuable above all as a reminder of the international links among the makers of conservative health care policy, and of their continuing efforts to demolish the edifice of public health care.
PRO'S:
Bark is Worse Than Their Bite

Medicare's hired watchdogs have uncovered huge evidence of substandard care under the program's new payment system based on diagnosis related groups (DRG's), yet have failed to penalize even a single doctor in many areas of the country.

The Government Operations Subcommittee on Human Resources of the House of Representatives reviewed data compiled by Medicare's PRO's (peer review organizations) from about 15 percent of the program's total cases, finding 891,000 instances of substandard or inappropriate care. Extrapolating these findings to the Medicare population at large, Ted Weiss (D-NY), the subcommittee's chair, projected "more than a million potentially life-threatening admissions for Medicare patients in one year."

The PRO's found unexpectedly high numbers of Medicare patients whose deaths could have been avoided, who received inadequate discharge plans, were discharged in unstable condition, contracted infections in the course of treatment, or were given improper medication. Weiss concluded that the data show "an increase in mortality" under the DRG system.

PRO's are boards of physicians hired by the federal government to monitor and improve the care that hospitals and doctors give Medicare's 32 million recipients. A second, private study questioned the PRO's commitment to its task of policing fellow doctors. The study, conducted by the Public Citizen Health Research Group, found that PRO's had failed to penalize a single physician in 23 states and the District of Columbia. "The failure to use sanctions at all," according to the report, "gives the signal that the peer review organization isn't very serious about doing disciplinary activity."

To obtain the House report, contact Representative Ted Weiss, House of Representatives, Capitol, Washington, DC 20515; 202-224-3121. For the Public Citizen's report, write the Public Citizen Health Research Group, 2000 P St., NW, Washington, DC 20036.

6,000 Calls a Month

Recognizing that the pain inflicted by AIDS extends far beyond the scope of medical expertise, the New York City Department of Health has developed a hotline which provides its callers with counseling as well as with information about testing.

The hotline staff—each employee has a background in psychology or social work—handle five to six thousand calls each month, ranging from factual questions about AIDS to serious personal difficulties related to the disease. Staff members make referrals to outside agencies, such as HIV-positive support groups, and schedule appointments at city test sites; their most important work, however, is counseling. Although principally intended for callers who request test information or who have tested positive for the AIDS virus, the hotline lends an ear to other problems as well.

"When you get to the end of a call," says Steve Panopoulos, a graduate student in clinical psychology, "you often realize that it wasn't so much about HIV infection or AIDS as it was something else—infidelity, religious conflict, moral or political issues."

Don Troise, the hotline's project coordinator, agrees that many calls are related to AIDS only tangentially: "We're having to counsel people around a really broad array of topics. We'll get people who call who have tested negative four times. Obviously, the issue is not just AIDS."

Though the hotline is limited in the therapeutic services it can provide, clients are frequently encouraged to continue calling. As Panopoulos says, the staff doesn't want callers to think that, "Well, I've already called the AIDS hotline. I can't call them anymore." He adds that callers asking for referrals are more likely to follow through—keeping test appointments or researching support services—if a counselor asks them to call back with their results. Counselors encourage those who have tested positive, in particular, to call back periodically for new information.
mation on AIDS.

The hotline’s overarching goal, according to Troise, is to empower people. “Basically, we’re about giving people information, all that they need to know, to make decisions on their own.”

“The best thing that the hotline does,” adds Panopoulos, “is to help people to become responsible—increasing people’s awareness about sexuality, about the way they see themselves and others, and, outside of a moral context, about the way that they live their lives in general.”

Sick and Without Beds

Having spent the last ten years getting rid of thousands of acute-care beds in its hospitals, New York City is now faced with severe overcrowding in those institutions.

“Patients are crowded into already cramped spaces,” according to Dr. Lewis Goldfrank, director of Emergency Services at Bellevue Hospital. “On average, 20 medical-surgical patients and 10 psychiatric patients await admissions lying inches apart, side by side on stretchers or sitting on hard chairs. Patients wait two, three or four days for a bed.” Goldfrank’s remarks came at a recent hearing of the New York City Council.

Speaking at the hearing, state Health Commissioner David Axelrod attributed overcrowding to the AIDS epidemic. Other health experts dispute this, though, citing increases in poverty and the elderly population. And while AIDS is part of the problem, evidence from other cities shows that it can’t be the whole story. Underutilization, not overcrowding, continues to be the problem in many cities, including those, like San Francisco, with large numbers of AIDS patients.

Meanwhile, a shortage of hospital beds exists throughout New York State. The causes of the shortage can be traced to state action. The state health department has been responsible, through its policy of “downsizing,” for closing more than 4,000 acute-care beds in New York City in the past decade. As recently as last summer, it was calling for the closing of 2,000 more. Then, suddenly faced with a citywide occupancy rate of more than 95 percent last December, Commissioner Axelrod called for an immediate reversal of that effort. Now he’s discovering that reopening beds will prove much more complex and time-consuming than closing them was.

Auto Workers Win Long-term Care Benefits

The United Auto Workers (UAW) achieved a major health benefit breakthrough in recent contract settlements with GM and Ford. The UAW, which pioneered outpatient psychiatric care benefits in the early 1960’s, has become the first major U.S. trade union to win coverage of home-based custodial care for disabled and retired workers.

The auto workers’ new contract provides for at least one year of nonmedical custodial care, aimed at helping disabled workers and family members perform the activities of daily living, such as bathing, eating, and dressing. The plan also covers one year of custodial care in a nursing home; respite care, which provides temporary caretaking for the disabled while relatives take time off; nighttime care; and care in “community-based programs.”

Between private and government payments, U.S. citizens spend $48 billion a year on nursing homes and other forms of long-term care. As many as 15 million people require another’s help in their daily activities. If other industries follow the auto workers’ lead, as some experts believe they will, we will see many of these costs shifted to the commercial sector.

Otis Bowen, Secretary of Health and Human Services, is encouraging such a shift by supporting proposals to enact tax breaks and other incentives that would encourage employers to provide coverage of long-term care. While we applaud the good news from the UAW, it’s important to recognize that incremental advances by the private sector may reduce pressure on legislators to provide comprehensive, publicly-funded coverage of these vital services.

Caren Teitelbaum

T.P.
In this epoch of AIDS, a drought of clarity and indignation is our second scourge, and the likes of Jonathan Swift and Doctor Rudolph Virchow are sorely missed.

Virchow, you may recall, was a 19th-century genius of medicine and politics. Generally recognized as the founder of modern pathology, he was also a fully engaged social activist. Commissioned by the Prussian government to investigate an epidemic of typhus in Upper Silesia, he dared announce that the blame lay in social conditions—inequities housing, unemployment. Only eight days after returning to Berlin, he was fighting at the revolutionary barricades of 1848. Throughout his life, Virchow mixed tireless scientific endeavor with direct action, serving the public through government, academia, and radical politics.

Swift, though performing public service in government and church, exercised his greatest talent in exposing the corruption, stupidity, and absurdity of his times. The best-known example of his searing satire is, of course, *Gulliver’s Travels*, still unsurpassed in elegance and effect.

Would that the great dean were alive today to witness the wrong-headed and repressive decisions being propagated by anti-scientific loonies, many in high places, who are using the horror and uncertainty of AIDS to run, roughshod, over the legitimate concerns of the public. Among the ripest idiocies Swift would surely impale on the tip of his rapier pen are these:

- Some school districts have responded to the presence of students with AIDS with a new variation on the theme of separate but equal, banishing the children to isolated classrooms where they are linked to teacher and classmates by electronic hookup. Other of our custodians of the next generation have been more clever: they bar the child in question from school, knowing full well that court relief will be sought and granted. That way, they protect themselves from suits the uninformed parents of other children might get them to bring.

- Chicago’s environmental agency, displaying a keen awareness of the modes of HIV transmission, asked a local AIDS authority to investigate the possible spread of the disease through groundwater contamination.

- The Radford, Va., schools barred a theater group because it had once included a person with AIDS in its performances.

- A school in Connecticut canceled a basketball game on the strength of rumors that an opposing player might have AIDS.

Not all the AIDS-mania is to be found in public institutions, though. Private individuals displaying similarly cool-headed behavior include the fastidious couple at a debutante cotillion in Chicago who donned surgical gloves during their stint on the reception line, and the citizens of Williamstown, Va., who deserted the municipal pool when a person with AIDS arrived.

Subduing the scourge of AIDS will require the acuity and courage of more than one Virchow. We are in equal need, certainly, of a great Swift to clear a path for them through the dense yahoo underbrush.

Quentin Young is a physician and the president of Chicago’s Health and Medicine Policy Research Group.

Quentin Young is a physician and the president of Chicago’s Health and Medicine Policy Research Group.
Watching Washington
State Funding For Worker Education
Barbara Berney

Good occupational health education is education for action—an action that reduces occupational hazards and secures a more democratic workplace and broader participation in decisions about what industry will produce and how. The New Directions program, started by the Carter administration, was a stellar example. It provided money for occupational health and safety education to unions, committees on safety and health (COSH groups) and other nonprofit organizations, universities, and employers.

New Directions’ success, and Reagan’s gutting of it, provided the impetus to establish several state programs. These programs, growing in number, suggest some lessons for those looking to replace federal initiatives in worker education with state programs.

First, funding. In Michigan, Connecticut, New York, and Maine, programs are funded by assessments on the workers’ compensation system. This is an appealing mechanism; legislators like it because it doesn’t tap into general funds and isn’t perceived as a new tax. Because the monies are set aside from an ongoing program, they are insulated from the vagaries of the appropriations process. The set-asides range from 0.2 to 1 percent of workers’ compensation premiums (in Michigan, of benefits). Although these percentages are small, the sums raised are considerable—up to $8 million annually.

Massachusetts’ programs, funded out of departmental budgets, provide a stark contrast. Grant-giving programs that support unions, COSH groups, clinics, small business associations, and safety councils create a wide constituency for worker education and for occupational health and safety in general. They also generate a variety of programs and insure support for experienced pro-labor training groups. Diana White, director of the Maine Labor Group on Health (a COSH), reports that state funding has given her group an imprimatur of respectability; companies that previously thought of MLGH as a fringe group now hire it to train their workers.

While the initiators of Connecticut’s legislation intended it to provide grants, the current program does not, and its staff teaches more about workers’ compensation than about health and safety. “The groups that lobbied for this program naively assumed that they would have a say over it and its staff,” commented Steve Schrag of the Service Employees International Union. “Their experience shows the importance of making the program goals clear and the grant-giving program mandatory.”

Third is the question of how to get the programs in place. The key, according to Dom Tuminaro, counsel to the chair of the New York State Labor Committee and a NYCOSH activist, is getting them placed high on labor’s agenda: “The labor hierarchy must be shown that local leaders and the rank and file care about the issue.” COSH groups, state labor federations, local unions, and groups that expected to be eligible for grants all testified and lobbied for the existing programs. COSH’s and union locals organized letter-writing and phone campaigns to persuade recalcitrant legislators. Mobilizing popular support has been effective; in Connecticut the legislation passed both houses unanimously.

These programs are hard to resist. They give workers the knowledge and skills needed to prevent injury and disease, and employers find them useful for meeting the requirements of right-to-know laws.

Second is the issue of grants. Grant-giving programs that support unions, COSH groups, clinics, small business associations, and safety councils create a wide constituency for worker education and for occupational health and safety in general. They also generate a variety of programs and insure support for experienced pro-labor training groups. Diana White, director of the Maine Labor Group on Health (a COSH), reports that state funding has given her group an imprimatur of respectability; companies that previously thought of MLGH as a fringe group now hire it to train their workers.

While the initiators of Connecticut’s legislation intended it to provide grants, the current program does not, and its staff teaches more about workers’ compensation than about health and safety. “The groups that lobbied for this program naively assumed that they would have a say over it and its staff,” commented Steve Schrag of the Service Employees International Union. “Their experience shows the importance of making the program goals clear and the grant-giving program mandatory.”

Third is the question of how to get the programs in place. The key, according to Dom Tuminaro, counsel to the chair of the New York State Labor Committee and a NYCOSH activist, is getting them placed high on labor’s agenda: “The labor hierarchy must be shown that local leaders and the rank and file care about the issue.” COSH groups, state labor federations, local unions, and groups that expected to be eligible for grants all testified and lobbied for the existing programs. COSH’s and union locals organized letter-writing and phone campaigns to persuade recalcitrant legislators. Mobilizing popular support has been effective; in Connecticut the legislation passed both houses unanimously.

These programs are hard to resist. They give workers the knowledge and skills needed to prevent injury and disease, and employers find them useful for meeting the requirements of right-to-know laws.

Barbara Berney is a consultant on health care and occupational health in Washington, D.C.

32 Health/PAC Bulletin Spring 1988
### INDEX TO VOLUME 17 #1-6

<table>
<thead>
<tr>
<th>TITLE (by Subject)</th>
<th>AUTHOR</th>
<th>ISSUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Painfully poor access, Vital Signs</td>
<td>Pittman, T.</td>
<td>5</td>
</tr>
<tr>
<td>Patient dumping in California, Vital Signs</td>
<td>Deresiewicz, W.</td>
<td>5</td>
</tr>
<tr>
<td>The Medicap flap, Vital Signs</td>
<td>Merzel, C.</td>
<td>5</td>
</tr>
<tr>
<td>AIDS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The wisdom of a county commissioner ignoring the epidemic, Reagan fails on AIDS</td>
<td>Young, Q.</td>
<td>3</td>
</tr>
<tr>
<td>The sounds of silence, Vital Signs</td>
<td>Pittman, T.</td>
<td>6</td>
</tr>
<tr>
<td>APHA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning from Las Vegas, Notes &amp; Comment</td>
<td>Burlage, R.</td>
<td>1</td>
</tr>
<tr>
<td>APHA Nevada nuclear test site demonstration</td>
<td>Guttmacher, S.</td>
<td>2</td>
</tr>
<tr>
<td>Asbestos</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asbestos: Medical &amp; Legal Aspects, B. Castleman, review</td>
<td>Kotelchuck, D.</td>
<td>3</td>
</tr>
<tr>
<td>Outrageous Misconduct, P. Brodeur, review</td>
<td>Kotelchuck, D.</td>
<td>3</td>
</tr>
<tr>
<td>Catastrophic Illness</td>
<td>Should we support catastrophic coverage?</td>
<td>Berney, B.</td>
</tr>
<tr>
<td>Commentary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Turning 20 and looking ahead from the editor</td>
<td>Gordon, J.</td>
<td>5</td>
</tr>
<tr>
<td>Welcome Health &amp; Medicine readers</td>
<td>Gordon, J.</td>
<td>3</td>
</tr>
<tr>
<td>Community Medicine Sidney Kark in America</td>
<td>Geiger, H. J.</td>
<td>5</td>
</tr>
<tr>
<td>Congress Congress's starvation tactics, Vital Signs</td>
<td>Staff</td>
<td>2</td>
</tr>
<tr>
<td>Dalkon Shield At Any Cost: Dalkon Shield, M. Mintz, review</td>
<td>Lipshutz, J.</td>
<td>3</td>
</tr>
<tr>
<td>Disabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reviews of books about the disabled</td>
<td>Gibbons, G., &amp; Thirfeld, J.</td>
<td>2</td>
</tr>
<tr>
<td>DNA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Broken Code: Exploitation of DNA, M. Lapp, review</td>
<td>Holtzman, E.</td>
<td>1</td>
</tr>
<tr>
<td>DRGs &amp; PPS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How PPS is transforming hospital care</td>
<td>Kotelchuck, R.</td>
<td>1</td>
</tr>
<tr>
<td>Premature discharge, Congressional testimony</td>
<td>Kratt, B.</td>
<td>2</td>
</tr>
<tr>
<td>PPS' impact on quality of care</td>
<td>Kotelchuck, R.</td>
<td>2</td>
</tr>
<tr>
<td>How good are the system's watchdogs?</td>
<td>Kotelchuck, R.</td>
<td>3</td>
</tr>
<tr>
<td>Drug Companies Manufactured a grassroots campaign</td>
<td>Berney, B.</td>
<td>5</td>
</tr>
<tr>
<td>Corporate Crime in the Pharmaceutical Industry, J. Braithwaite, review</td>
<td>Strelnick, H.</td>
<td>2</td>
</tr>
<tr>
<td>Drug Therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More attention needed to help ease pain</td>
<td>Levin, A.</td>
<td>3</td>
</tr>
<tr>
<td>Environmental Health Know your rights</td>
<td>Berney, B.</td>
<td>6</td>
</tr>
<tr>
<td>Public health roulette: Nevada's dangerous odds</td>
<td>Kotelchuck, D.</td>
<td>1</td>
</tr>
<tr>
<td>Now they tell us, Vital Signs</td>
<td>Staff</td>
<td>2</td>
</tr>
<tr>
<td>Ethics, Medical Campaign for medical ethics in S. Africa, Vital Signs</td>
<td>Staff</td>
<td>2</td>
</tr>
<tr>
<td>Health Education 2001: a health education odyssey</td>
<td>Freudenberg, N.</td>
<td>6</td>
</tr>
<tr>
<td>Reassessing communities</td>
<td>Freudenberg, N.</td>
<td>5</td>
</tr>
<tr>
<td>Educating for sexual health and freedom</td>
<td>Freudenberg, N.</td>
<td>3</td>
</tr>
<tr>
<td>New &quot;Coke&quot; not all it's cracked up to be</td>
<td>Freudenberg, N.</td>
<td>2</td>
</tr>
<tr>
<td>Health Maintenance More is not always better</td>
<td>Levin, A.</td>
<td>2</td>
</tr>
<tr>
<td>Health/PAC Event National Health Program Conference</td>
<td>Burlage, R.</td>
<td>5</td>
</tr>
<tr>
<td>Health Promotion Immunization policy, a shot in the dark</td>
<td>Levin, A.</td>
<td>4</td>
</tr>
<tr>
<td>Health screening, rational or fashionable?</td>
<td>Levin, A.</td>
<td>1</td>
</tr>
<tr>
<td>More is not always better</td>
<td>Levin, A.</td>
<td>2</td>
</tr>
<tr>
<td>Response to &quot;More is not always better&quot; (letter)</td>
<td>Nelson, M.</td>
<td>3</td>
</tr>
</tbody>
</table>

Index prepared by Ann Umemoto.

Spring 1988  Health/PAC Bulletin 33
<table>
<thead>
<tr>
<th>TITLE (by Subject)</th>
<th>AUTHOR</th>
<th>ISSUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>HMO's The future of HMO's, Vital Signs</td>
<td>Merzel, C.</td>
<td>1</td>
</tr>
<tr>
<td>Homelessness Empowering the homeless, Vital Signs</td>
<td>Staff</td>
<td>2</td>
</tr>
<tr>
<td>Hospitals, Public City hospitals: die or repoliticize?, Vital Signs</td>
<td>Staff</td>
<td>1</td>
</tr>
<tr>
<td>Cook County Hospital</td>
<td>Young, Q.</td>
<td>3</td>
</tr>
<tr>
<td>Hunger Three eggs for four people When knowing where to go is not enough (letter)</td>
<td>Steinhardt, D.</td>
<td>3</td>
</tr>
<tr>
<td>Insurance, Health Should we support catastrophic coverage? Local anesthetics: state health programs for uninsured The massacre of MASSCARE: the defeat of Dukakis' plan</td>
<td>Berney, B.</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Hughes, D.</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Danielson, D., &amp; Abrams, S.</td>
<td>5</td>
</tr>
<tr>
<td>Licensure Credentialing for what?</td>
<td>Freudenberg, N.</td>
<td>1</td>
</tr>
<tr>
<td>Malpractice The clash over quackery: protecting alternative care</td>
<td>Caplan, R.L.</td>
<td>6</td>
</tr>
<tr>
<td>Maternal Health Service Improving prenatal care, Vital Signs</td>
<td>Pittman, T.</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Stein, A.</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Chavin, W.</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Mansfield, P. U.</td>
<td>2</td>
</tr>
<tr>
<td>Medicaid The Medicap flap, Vital Signs</td>
<td>Merzel, C.</td>
<td>5</td>
</tr>
<tr>
<td>National Health Program The National Health-Care Campaign</td>
<td>Semmel, H.</td>
<td>3</td>
</tr>
<tr>
<td>National health is back on the agenda</td>
<td>Semmel, H.</td>
<td>5</td>
</tr>
<tr>
<td>National health is sparking interest Anatomy of a national health program: Dellums bill Nicaragua</td>
<td>Young, Q.</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Rodberg, L.</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Strelnick, H.</td>
<td>5</td>
</tr>
<tr>
<td>Nuclear Testing Justice Downwind, Howard Ball, review Nuclé food dumped in Sri Lanka, Vital Signs</td>
<td>Bale, T.</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Staff</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Gordon, J.</td>
<td>6</td>
</tr>
<tr>
<td>Occupational Health New Jersey radium dial painters in the courts A workplace victory for hospital employees Holding the line: labor's safety &amp; health movement That ole radium show, Vital Signs</td>
<td>Bale, T.</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Staff</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Compa, L.</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Bale, T.</td>
<td>6</td>
</tr>
<tr>
<td>Organizing, International NAMDA: fighting for nonracial system in S. Africa HWA: an organization for all workers in S. Africa</td>
<td>Staff</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Staff</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Staff</td>
<td>1</td>
</tr>
<tr>
<td>Quality of Care Some thoughts on quality</td>
<td>Bale, T.</td>
<td>2</td>
</tr>
<tr>
<td>Health care is fine in St. Louis (letter)</td>
<td>Hines, C.</td>
<td>4</td>
</tr>
<tr>
<td>Organizing, National Unhealthy business: U.S. health corp(s) in S. Africa</td>
<td>Friesner, J.</td>
<td>4</td>
</tr>
<tr>
<td>Home health workers seek gains, Vital Signs</td>
<td>Pittman, T.</td>
<td>4</td>
</tr>
<tr>
<td>Parenting Progressives on surrogacy, Vital Signs</td>
<td>Staff</td>
<td>4</td>
</tr>
<tr>
<td>Personnel, Health Harassment of health workers in El Salvador (letter)</td>
<td>Capps, L.</td>
<td>5</td>
</tr>
<tr>
<td>Physicians MDs &amp; seniors battle over double billing, Vital Signs</td>
<td>Staff</td>
<td>2</td>
</tr>
<tr>
<td>Dealing with doctors Young, Q.</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>60 hours without a break, Vital Signs</td>
<td>Pittman, T.</td>
<td>5</td>
</tr>
<tr>
<td>Professional Review Medical consumers' right to know, Vital Signs</td>
<td>Staff</td>
<td>3</td>
</tr>
<tr>
<td>Proprietary Health Care Two days in October: Wall Street crash</td>
<td>Editors</td>
<td>6</td>
</tr>
<tr>
<td>National Medical Enterprises: meaner and leaner</td>
<td>Staff</td>
<td>3</td>
</tr>
<tr>
<td>Proprietary medicine man changes mind, Vital Signs</td>
<td>Pittman, T.</td>
<td>5</td>
</tr>
<tr>
<td>Smoking American cigarettes come to Taiwan</td>
<td>Papke, E.</td>
<td>6</td>
</tr>
</tbody>
</table>
Title: South Africa
Author: Gordon, J.
Issue: 4

South Africa: state of ill-health
Killing the healers: Pretoria's response to dissent
Apartheid will go: interview with Diliza Miji
U.S. health corporations in South Africa
Children behind bars: report documents abuses
The mistreatment of detainees
NAMDA: fighting for a nonracial health system
HWA: an organization for all health workers
The Kark Movement: S. Africa's healthy import
South African detentions (letter)
Vital signs, medical ethics in South Africa
Nosipho's gift: a South African nurse's story
Witness to Apartheid, S. Sophier, film review
CHISA Newsletter, review

State Health Program
Report on Massachusetts' first national health referendum

Women
Women and Children Last, R. Sidel, review

Spring 1988

Health/PAC Bulletin

Need More?
Copies of this special issue are available for $5 each ($12 for institutional subscribers), postage paid.
Send your name, address, and your check or money order to:
Health/PAC
17 Murray Street
New York, NY 10007

Healing Our Sick Health System-
Healing Ourselves:
A Retreat for Health Activists & Clinicians
Thursday, July 21 to Sunday, July 24, 1988
Vassar College, Poughkeepsie, NY

Sponsored by the Health Policy Advisory Center (Health/PAC) and Montefiore Medical Center/Albert Einstein College of Medicine.

A four-day retreat celebrating Health/PAC's 20 years of health advocacy. Join with us in exploring the connections between our personal lives and careers, and the health and political systems in which we work and struggle.

Invited speakers
Barbara Ehrenreich
Robert Coles
Rhonda Copelan
Molly Coye
Nick Freudenberg
Jo Boufford
Henry Nicholas
Maggie Ruhn
Wendy Chavkin

Families welcome.
Sliding-scale registration fees and scholarships available.

For more information write:
Hal Strennick, Department of Family Medicine
Montefiore Medical Center
3412 Bainbridge Ave., Bronx, NY 10467
Inside: Providing health care for all without spending more  page 21
From the AIDS unit: a social worker's story  page 14
Living with AIDS-related complex  page 12
A critique of "And the Band Played On"  page 16
HMO's in Britain—Thatcher wants 'em  page 27