Health Policy Advisory Center

From its inception in 1968, the Health Policy Advisory Center—Health/PAC—has been a unique progressive voice on domestic and international health issues. Through the Health/PAC Bulletin and the books Prognosis Negative and The American Health Empire, as well as outreach to a national network of grassroots groups, Health/PAC continues to challenge a "medical-industrial complex" that has yet to provide decent, affordable care.

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25 Years of Speaking Truth to Power

This issue of the Bulletin celebrates 25 years of Health/PAC and much more than 25 years of struggle for just, compassionate, and high-quality health care services by a number of our friends and colleagues. We chose to celebrate our organizational survival of this quarter-century by asking some of them to contribute brief articles that speak to their experiences, past and present, as planners, advocates, and workers and to their thoughts of the future. We are delighted that so many responded and seemed genuinely pleased to be able to participate in this celebratory issue. Unfortunately, because of the demands of working on the "front lines," some whose participation and perspective we eagerly sought could not respond in time to be included.

Our 25th anniversary year will also be marked by the publication this winter of Beyond Crisis: Confronting Health Care in the United States, Health/PAC's new anthology, edited by Health/PAC's executive director, Nancy McKenzie. And we invite you to join us for yet another celebration—at our 13th annual APHA—Health/PAC party, which takes place in San Francisco, Tuesday evening, October 26.

Of course, any marking of the passage of 25 years would not be complete without a comment from Robb Burlage, who founded the "PAC" in 1968. Robb is (along with two other Health/PAC "originals"—Dave and Ronda Koteluch) a remarkable example of a life of continuous organizational commitment and involvement in struggles for health and social justice.

—Arthur Levin

Health/PAC was founded 25 years ago to speak grounded truth to sectoral powers whose endurance we never could have predicted:

- To ... emperors (and feudal department lords) of academic medical center complexes, who, under white protective coatings, are ever-corporatizing their networks and joint ventures, which turn out to be the only service choice for the most at-risk communities.
- To ... voodoo-economist pitchmen selling medical-marketplace nostrums for those already most medical-market injured.
- To ... dazed bureaucrats who haven’t realized that community-consumer organizing and community-public partnerships, not new privatization schemes, are essential for accountable regional public system-building.

Today we seek for the Health/PAC Bulletin to reflect both a political-economic realism (as in "managed competition" explication and critique) and a critical qualita-
tive rootedness (as in the "new urban health movements" and "health apartheid"). One major self-imposed task through these years has been the attempt to characterize or "map" for our various movement constituencies, the uneven development of U.S. health care entities, institutions, and networks, whether local, regional, or national.

These entities increasingly dare to reinvent themselves as a national concatenation of institutions and industries—or "insti-industry." Nationally, today’s map of chain-linked academic medical center complexes and corporate health providers is rapidly enrolling physicians, both primary and specialist, and consuming ever more quantities of technological and pharmaceutical products. All this is underwritten by an increasingly strained and fragmented insurance industry directed by the commercial industry’s Gang of Five (who, with amazing dexterity, get to sit at both Hillary’s and Alain’s right hands), abetted by the increasingly embattled Blues, whose criminal wrongdoing, corporate mismanagement, and moral corruption have more than realized the worst nightmares of consumer advocates.

In the 1960s, health care became a civil rights issue, a peace issue, a feminist issue, a worker’s issue, and an environmental issue. In the 1970s, health care threatened briefly to become a universal issue. In the 1980s, in the face of infectious and social epidemics, health care became an issue of survival. Now, in the 1990s, the depressed national and regional economies and the riven health care sector are sinking. Flailing together they pose not only a lobbying juggernaut ("insti-industry"), but a formidable bastion of resistance to universal health care reform and to essential, sustainable, public-led, economic community development.

Everywhere that we encounter our friends and colleagues, whether at the January march on Little Rock, Walter Lear’s Philadelphia May 1993 history of movements conference, UHCAN! in Chicago this past summer, or APHA meetings around the United States, it is personally overwhelming to realize the uniquely creative good will and determination of those "out there." This issue is but a small sample of the diverse, reflective, and very much alive activist spirit and work that has graced these pages for decades.

We hope to be able to continue to play our political-educational role in this movement that cannot end so long as health, life, and democracy are at issue. Keep writing, organizing, advocating, and being critical, even of our own mistakes and omissions, until we all get it right together.

—Robb Burlage
We Have Seen the Enemy
It Isn’t Us

Barbara Ehrenreich

Health/PAC’s analysis of the health care system over the past 25 years illustrates a fine old radical principle: Things are often simpler than they seem.

In the media, “health reform” has become a mind-numbing swarm of issues and marginally distinguishable options. We are told that the way ahead is difficult and murky; that only experts can possibly make it out; that, despite our current extravagant expenditures on health care, real reform will require “painful sacrifice” on the part of average citizens. The majority preference—for a Canadian-style system of national health insurance—has been brushed aside as naïve and unsuited to American reality. Other nations have functioning systems of public health care; our case is made out to be uniquely baffling and complex.

There is something uniquely paradoxical about the American health care system: We spend more money on it, per capita and as a percentage of GDP, than any other nation, and we get far from our money’s worth in return. Some $768 billion dollars were pumped into the American health care system last year, yet 37 million Americans have no insurance at all, millions more are inadequately insured, and our mortality rates, especially for the poor and people of color, compare unfavorably with those of many third-world nations. Infant mortality in the United States is higher than that of Costa Rica, and Harlem is a deadlier place for a man to live in than Bangladesh. Somehow, our vast expenditures do not translate readily into “health.”

The system, in the conventional formulation, “doesn’t work.” This understanding is a huge advance over the denial characteristic of the Reagan and Bush administrations, when our leaders routinely praised American health care as “the best in the world.” But it also misses the point. There is a far starker analysis in the pages of the Health/PAC Bulletin: that the American health care system “works” just fine—if you acknowledge that delivering health care is not its primary goal.

The System is Successful

Central to Health/PAC’s analysis is the insight that the American health care system is highly successful at at least one thing: making money for the private interests that dominate it. Physicians are among the most highly paid professionals in America. Drug and medical equipment companies generate steady, and sometimes spectacular, profits for their investors. Hospitals are increasingly likely to be part of giant profit-making chains, and even legally non-profit facilities generate invisible surpluses in the form of handsome salaries and perks for their top doctors and administrators. Anyone who thinks the health care system “doesn’t work” should take a look at an investment guide to the medical industry.

Health care, in other words, is only a by-product of the American health care system. Yes, the system does provide care—in some cases excellent care—for millions. But it far more reliably and consistently provides wealth and security for a small elite.

The trouble is, we all pay for it. Through Medicaid and Medicare, the public sector plays a major role in funding private health care. About $390 billion dollars, or 51 percent of the money spent on health care, originates as taxes and represents the potential power of the public. Yet, as Health/PAC’s studies have repeatedly shown, the public sector effectively subsidizes the private, profit-making side of health care—most notably, by underwriting the care of millions who are too old, too poor, or too sick to be profitable to care for on their own. And throughout our current debate over health care reform, private forces have lobbied energetically to maintain their comfortable and protected status.

In the 25 years that have passed since a young economist named Robb Burlage founded Health/PAC, nothing has happened to alter this basic analysis. If anything, the dimensions of what even Richard Nixon dis-
cerned as a “crisis” in 1969 have grown catastrophically. Costs continue to escalate, bringing ever more desperate and punitive attempts at control. Insurers—public and private—have been a dominant presence on the medical “team,” making what can be life-or-death decisions. Dozens of public hospitals have been closed in the interests of budget cutting. Employers by the droves are wriggling out of long-standing health insurance guarantees for their workers and retirees.

The health care system “works” just fine—if you acknowledge that delivering health care is not its primary goal.

Health care is not, of course, the only factor determining health. Life-style, environment, and standard of living all play their part, and, tragically, these other conditions have deteriorated for countless Americans just as the health care system has withdrawn further and further from the business of providing care. We may smoke less than we did 25 years ago, but we also work, on the average, far harder, with diminishing time for sleep or family life. And, while 25 years ago we prided ourselves on the “conquest” of infectious diseases, AIDS and tuberculosis now rage at epidemic force.

One of the saddest measures of deterioration is the diminishing status of health care as a political issue for the poor. When Health/PAC began its work in 1968, health care was, along with education and welfare, a key issue mobilizing the urban poor. Today, health care has been all but overshadowed by more immediate needs—for mere shelter, for example, and protection from gunfire in the demoralized, economically moribund inner cities.

The Hazardous Health System

But perhaps the scariest feature of the health crisis of the 1990s compared to that of the 1960s is that the health system itself has become hazardous to our collective health. Escalating health costs add a massive dead weight to the federal deficit, inhibiting efforts to reform health care or do anything else that might improve the general health, like cleaning up the environment or rebuilding the inner cities. Health costs also hobble the private economy, and are an important factor contributing to the corporate downsizing that has eliminated so many jobs. The problem, then, is not just that the health system “doesn’t work” or works to the wrong ends—but that it has become a blight on the entire economy, a huge, bloated, parasitical growth.

As Health/PAC’s analysis has shown, the “managed competition” reform proposed by the Clinton administration does not even begin to address the problem. The Clinton proposal originates in the fanciful assumption that consumers are to blame for “overutilizing” health services and otherwise failing to control costs. In fact, Americans underutilize health care compared to the people of other industrialized nations and have little control over the costs or the nature of the services they do use. It’s the doctor—or, increasingly, the insurance company—who determines whether a headache merits nuclear magnetic resonance imaging or just an aspirin. Health care is one case in which we have seen the enemy—and it isn’t us.

Marketplace Medicine Has Failed

The solution Health/PAC points us toward is both conceptually simple and politically daunting: Take the profit out of health care. This is a matter of empirical evidence, not ideological bias. Marketplace medicine has had its chance, and it has failed. Attempts to squeeze more care per dollar out of a system that is fundamentally dedicated to something other than care can only fail. Besides, many of our most urgent needs—for preventive care and care for the poor—will never be profitable and will inevitably be neglected in a profit-driven system.

So then where will the incentive come from to provide care for a nation of 250 million people, the great majority of whom will never be entirely profitable to serve? We have a hard time imagining anything getting done without the incentive of personal or corporate gain. Yet most other nations manage, somehow, to provide health care or health insurance in a nonprofit fashion, through the public sector. We are not so congenitally different from the British, the Swedes, or our neighbors in Canada.

The solution is both conceptually simple and politically daunting: take the profit out of health care.

Health/PAC reminds us that the United States boasts a tradition other than individualism and profit-seeking. It is a tradition of mutual help and organizing for change: unions struggling for safe workplaces and health benefits; people with AIDS acting up for care and a cure; women confronting a sexist medical system; poor people organizing for community uplift; health workers advocating for low-income communities. And finally there is Health/PAC itself—a tiny band of thinkers and activists whose vision of a just and caring health system should inspire us all. ☐
Getting Here from There
A Health/PACer’s Odyssey
Ruth Galanter

Can it really be 25 years since the beginning of Health/PAC? It feels like yesterday, but then it also feels like a long, long time ago. I came on as part of the first expansion in October 1968. Since leaving in 1970, I’ve drifted increasingly into more straightforwardly environmental issues, back toward housing and urban planning, where I started out, and now into electoral politics. I’ve served as a member of the Los Angeles City Council since 1987. It’s been a slow evolution, and looking back at it, it seems like the seeds of nearly everything I’ve done were in or triggered by the early Health/PAC experience.

I learned a lot of things at Health/PAC. My first assignment—to figure out how New York City decides where a city hospital should be located—taught me a very important lesson about government and about life: Two government agencies with complementary but different mandates, each doing exactly what it is supposed to do, will probably reach different and conflicting conclusions. Someone has to resolve that conflict and make a decision, and that someone is going to be a person, not an institution, who should be approached and treated as a genuine human being facing a difficult problem.

Sometimes you have to create your own staging. Maxine Kenny and I are probably the only people who remember that we picked the office at 17 Murray Street, half a block away from the mayor’s office, so that we could print the rumors we heard by attributing them to “sources close to City Hall.”

Sometimes, no matter how delicious the alternative, you have to admit that things may be exactly what they seem. I still always get a laugh—but one of recognition—when I tell people I used to believe in the conspiracy theory of history until I discovered incompetence. Alas, very few people are well enough organized to run a good conspiracy even if they wanted to.

Most organizing techniques are essentially the same, regardless of the issue. Organizing is very slow and unpredictable. It requires lots and lots of patience. For impatient people like me, I’ve learned, there’s another way to go about making change. Sometimes it’s easier and quicker to just go do it than to organize a group of people, build consensus about what needs to be done, and then go do it.

Being Handed Harlem Hospital

In the last ten years or so, as I drifted toward running for office, I’ve been struck by two things. First, people seem to have lost the spirit of the ‘60s and now expect the government to do everything for them. This is a nonpartisan phenomenon. People want to know what the city is doing to reduce crime in their neighborhood but do not want to discuss what they as residents could do to reduce it. Organizations want government funding but do not want to seek private funding—unless, of course, the government will seek it for them. It does make me wonder sometimes about whether people really want “empowerment,” although I certainly know many who do and who use their empowerment to great community benefit.

Second, my odyssey seems distressingly unusual. In 1969 at Health/PAC we lived in fear that some city official would say to us, “Okay, if you’re so smart, you run Harlem Hospital!” Of course, none of us wanted to be a hospital administrator and wrestle with the daily details; it was much more exciting to be a critic. I’m sure those of you who knew me in the ’60s will join me in marveling that I’m now an elected official representing a district of 230,000 in a city of 3,500,000 people.

Organizing is very slow and often unpredictable. For impatient people like me, sometimes it’s easier and quicker to just go do it.

How did I get here? In the ’60s, everyone said, “You’ve got to be an organizer; it’s everyone’s social responsibility.” In the early ’70s, a close friend said, “You’ve been a critic long enough; it’s time to see if you can do better.” In the late ’70s, a prominent ’60s activist said, “You know, one day you really have to put all this stuff in front of some constituency.” And in the ’80s, another friend said, “How can you presume to make state and federal policy if you can’t take care of your own backyard?”

I had no respectable answer to any of these points, and I’ve never found anyone else who does either. Yet most of us who care deeply about the future of the health system, our people, and our planet still seem to live in fear of being handed Harlem Hospital. I want to express my gratitude and support to those who’ve overcome that fear, headed health departments, and run for office. For a long time, I didn’t appreciate you as I should have, but I sure do now.

Ruth Galanter, one of the earliest staff members of Health/PAC, is a member of the Los Angeles City Council.
The Experience of Health/PAC

Walter J. Lear

For those who staffed Health/PAC during its early years, the experience was personally profound—exciting and rewarding, demanding and painful, and, in the long term, influential. This stands out in interviews I conducted with six such early Health/PACers: Leslie Cagan, Ollie Fein, Ruth Galanter, Maxine Kenny, Ken Kimmerling, and Howard Levy. Although my questions emphasized the work of Health/PAC, the answers emphasized the character of the experience.

We altered the public consciousness about health care.” —Ruth Galanter

Different aspects of Health/PAC’s early work were highlighted by those interviewed—no doubt because of their different assignments, interests, and times of involvement:

- The bungling of the New York City Health and Hospitals Corporation.
- The fascistic character of therapeutic communities for drug addicts.
- The struggles of the Young Lords at Lincoln Hospital.
- The lawyers’ brainstorming about legal attacks on the two-class structure of medical care.
- The orphaned status of prison medical care.
- The disruptive demonstration at Blue Cross rate increase hearings.
- The proprietary drug industry as the advance force of the for-profit takeover of the health field.
- The political deficiencies of the Medical Committee for Human Rights (MCHR).
- The academic medical centers’ self-centered, exploitative use of their power.

Walter Lear, a physician and former public health official and health activist, is now President of the Institute of Social Medicine and Community Health in Philadelphia. He is devoting full time to research and writing about the history of the U.S. health left from 1875 to 1975 and assembling an archive for the U.S. health left.

These, like most of Health/PAC’s early efforts, broke new ground in finding and analyzing information and in political conceptualizing of policy and practice in the health field. As Ollie Fein put it, “We were able to see something others couldn’t see.”

“Because our work cut across class and race lines,” said Maxine Kenny, “health care became a political and social issue which everybody could relate to.” According to Ruth Galanter, “We altered the public consciousness about health care.” And, at least in New York City, the locale for most of its early work, Health/PAC was taken seriously, Kenny noted: “We got lots of flack about our criticisms of the city hospitals and of the therapeutic communities—even threats to sue us, which never materialized.”

“Combining analytical work and community-based activity was unique and enjoyable,” remembered Leslie Cagan. “Each of us had, more or less, our own ‘beat’ as a participant/observer,” explained Fein. “Mine was the Lower East Side; the Ehrenreichs had the Bronx; Maxine had Columbia.”

More important than Health/PAC’s impact on particular parts of the health field was its indirect impact through the people it touched. “We turned on many people—medical students and others,” stated Galanter. “We told them it was okay to organize around health issues. We made legitimate a new way of thinking about quality of care and equality of access.” There was an empowering effect: “Even if one can’t change the system, one feels empowered to know how the system works, why it makes the decisions it does,” observed Fein. “Central to such understanding is the concept of the industrial-medical complex, pioneered by Health/PAC and later picked up and elaborated by others.”

Another indirect but long-term impact of Health/PAC was reported by both Ken Kimmerling and Maxine Kenny: “We affected the career decisions of our readers” and “the kind of influence they in turn exerted on the institutions they worked in.”

We couldn’t get past the particular paradigm of the good guys—the people—and the bad guys—the medical schools.” —Howard Levy

“Of major significance was our advocacy of community control,” noted Kimmerling. This principle was applied to Health/PAC’s own work, according to Fein: “We did not see ourselves as expert consultants to the community. Such a relationship would have violated (a) our respect for the contributions non-health movement people could make to the analysis of health system problems, and (b) our political commitment to share problem solving with those affected.”
We operated as a group—sharing ideas, research, writing, typing, and other customary office tasks.”
—Maxine Kenny

This problem was compounded by three other factors. First, according to Fein, “We were more than sympathetic reporters; we were ourselves participants in the community and health worker struggles we were writing about. We became too identified with them; to have been critical would have undermined our role as participants.” “It was a very tricky relationship we couldn’t work out,” Howard Levy concurred.

Second, Fein noted, “We were middle-class intellectual/professional whites, while most of those in the community and health worker struggles were working-class blacks and Puerto Ricans. This made criticism of them by us very difficult.” And third, “Public criticism of public hospitals and movement efforts could play into the hands of the enemy—perhaps lead to the firing of friends or cutbacks in needed services.”

Big egos got cut back by collective criticism, but healing was easier in the presence of a strong commitment to working together.”
—Ken Kimmerling

As a result, the main purpose of a number of Health/PAC articles was to provide support to allies. The notable exception, the article about MCHR, engendered great private debate and much personal bitterness. “Major retrenchment of civil rights and anti-Vietnam War activities made cheering a short-sighted function,” Levy argued. “Good critiques were what would have been valuable.”

The quality and scope of Health/PAC’s critical capacity also troubled some. “We couldn’t get past the particular paradigm of the good guys—the people—and the bad guys—the medical schools—first laid out in Robb Burlage’s outstanding breakthrough study,” explained Levy. “For this reason, serious problems in the public sector were glossed over. And we couldn’t add to our important economic orientation concern for the complex cultural dimension of the health field, the ‘soft’ issues not amenable to the narrow, science-based type of analysis traditional in the Left.” But these regrets about a projected but unrealized potential should be coupled with another part of Levy’s evaluation. “Much of our work was good for its day; some of it can still be read with profit.”

The Collective Process
As special as were the products of Health/PAC’s early years, more memorable yet was the experience of being part of a highly intellectual, highly political, interdisciplinary work collective. These early Health/PACers came from the fields of journalism, law, medicine, political organizing, and planning.

I picked up this way of thinking, analyzing—not taking things for granted.”
—Leslie Cagan

“We operated as a group—sharing ideas, research, writing, typing, and other customary office tasks,” remembered Kenny. “Everything written was seriously read and intensively discussed. This resulted in sharper argumentation and better-written articles,” noted Fein. “The MCHR article was a good example of our process. It was hotly debated, as it involved questions of politics and of direction.” “Political agreement was always reached; I don’t recall any instance with a strong dissent,” added Kenny.

The collective intellectual process was strenuous; most had not worked in that way before. For example, “It forced me to read more, to search for better answers” (Levy). “For those with difficulty in writing, it improved their style a great deal” (Fein). “Everyone was frustrated some of the time. Big egos got cut back by collective criticism. It took its toll in emotional energy, but healing was easier in the presence of a strong commitment to working together” (Kimmerling). “There was always a lot of tension on how far to go with criticism. We finally reached consensus on each of the three articles that were the most critical of allies” (Levy).

Lasting Consequences
Working at Health/PAC proved consequential for these early Health/PACers both at that time and subsequently, as each of those interviewed attested. “It was an especially exciting opportunity to work collectively with such bright and political people” (Kimmerling).
"These incredibly dynamic and caring people took us young people [Cagan and Kimmerling] seriously" (Cagan). "It was a very good experience—it taught me a lot" (Levy). "It confirmed and bolstered my political perspective" (Kenny). "It consolidated my values, the bedrock of my career" (Fein). "I picked up this way of thinking, analyzing—not taking things for granted," added Cagan. "At first this helped me understand the political dimension of the health care system. Later, by extension, I could understand other American institutions."

**It consolidated my values, the bedrock of my career.**

—Ollie Fein

Their experience at Health/PAC proved to be the forerunner of future activist careers for many Health/PACers. "Health/PAC showed me how much can be done by so few. You don't have to be the majority to be right," said Galanter. "It gave me great confidence to act politically without the backing of a large number of people. With this approach I did politically what I thought was right and eventually was elected to the Los Angeles City Council."

**Health/PAC showed me how much can be done by so few. You don't have to be the majority to be right.**

—Ruth Galanter

Similarly, "I gained enough confidence in my organizing skills to become an organizer," Kenny explained. "Prior to Health/PAC I had been a journalist." "I learned how to submerge my ego, to prefer a collective work style," recalled Kimmerling. "This has stayed with me as director of the Puerto Rican Legal Defense Fund." And Cagan, also still an activist, stated, "Coming directly out of the student movement, I felt lucky to be doing political work and making a living. This gave me hope that such a career was realistic—and it was, for I have earned a living in the movement ever since. □
Health/PAC and the Uncertainty Principle

Susan Reverby

In October 1970, as a newly declared feminist, history graduate school dropout, and legal abortion clinic worker in New York City, I was hired as a staff member to write about women's health at the two-year-old Health/PAC. I was 24 years old, and all I knew about health care I had gleaned at the abortion clinic or as a child at the family dinner table. For the next three years I learned a lot very fast, as I wrote, edited, and traversed the country giving speeches on the politics of American health care, women's health, and, eventually, the history of nursing.

The problems seemed more difficult than I had first imagined and the solutions more difficult to create than I had hoped.

Health/PAC was a real postgraduate education. It provided me with an analytic overview of the health care system from The American Empire, the book we affectionately called "Das Hospital." It taught me how to do research, read memos upside down on powerful people's desks, interview, write to a deadline, get devastating criticism, and rewrite in a sleepless haze. It forced me to speak quickly on my feet about things I knew almost nothing about, and made me value the incredible grassroots efforts women and men—but especially women—were making to change the behemoth we called even then the "American health empire." It introduced me to women like Rachel Fruchter, Helen Rodriguez-Trias, and the members of the Boston Women's Health Book Collective who were struggling to make women's voices heard.

As I worked with others who were "boring from within" in hospitals, medical centers, and nursing schools, Health/PAC often seemed like a "DP" camp—a place where displaced professionals could find solace. On a ratty old couch in a run-down office building on Murray Street, and over bad cups of coffee and soggy sandwiches from the "Quik-Time" deli, we provided a place where the endless stream of visitors could speak their piece about American health care and not be considered crazy.

I learned many truths in those years. I came of age understanding that doctors would treat women who complained of vaginal infections with antidepressants, that the IUD of choice for "nulliparas" could mutilate and kill us, that hospitals seemed determined to ignore the needs of people of color. I grew suspicious of the health care system's priorities. I learned to be a doubter and to question the bravado and the certainties in American health care. I thought we had the answers—community control of health institutions, strict regulation of the medical-industrial complex, alliances of consumers and providers—and a way to analyze the problems. But after three years the problems seemed more difficult than I had first imagined and the solutions more difficult to create than I had originally hoped. In desperate need of more perspective and more time to write thoughtfully and historically about the issues, I returned to graduate school.

'Science World' vs. 'Life World'

Twenty years later, I am no longer a displaced professional. As the chair of the Women's Studies Department of Wellesley College, an historian of nursing and American health care, and a friend of the members of the Boston Women's Health Book Collective, I became this January the consumer representative on the Obstetrics and Gynecology Devices Advisory Committee of the U.S. Food and Drug Administration (FDA). At the first public hearing I attended, I was forced to reconsider and reflect on much of what Health/PAC had already taught me.

The occasion was a two-day public hearing on a pre-market approval application from a medical device company that manufactures home uterine activity monitors (HUAMs) to detect pre-term labor. We also considered guidelines for medical device manufacturers on how to provide supporting scientific studies on HUAMs and heard

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from consumers, clinical investigators, FDA scientists and engineers, and company representatives.

Echoed at the hearing was the clash I had first witnessed at Health/PAC between the “science” world of medicine and the “life world”—in this case the world of some of the mothers who had experienced pre-term labor. The “science” world spoke in terms of outcomes, chi-squares, the validity of cervical dilation as a statistical endpoint measure, sample sizes, etc. This world used slides and overhead transparencies and spoke at length. In contrast, the “life world” spoke in terms of the anguish of dead babies, of an existence tied to fear of loss, of the sense of control and hope that the HUAMs provided, of the need for women’s “choice.” This world used photographs of babies destined for death lying in neonatal intensive care units and letters from hundreds of mothers whose children were supposedly saved by the HUAMs. These women had three minutes each to compact their sorrow and concerns.

The medical and research issues that the panel primarily debated only served to highlight the uncertainty and disagreement in this particular arena of medical care and the different “languages” of the debate. Much of the hearing focused on the kinds of scientific studies needed to really demonstrate the “effectiveness” of this device in detecting pre-term labor, since it is primarily an alarm system that allows a clinician to know that a pregnant woman is having increased uterine activity. But there is clearly much disagreement about precisely what pre-term labor is, when it starts, what can be done about it, whether the currently available drugs can do anything about it, and whether careful monitoring by a nurse is as important as or more important than monitoring by the device.

Unprepared for Uncertainty

Twenty years ago, Health/PAC was too focused on critiquing health care as a business to consider medicine as both an art and a science, as this hearing clearly showed it to be. The early Health/PAC’s concern with the profit motive as the engine of American health care, the paternalism that lulled women into accepting clinicians’ views, and our sometimes naive belief that a better science was possible didn’t quite prepare me for the level of complexity that the HUAM issue presented. This technology and the hearing involved a level of uncertainty—about medical science, clinical assumptions, and women’s relationships to technology and to their hopes for their pregnancies—that I would not have understood 20 years ago.

Health/PAC had prepared me to hear the women’s voices and to appreciate their concerns. The women testifying used all the right words about empowerment and control—the very things that Health/PAC and the women’s health movement had taught me to want for women. In their statements to me and to the panel, they made clear that they believed that the device gave them more control, helped them have living or healthier babies, and empowered them. They spoke of the device as “their best friend,” which “provided emotional reassurance.” A number of them testified that the device made them feel more in control because, without it, if they could not feel the contractions they felt “at fault.” Ironically, it was a male panel member who suggested that women could do their own palpation to determine as much as the machine did. The women booed him, insisting that it was practically impossible to feel the contractions without the device.

As a mother who also has had a miscarriage, a woman, and a feminist, my sympathies were certainly with these women and their anguish. As an historian and critic of health care, however, I worried over their dependence on this questionable technology to resolve an uncertainty that simply may not be so easily resolvable. Health/PAC hadn’t prepared me to consider that what women said they wanted might not always be the best thing for them and that their beliefs might have been mediated in ways we or they didn’t understand. I wouldn’t have considered then that my own questions might turn into a form of paternalism.

We were too focused on critiquing health care as a business to consider medicine as both an art and a science.

I was also very aware of how the unspoken language of our very dress seemed to separate me from these women. They wore pink or pastels, often pinning on their breasts their dead or surviving baby’s newborn nursery bracelets bearing the child’s name—coding themselves as feminine mothers. I was in my “professional best,” consciously choosing a new pink and blue suit (colors I almost never wear) and very simple earrings in part to code for gender uncertainty and an undeclared reproductive state.

As I listened, I thought about the questions that Health/PAC had taught me to ask about the relationship between women and medical technology. Were these women manipulated by the device companies or lulled into these beliefs out of reasonable fears? Could I see these mothers as anything other than victims of rapacious medical businesses? I thought about the false reassuran-
ces we had gotten in the 1970s on the Dalkon Shield, the pill, and DES. Then, we had worried about safety. In the case of the HUAMs, I worried less about safety and more about effectiveness. I pondered whether the use of this device in fact unnecessarily “medicalizes” a pregnancy or diffuses an unnecessary and expensive technology into the health care armamentarium.

I also worried about the women we did not hear from. Many of the women who came to testify were part of organized support groups for women experiencing high-risk pregnancies or were the mothers of multiple-birthed children, and some belonged to an organization that appeared to have received at least some support from the maker of the one HUAM that the FDA had approved. I was concerned that our panel did not hear from women who used the device and still lost their babies, who could not afford to pay for the device, or who were given drugs to halt pre-term labor and either experienced it anyway or were really not beginning pre-term labor at all. In sum, I did not think about women as one undifferentiated group without competing needs or differing understandings of their medical concerns.

The Uncertainties of Science

The world of science promises more certainty than it delivers. Just how shaky is the “science” that we depend upon to make decisions on medical safety and effectiveness is suggested by the apparent need for a high FDA official to give the captive audience of device manufacturers and their clinical researchers a brief “continuing education” lecture on how to design a clinical research study. An internal FDA report had been critical of the existing research on medical devices. The old canard is that a collection of anecdotes isn’t data. But badly done science may be simply “old clinicians’ tales,” as useful as data upon which to make decisions about effectiveness and safety as “old wives’ tales” or, in this case, “old mothers’ tales.”

While Health/PAC did teach me to consider many of these concerns, I suspect that 23 years ago I would not have seen the uncertainties of medicine in quite this complex a light. I would have listened to the women and not understood their willingness to rely upon this technology. I might have judged their belief in the device’s effectiveness as a kind of naivete on their part. I doubt I would have understood then their desperate desire for a healthy baby. I would have been as suspicious as I am now of the device companies, but perhaps not as attuned to the uncertainties of medical and clinical judgment or the possibilities that both making a profit and doing something effective and safe were possible. I would have understood rhetorically the importance of nursing care but would not have believed in it to the extent I do now.

Above all, however, Health/PAC taught me to be critical and listen. After a quarter of a century, Health/PAC’s vision of health care as truly a right has never wavered, even if its analysis, as well as mine, has grown more sophisticated and appreciative of the complexities we must confront. I am no longer a displaced professional. But the willingness to question how we deliver and structure American health care, first shaped for me in Health/PAC’s “DP” camp in those heady early 1970s discussions, is a skill I hope I never lose.

Coming Full Circle
Lessons from Health Care Organizing

Terry Mizrahi

What a wonderful opportunity to use the 25th anniversary of Health/PAC to reflect on my own 25-plus years of health organizing and comment on the opportunities and challenges that lie ahead. The Bulletin has provided sustenance to many of us; it keeps us going—and we use it to impart to a new generation our collective experiences and visions.

Health/PAC was more than a think tank—it conducted action research at the same time that it helped influence the health care debate.

While I remembered being there at Health/PAC’s “birth” in its very first office on lower Broadway, I was truly surprised when I reviewed my early Bulletins to uncover so many connections so early on with Robb Burlage, Oliver Fein, Dave and Ronda Kotchuck, and Barbara Ehrenreich, among others of the early Health/PAC staff. As a young health organizer, I was one of the people whose work Health/PAC sought out as a “laboratory” to test their theories. However, Health/PAC was more than a think tank—it conducted action research at the same time that many of its members helped create and influence the direction of the health care debate. But the Health/PAC founders never pretended to be “organizers” in the elitist mode of moving into communities.

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taking over campaigns, or supplanting the efforts of local organizers and activists. Rather, they were there as supporters, advisors, participants, and as learners. The relationship between Health/PAC and the community organizers and leaders with whom they interacted was one of reciprocity and exchange—each of us learning from and educating the other.

That time and that community were a hotbed of activism and progressive social change.

I was a trained community organizer right out of social work school who went to work for the Lower Eastside Neighborhoods Association (LENA) in late 1966. I was hired and mentored by Ana Dumois, a consumate organizer (who is quoted in the first Bulletin in June 1968) with NENA (North East Neighborhood Association), an affiliate of LENA and the first community organization to receive federal funds to plan and operate a neighborhood health center. The NENA health center became a model for the country. (Several articles appeared in Health/PAC Bulletins about NENA’s development over time, beginning with one in its second issue.) It had great potential, but also had a rocky history over the years. Nevertheless it has survived and still provides needed health care to thousands of Lower East Side residents.

The Struggle for a New Community Hospital

Although I lacked any prior interest in health issues, my first assignment was with LENA’s health committee to investigate why the building of a new Gouverneur Hospital on the Lower East Side—promised ten years earlier to replace an old inferior one that had been closed by the city—had been stalled. My job was then to organize another campaign to obtain the new hospital, which had been promised the Lower East Side community first by Mayor Wagner and then by Mayor Lindsay. LENA had spearheaded that movement in the late 1950s. Ten years had passed, and there still was nothing but a hole on Madison Street with only a sign to indicate that it was to be the site of the new Gouverneur Hospital. In the next six weeks, I became an instant expert on health politics as well as health organizing, in ways I hadn’t anticipated.

My personal reaction to the Gouverneur assignment provided a clue as to one of the primary difficulties inherent in organizing around health care: people don’t believe they can effect change. I had never been sick myself, and I thought that only doctors and other health professionals had the expertise to understand health problems. I learned that it is difficult to get people to identify with a health issue when they are healthy. It also became clear that it takes a great deal of community education to convince people that their familiarity with and stake in the health care system as consumers and as

community residents gives them as much legitimacy and expertise as the bankers, businessmen, and other lay people who usually sit on the boards of directors of hospitals. Nevertheless, we were able to obtain 10,000 signatures on petitions, which we presented at a rally of several hundred people to then Manhattan Borough President Percy Sutton.

The Power Brokers

The second major difficulty in organizing around health I uncovered unintentionally: it is the veiled and private nature of the health power structure. It was still a few years before the appearance of The American Health Empire, and while a “two-class” system of health care was clearly evident in the Lower East Side community, it was not yet fully understood. In the course of negotiating for the new Gouverneur hospital, we attended a meeting at the borough president’s office. We would also be meeting with the commissioner of hospitals, Howard Brown, a progressive leader in health care reform whom we expected would be an ally.

When we arrived, the room was filled with several additional white men. They were from Beth Israel Hospital and from an organization I had never heard of, but which, in fact, was one of the most powerful players on the health care scene: the Hospital Review and Planning Council of Southern New York. (The private, corporate nature of the HRPC was also discussed in the first issue of the Bulletin in relation to its desire to become the health planning agency for New York City.) It turned out that Beth Israel, as a voluntary hospital, had secretly been given control of the new Gouverneur facility. The HRPC had killed the plans for a new hospital and, unbeknownst to anyone in the community, approved the Gouverneur site instead for a long-term care nursing home facility.

In six weeks I became an instant expert on health politics as well as health organizing.

It was then that I learned, what Robb Burlage would soon expose in a Health/PAC report on the New York City municipal hospitals: namely, that through affiliation contracts, the private teaching hospitals controlled the public sector. Moreover, as a private body with quasi-governmental authority to approve new facilities, the HRPC was dominated by the private hospital interests and not directly accountable to the public for its decisions. This one meeting opened all of our eyes to the power of the so-called “voluntary sector” and the weakness of the public hospital system.

Needless to say, LENA and its affiliates were outraged, and we began to organize a campaign to take back the planning and direction of the facility. Enter Oliver Fein and Robb Burlage from the newly formed Health/PAC,
who provided some advice and direction as we discussed political and technical strategies, conducted open community meetings, and held behind-the-scenes negotiations with members of Brown's and Sutton's staffs.

The final outcome, arrived at over a period of a few years, was a new hospital, destined to be beholden to Beth Israel through an affiliation contract, that included the Gouverneur Ambulatory Care program and additional medical inpatient services but omitted obstetrics and surgical services on the grounds that they were too expensive to operate. This compromise, the best the community leaders thought they could obtain at the time, was considered a victory—albeit partial and ultimately short-lived. As a result of the community's efforts, the new hospital had the most elaborate patient advocacy department in the city, but it was costly to run, leading to eventual loss of the inpatient service during the city's fiscal crisis in the mid-1970s. Nevertheless, Gouverneur's quality outpatient and chronic health and mental health services remain and have been developed with a multicultural framework to meet the needs of a highly diverse community.

The lesson learned from planning for the new Gouverneur hospital is that it is more difficult to organize when there is a decentralized private power structure operating the system. Consumers have more leverage and influence as citizens, taxpayers, and consumers when they are organizing around such issues as welfare, schools, and public housing, which are publicly funded and government controlled services. These systems are also visible public bureaucracies, and it is easier to know who the critical actors are.

Thus, the infusion of Medicaid and Medicare and other government funding into the financing of hospitals in the 1960s began to give citizens and their political leaders more legitimacy in making their needs known and demands felt. It was no accident that another of these newly passed federal programs—the Neighborhood Health Center Act—linked LENA, myself, and Health/PAC in significant and fateful ways. The confluence of ideas, conditions, commitment, experience, contributions, and resources made that time and that community a hotbed of activism and progressive social change.

The Lower East Side Neighborhood Health Council—South

At the same time that the organizing campaign for the new Gouverneur hospital was underway in 1967, Beth Israel was attempting to obtain funding from the Office of Economic Opportunity (OEO) Neighborhood Health Center program to expand the Gouverneur Ambulatory Care Program, then funded by the city. Receipt of funds from the Neighborhood Health Center program, which constituted about half the budget for the Gouverneur Ambulatory Care Program, required representation from the poor and from the recipients of service (known as the “maximum feasible participation of the poor” doctrine).

LENA joined the Health Committee of the Lower East Side Community Corporation (LESCC), the local OEO-funded review and planning body, in reviewing Beth Israel's proposal, and I became the staff person for the committee. Together with several community leaders and progressive health providers from a variety of agencies (including the Gouverneur Ambulatory Care Program itself), I helped to organize an independent organization known as the Lower East Side Neighborhood Health Council—South. Over the years, the relationship between this new group and Beth Israel changed from cooperation to conflict to accommodation when, in the early 1970s, both sides recognized that neither could defeat the other. Health/PAC became involved early on in observing and participating in the process, with several stories appearing in the Bulletin during its first year. (Chapter 19 in The American Health Empires also describes the struggle.)

It is difficult to get people to identify with a health issue when they are healthy.

The perseverance of the members and staff of the Lower East Side Neighborhood Health Council—South allowed it to weather many storms. In spite of attempts by Beth Israel to defund the Health Council, which had obtained earmarked OEO funding for its own staff at that time, the council and its advocates were able to convince federal officials to fund an office as well as additional staffing. By that time I had left LENA but maintained an advisory role with the Health Council as a staff member of the Federation of Protestant Welfare Agencies (FPWA). The Lower East Side Neighborhood Health Council—South continued to exist through the mid-1970s as a result of the work of Judy Wessler, the incredible health activist who eventually took my place.

During the early 1970s, the Lower East Side Neighborhood Health Council—South hired two workers—Paul Ramos and Thomas Tam—to be more responsive to the area's Hispanic and Chinese communities, among their other responsibilities. Both of these men have had an incredible impact on health care in the Lower East Side since then. Both got their starts under the tutelage of a group of professionals and consumers who believed that health care was a right and that neighborhood services should be developed to meet the needs of the people with their participation. When funding for the Health Council ended, Ramos and Tam both went to work as the first patient advocates of the new Gouverneur Hospital, while pursuing their community involvement on their own time.

Ramos and a group of community supporters founded the Betances Health Center (originally the Judson Mobile Unit, supported by the Judson Memorial Church). Serving the Hispanic community and other low-income residents, with Ramos still as its director, Betances remains a model of comprehensive primary care.

Tam and a group of young Chinese students identified the lack of health services for the growing Chinese community. I helped them get their first grant from the FPWA.
to hold the historic first Chinatown Health Fair on Mott Street in 1971. This led to a series of community health initiatives, culminating in the thriving Chinatown Health Clinic that stillerves the Chinese community in the greater New York area today.

Forging Ahead

Space does not permit me to go into detail about my third area of overlap in organizing with Health/PAC in the late 1960s: a citywide coalition to ensure that the first comprehensive health planning agency established in New York City under the Comprehensive Health Planning Act was a public, community-based agency instead of the Hospital Review and Planning Council. This exciting and significant effort resulted in a partial victory, officially defeating the private sector but with limited ability to affect their power outside the Comprehensive Health Planning (and later Health Systems Agency) structure.

This country is on the brink of either real change in health care or missed opportunity—one more time.

From my history of professional organizing in health care, I have learned that several components need to be in place for successful health change to occur. First, competent organizers are needed who can mobilize people and sustain their involvement in health-related struggles. Funds must be available to pay organizers to assume this function; otherwise, other community agencies need to make staff available to fulfill that role. Second, we need competent and committed government officials who believe in consumer and community involvement in health affairs and who are willing to enforce or develop regulations that mandate an open process. The final component is a few community leaders and patient advocates who understand the complex health system and are willing to challenge professional authority.

The connection between the past and present continues to amaze me. So many of us continue in our own ways to advance the issues of social and economic justice.

This country is on the brink of either real change in health care or missed opportunity—one more time. While the “grassroots” movement for health reform has been lead primarily by a coalition of labor and senior citizen organizations, along with some consumer and public interest groups, after 25 years it still remains extremely difficult to actively sustain the involvement of groups in low-income neighborhoods or communities of color around health reform. Yet we keep forging ahead in this era of cautious optimism. ☐

‘As Though People’s Lives Depended on It’

Joe Gordon

The quarter-century anniversary of Health/PAC marks an occasion worthy of celebration. Its survival—and service—during the difficult Reagan-Bush years speaks to the tenacity of its resourceful staff and volunteer board members. That the nation was set back hugely during this time, only a fool could doubt. The socially vacant Bush was killing us and didn’t even know it. Who can forget the other-worldly faces of our last two chief executives, smiling those Valium-like smiles as they knocked back gains that had taken years to come by.

The Clintons deserve our support. Bill’s job is far harder than any recent president’s. Half of America is in the emergency room, and the other half can’t find it. They face a daunting political challenge, and I am rooting for them.

I leave it to others to comment on where the current reform efforts might lead, as I’m really not qualified, but let me put my wishes on the table. In the short term, I support a universal, single-payer system, with a package of services as broad and as ambulatory as a herd of galloping elephants. In Clinton’s second term, I’m for a fully developed national health care service—one that’s truly accessible, aimed at fostering health and fine-tuned to meet the contours of every rippling difference among our nation’s people—which includes everyone, even newly arriving Haitians.

Living, Breathing, Imperfect

Now, to focus on what I really want to write. It’s a short story, which goes like this: I am a devoted reader and one-time editor of this journal. For me, much of the Bulletin’s special appeal has always lain in its modest scale and simple production values. Out of this simplicity bursts forth some truly memorable reporting and analysis. Upon opening it for the first time close to 15 years ago, I did a kind of neural double-take. “Wow! This is something!” I felt as though I had discovered a genius.

Yet, for all its technical competence, for all its energy, for all its currency, the Bulletin is still regarded by many smart people (who should know better) as a quaint relic.

Joe Gordon is the fundraiser for the Safe House for Lead Poisoning Prevention at the Montefiore Medical Center in the Bronx, New York, and the former Editor of the Bulletin.
of the "sixties" or "the left." It may be quaint in one way or another, which is not a bad thing, but it is hardly an artifact. For me, it is very much a living, breathing, imperfect publication. As John Dewey would say of the most usable knowledge, it is relevant.

The Bulletin considers the real social, political, and human conditions of people. It wonders aloud about the ways their various situations affect their health—and it builds on this wondering by imagining alternative ways of improving the quality and content of that care. In my reading experience, this is not an everyday occurrence.

"Useful": The Highest Compliment

For me, the humanness of the Bulletin makes it a graceful and highly useful publication. And in the subculture to which my family belongs, when we speak of someone or something as being "useful" it is the highest compliment we can pay. That's because one of us, my delightful and determined daughter, can't walk and has an uncontrolled seizure disorder. So, in our parlance, an uncut sidewalk or rampless building entry is not at all "useful"—whereas a toilet able to fit a child-sized person is very "useful" indeed (talk about people falling through the cracks!)

The Bulletin is useful.

In matters of health, there are really no barriers between people, except the ones we invent.

Health/PAC's 1970 book, The American Health Empire: Power, Profits and Politics, was a classic, above-ground work of muckraking analysis. The people at Health/PAC have worked hard to extend its broadside thrust in the decades since. Health/PAC remains a progressive rallying center where consideration and direct voice is given to the vital health needs of people: gay people, chronically ill people, people with disabilities, people battling violence or racial prejudice, addiction, homelessness, environmental degradation, and exploitive working environments.

Their various-textured voices speaking through the Bulletin have shown me again and again how the seemingly dissimilar situations of others are in fact very strong-ly similar to my own. In matters of health, there are really no barriers between people, except the ones we invent. Health/PAC taught me this.

It is only through careful listening that the needs of care-seeking people have a chance of being fulfilled.

I have also borrowed from Health/PAC the idea that human service systems only become and remain rational when they respond to our complexities and subtleties. It is in this connection that the uses and misuses of language and time can make or break one's efforts to create services that are truly helpful to people. This sounds more philosophically formal than I want it to. What I mean to say is simply that providers should schedule clinic hours for the convenience of care-seekers, not staff members. And in using clinical or social definitions, our words should function not as labels but as tools to penetrate to and meet a person's needs. The assignations "HIV-positive," "mentally retarded," or "drug-addicted," for instance, become cursed when used to classify, pigeon hole, or otherwise "manage" a person in need.

I have learned through my experiences that our programs, organizations, and institutions stay useful only when they are constantly adapting to the changing circumstances of people, the way that a living language does. The readers of this publication understand that knowledge or technology can be useless in the hands of a highly trained person who has forgotten—or doesn't know how—to listen, or is afraid to observe a changing person. It is only through careful listening that the needs of care-seeking people assume primacy and have a chance of being fulfilled. This is such a basic concept, yet on the busy floors of the health care arena, integrating it is not so easy.

When I was a student journalist learning the craft in New York City's far-flung neighborhoods almost 20 years ago, a seasoned reporter once instructed me: "Listen carefully, use all your senses of observation, organize the content logically, and then deliver it as though people's lives depended on it." I believe the Bulletin lives up to this credo, which is why I salute you, Health/PAC, and celebrate your 25 years of good listening.
Make-Up in the Morgue
Liberal Reform and American Health Care

Matthew P. Dumont

Often guided by Health/PAC's brilliant illumination, I watched, during the last quarter of a century, the sad, unrelenting degeneration of my profession. Medicine's loss of social function has only kept pace with that of the other crumbling institutions of this decadent society. Capitalism has entered its agonal phase, a mirror image of the manic, murderous times a half-millennium earlier when in its "primitive" form it burst out and spread like a malignancy from Europe, that decaying, still-decaying continent.

In particular, I have watched psychiatry, my own specialty, deteriorate from a relatively open, curious, and intelligent endeavor to become nothing more than a mercenary to a predatory pharmaceutical industry.

I watched, during the last quarter of a century, the sad, unrelenting degeneration of my profession.

When Health/PAC first appeared on the scene, I was at the National Institute of Mental Health, in charge of a center devoted to exploring the relationship between urban violence, poverty, and racism. Elsewhere at NIMH, epidemiological studies demonstrated that mental illness was somehow related to such issues as social class, unemployment, migration, and residential density. There was a national mental health services program built around the direct federal funding of salaries for mental health workers (including "indigenous non-professionals") in community clinics. Community control and primary prevention were obligations. The prevailing paradigm of psychiatry, burdened though it was by psychoanalytic theory, was nevertheless social and dynamic.

The Destruction of Community Mental Health

Twenty-five years of economic decline and political reaction (including the Democratic variety) has seen the destruction of both the paradigm and reality of community mental health and social psychiatry. What is left of a public mental health program, including the state hospital system—the rock bottom safety net for the im-

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pov-erished mentally ill, is being “privatized.” Increasingly, large corporate providers are sweeping up the crumbs of profitability, while growing numbers of helpless and destitute people are being dumped into a condition of homelessness without any form of social infrastructure, a poverty as dehumanized as the wealth which caused it.

There is no place for profit making in any aspect of health care.

Psychotherapy, despite its contradictions, was, at least, an interpersonal intervention. It has been replaced with fragmentary, medically dominated, disease-oriented, pharmaceutically driven manipulations dominated by business managers who act like field marshals to proletarianized clinicians. Professional organizations that once cooperated in advocating for mental health have retreated to a guild mentality, with each trying to get a bigger piece of a dwindling pie with a rotten recipe.

Mental health professionalism has adopted a narrow-minded, intellectually bankrupt, and self-serving ideology of biological determinism. The nebulous complexity of human behavior is forced into a culturally blind and clue-laden classification system whose categories are deemed to exist in nature as a hereditary consignment of constitutional defects. Not since the headsy days of the 1930s in Germany has there been such an obsession with the genetic origin of mental illness. Current pedigree studies of twins are the merest refinement of Dr. Mengele’s groundbreaking research.

As another reprise of Nazism (and, for me, a perverse and nightmarish deja vu), the current strategy at NIH for dealing with urban violence is to detect by the age of 5 those individuals who are likely to become violent later in life. We were not told what “preventive interventions” would be performed on those poor kids of color.

But enough of psychiatry. Functioning at the trembling edge of deviance, it has always amplified the social, political, and economic values of its age.

From Hyperbole to Platitude

When Health/PAC first identified major medical centers as “empires,” we thought it was a matter of hyperbole. Since then, the one I have been connected to in Boston has come to make the word seem a platitude. When once lip service was paid to concern for the health of the community and the prevention of unnecessary hospitalization, now we are directed to admit as many people as possible for as brief a period as possible to “keep the beds filled.” This is to justify the construction of half-billion dollar towers for more beds, which every analysis of health care in this area concludes are not needed. MRI machines are being built in every telephone booth, while state “determination of need” requirements are brushed off with contempt. What was once primarily a hospital has become primarily a real estate venture, as more and more neighborhoods are...imperialized. Research “grants” from multinational corporations result in the exploitation of patients as subjects of investigations whose purpose is pure profit.

And the whole “non-profit,” tax-free enterprise, underwritten by the public, lays off staff, increases productivity demands, and busts unions in the name of cost-cutting, while declaring multimillion dollar “reserve” surpluses for the banks, insurance companies, and real estate interests that dominate its board of trustees. The medical director of this, as in the other Harvard teaching hospitals, is paid off with salaries approaching a million dollars annually. This permits him, without choking on the contradiction, to complain about the exorbitant cost of providing health insurance coverage to the hospital’s own employees.

Current “liberal” programs of medical reform have to be seen against this background of mean-spirited and cynical corruption on the part of the standard bearers of American medicine. Even the single-payer model we are struggling for is likely to be a compromise with this corporate hegemony.

We have to stop being afraid to use the term “socialized medicine.” There is no other kind.

Liberalism has always been a “co-dependent enabler” of fascism. At critical times, such as in Germany in the 1930s and the United States in the 1950s, liberalism always sides with the Right and stabs the Left in the back. Like the meaningless choice of leadership we are given every four years to distract us from the realities of power, the current options for reform of the health care system are within too narrow and arbitrary a frame of reference.

No Place for Profit

There is no place for profit-making in any aspect of health care, whether it is the use of our labor or the drugs we prescribe. There should be a national program that salaries health workers in a network of community settings with the responsibility to identify and confront—to treat—anything that relates to the health of people, whether a single infection or a polluted river or a closing factory. Every patient should be a student, so that every professional intervention is at the same time a sharing of professional knowledge. Professionalism, like all sources of power, must constantly be redistributed. We have to stop being afraid to use the term “socialized medicine.” There is no other kind. Its practice needs to be redefined as an instrument of social revolution.

This has always been Health/PAC’s vision and must remain its mission.
'To Make a Difference'

The Lincoln Collective

Harold Osborn

The Lincoln Collective was born in 1970 as a grassroots effort of health and community workers to start the kind of nonhierarchcal community-oriented program described in this article. The idea of two residents who were already at Lincoln Hospital, the notion was given official approval because of the influx of young, American-trained physicians and nurses it would bring. But, as the experiment was advertised by word of mouth to members of the Student Health Organization, the Medical Committee for Human Rights, and other health workers involved in antiwar activities, the hospital administration got more than it bargained for.

The sky over Lincoln Hospital was black with smoke that first day in July 1970 when a group of 45 interns, residents, and nurses—the Lincoln Collective—reported for duty. The South Bronx was on fire. The sky stayed darkened for months. Only later did we learn that most of the fires were tenement fires being set by slumlords who wanted to collect the insurance and quit the South Bronx.

Built as a nursing home for runaway slaves in 1839, Lincoln Hospital was sold to the city in 1922 and had become part of the New York City public hospital system. It was located in a blighted area of the Bronx, underneath the Bruckner Expressway, amidst garages, small factories, and abandoned buildings. The previous inhabitants of the neighborhood—Irish, Jews, and Italians—had long since gone, and now the community was almost exclusively black and Hispanic. It was an area characterized by grinding poverty and horrible health conditions, and it had been largely forgotten by the city.

The civil rights movement, the opposition to the war in Vietnam, and the counterculture of the 1960s had created a new consciousness among health professionals. Many of us had participated in these struggles and had worked in projects sponsored by the Student Health Organization (SHO) and the Medical Committee for Human Rights (MCHR). Many of us had read Franz Fanon, Malcolm X, and R. D. Laing. We knew about the Mound Bayou and Columbia Point projects and had heard about the struggle in a state hospital in Topeka. Our physician role models were Norman Bethune and Che Guevara, not Cooley and DeBakey. We believed that health care was a right, not a

Rally at Lincoln Hospital, July 1970.

We had come to transform the community, and yet we were transformed in the process.

privilege, and we knew that there was something profoundly wrong with the health care system in this country. We owed our understanding of the contradictions in health care in large measure to the pioneering work of our colleagues at Health/PAC. We had read the Health/PAC Bulletin since its inception, and The American Health Empire was "required reading" for the members of the Lincoln Collective. We believed that medicine and politics were inseparable.

Transformations

We came together in the South Bronx to "make a dif-
Lincoln Collective members with Helen Rodriguez-Trias, fourth from left, after her induction as president of the American Public Health Association in November 1992.

ference” in an underserved area and to escape the medical hierarchy, which we detested. We were enthusiastic, committed, and self-righteous. We were right about what was wrong with the system, but we were wrong in other ways: We believed that the answers to most questions were simple, and we thought that change would come quickly. We learned a lot in relatively short order—from each other and from the community we had chosen to serve. It was humbling to see how people in the South Bronx lived and inspiring to see how many persevered despite all the adversities. We had come to transform the community, and yet we were transformed in the process.

Over the course of the next six years, more than 100 health professionals became members of the Lincoln Collective. The collective was responsible for many innovations: the first “night float” system in the country (instead of residents remaining on duty all night and the next day, a fresh resident “floated” in to cover the night shift); a community outreach program that performed door-to-door lead screening and trained community members as paraprofessionals; a house staff evaluation process that included patients and hospital workers; and an admissions committee to screen new applicants composed of community people and hospital workers as well as house officers. We instituted the Weed system of problem-oriented record keeping and developed a curriculum in social medicine. We changed the specialty clinics into general care clinics. Many of us lived collectively. A collective house on Willis Avenue was purchased and was subsequently turned over to a community group. We created a system of small groups, which met throughout the year to work on interpersonal issues. There were major struggles within the collective concerning racism and sexism.

Along the way, the hospital was taken over by a group of activists led by the Young Lords, demanding more services for the community and greater accountability from the hospital. We eagerly joined the struggle against cutbacks at the hospital and for new programs like a detoxification center for drug abusers (which still continues) and a day care center for hospital employees. We were largely self-taught and all too often disdainful of academic medicine. But we cared, and despite our occasionally excessive behavior, most people came to respect us.

25 Years Later

Now, almost 25 years later, we continue to struggle for better health. Collective members have provided health care at Wounded Knee, in Appalachia, and in developing nations throughout the world. They have worked in the National Health Service Corps and in women’s clinics. We still believe in the concepts of community control and serving the people. The majority of us are still involved in delivering primary health care to underserved areas.

To my mind, the lessons of the Lincoln Collective include the following: that to be effective, political progress must be accompanied by personal growth; that real change comes slowly, and we must be prepared for the long haul; that a small group of activists, no matter how well-intentioned, cannot make a lasting impact without popular support; that to be successful we must seek those things that unite people rather than those that divide people; and that the struggle requires theoreticians (thinkers) and organizers (doers) who must work together and respect each other’s contribution.

The Lincoln Collective did not succeed in transforming the health of the South Bronx. We didn’t even come close. But the experience had a profound effect on us and prepared us for future struggles large and small. The

Managed competition won’t make a dent in the problems of the South Bronx, where the major epidemic is poverty.

health care crisis in the South Bronx continues. Although the promise of health care reform is in the air, the officially sanctioned proposals are driven more by a need to contain costs than a recognition that the system is fundamentally flawed. Managed competition won’t make a dent in the problems of the South Bronx, where the major epidemic is poverty. We need to fight to place a universal access, comprehensive, single-payer health care system on the agenda. Beyond that, the last 25 years should remind us that the struggle for better health is inextricably linked to the fight for economic and social justice.
The Leap to Health Care Reform
Starting from a Different Place

Oliver Fein

In 1970, John Ehrenreich and I wrote an article for the Health/PAC Bulletin entitled, "National Health Insurance: The Great Leap Sideways." Richard Nixon was looking at health insurance as an issue that might quell the prevailing social crises of America, not unlike, we pointed out, Otto von Bismarck in Germany almost 80 years earlier. The problem with national health insurance was precisely that it was only insurance: it would funnel dollars to the same old actors on the health scene—doctors, hospitals, insurance companies, and the medical-industrial complex—without reorganizing how health care is delivered.

Now, 23 years later, Bill Clinton proposes to do an overhaul of the American health care system. It is striking how the critique of managed competition today resembles the critique of national health insurance back then:

- All of the plans will leave the system dependent on private health insurance companies.
- National health insurance plans have come up with no workable and equitable mechanism for controlling costs.
- Most of the proposals for national health insurance are based on regressive methods of taxation.
- None of the plans makes any provision for significant consumer-community participation in program planning or in budgeting.

So, has nothing changed in more than two decades? I’d like to recount some of my own experiences as evidence that we are in a different place today than we were in 1970.

Pursuing Primary Care in the Academic Medical Center

After national health insurance was defeated in the early 1970s, more because of Watergate than in response to our critique, many of us turned to institutional rather than legislative change. There just didn’t appear to be a mass movement favoring reorganization of health care. I, for one, returned to residency training and then decided to locate myself within an academic health center, the root of the specialty-dominated organizational structure that I wished to change. My mission was to advocate for equal access to the "most positive moments" of private health care for the indigent and for a reorganization of medical training toward primary care.

I chose the academic health center, rather than corporate medicine such as the nascent health maintenance organization (HMO) movement, because I felt that academic medicine embraced many of the values that needed to be preserved and expanded in a reformed health care system. Most academic health centers delivered care to both rich and poor, albeit often in separate and unequal settings. Within the academic conscience, however, there was pressure for equity. Disparate populations frequently were served under the same roof, if not in the same rooms. The tension for change was almost built into the structure of the academic health center. In addition, academic health centers had the intellectual core to critique for-profit medicine, excessive specialization, and unnecessary procedures, although they had not done it consistently. Academic health centers also had the skills to do population-based research and move toward delivery models that take community need into account.

Initially, my energies focused on building a general internal medicine faculty group practice with a mission to deliver high-quality medical care to a community population. We were not a clinic. Patients could reach their doctors 24 hours a day, 7 days a week, rather than one-half day per week in the clinic. They were given timely appointments and saw the same doctor rather than a different doctor on each visit. When hospitalized, patients were admitted and seen in the hospital daily by their primary care physician, rather than being admitted to the ward service, where their outpatient physician rarely knew
they had been hospitalized. These were simple, basic reforms that formed a definition of primary care—first contact, accessible, comprehensive, coordinated, longitudinal care—one of the basic building blocks for a reorganized system of personal health care services in the United States.

The problem with national health insurance was precisely that it was only insurance.

Pursuing primary care in the tertiary academic health center was a struggle. Basing our advocacy on a community population that was largely indigent made the struggle even more difficult. Through the efforts of a dedicated multidisciplinary staff, including clerical workers, nurses, social workers, nurse practitioners, administrators, and physicians, we built a credible reputation among patients and specialty colleagues. From my point of view, we put some flesh on the skeleton of a "system of care" that many of us at Health/PAC felt was lacking in 1970.

The next step was to go outside our practice into the community. New York State facilitated the process by insisting that our academic health center build and staff a network of neighborhood health centers based on the model of primary care within our group practices. Over the years, community activists prodded the institution to live up to its commitment. Four of five promised community-based sites have opened.

At the same time, the population perspective in teaching and research began to achieve some prominence on a national level through a program entitled Health of the Public. This program suggested that academic health centers take responsibility for "defined populations." Our academic health center was awarded a grant by this program to advance population science in teaching and practice. This ongoing, foundation-sponsored program adds another dimension to the primary care-oriented "system of care" described earlier. By moving the academic health center beyond personal health services delivery into community outreach and assessment, a public health dimension has been added.

Single Payer Revives National Health Insurance

In 1986, Lucy Candid, a family practitioner in Worcester, Massachusetts, convened a nationwide retreat of health care activists around the theme of Poverty and Health. At this retreat, two activists, Steffie Woolhandler and David Himmelstein, argued that the time had come to raise the issue of national health insurance once again. They pointed to Canada's single-payer system as a concrete example of a successful national health program that provides access to a comprehensive set of benefits at affordable costs, without any copayments or deductibles. They argued that the 1980s were different from the 1970s.

The Canadian model did not exist in 1970 (it was just beginning then), and, by the mid-1980s, the crisis in access and costs in the United States had reached such proportions that major reform was necessary.

At first, I was dubious that there was public support for health care reform. So many other needs—food, housing, education, and basic social services—seemed more pressing. But the single-payer focus certainly pinpointed the limitations of the U.S. insurance-oriented approach, and the Canadian example illustrated the enormous administrative waste in the U.S. health care system.

Several years later, when Physicians for a National Health Program (PNHP) was organized, I joined. Although I was hesitant about the physician orientation of the group, I felt it was an honest expression of where I, as a physician, was coming from at that time. PNHP's initial approach seemed to emphasize financial reorganization of health care, rather than reorganization of the delivery system (recalling our original critique of national health insurance, the great leap sideways). One thing that was different for me in 1990 than in 1970 was that I had developed a vision and a living example of how I wanted to reorganize the health care delivery system. The essential ingredients included a primary care foundation and the population/community orientation.

As we wait for Hillary and Bill Clinton to unveil their plan, two major health reform proposals appear to have survived: managed competition and single payer. Both are based on a primary care foundation. Gone are proposals for tax credits, pay or play, and all the myriad others that only a year ago were major contenders. It is a testimony to PNHP and the substantiveness of single payer and primary care that these two concepts that were hardly mentioned in 1970 are dominant themes in the discussion today. Although it remains uncertain what the Clintons will propose, the terms of the debate will certainly be different than they were in 1970. Perhaps this will also spell a different outcome this time around.
The More Things Stay the Same...

The Evolution of the Hospital Dinosaurs

Dennis Rivera


Having helped organize hospital workers in my homeland, I got a job as an organizer at 1199. I was quickly thrust into the maelstrom of New York’s health care politics. Ever since I received Health/PAC’s invitation to contribute to its 25th anniversary issue, I’ve been thinking about changes I’ve witnessed in the 16 years I’ve been here.

Sixteen years, an AIDS epidemic, and $400 billion later, I see the same problems, only worse.

The more I think about it, the less I see. In 1977, advocates and critics were angrily pointing at the disgrace of high infant death rates, poor health statistics, and high insurance costs for millions of New Yorkers. The Medicaid program was in crisis, with budget snipers coming from every direction. In fact, a full freeze had just been put in place, and hospitals across New York City were warning of imminent demise.

At the same time, pushed by unacceptably high levels of public spending, the state health commissioner had just announced plans to downsize the inefficient New York hospital sector. Everyone decried the lack of management skills among health care administrators, and there was widespread dissemination of “hospital as a business” rhetoric.

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The challenger in that year’s mayoral race was bashing the New York City Health and Hospitals Corporation as wasteful and corrupt and making noises about the need for the city to get out of the hospital business. He won election that November. By that time there was widespread agreement that HMO-type organization was the best panacea to the joint crises of cost and access, even though the principle advocate, Richard Nixon, had been chased from office.

Sixteen years, an AIDS epidemic, and $400 billion later, I see the same problems, only worse, and hear the same voices, louder and more desperate.

Changes in Power

Yes, there has been change. Most of the city’s once imperial medical centers are struggling for definition and stability amidst a health care crisis that seems never to end. Where once they shunned Medicaid recipients, now places like Columbia-Presbyterian and Mount Sinai Medical Centers receive one-third of their revenues in return for caring for these patients. Having adapted, more or less, to the enormous demands made for care of HIV-positive people, they were suddenly confronted by a drug-resistant TB epidemic that threatens not only the health of their patients, but the well-being, and sometimes lives, of workers.

In the 16 years I’ve been here, HHC has had seven presidents. Columbia-Presbyterian, at last look, had just changed CEOs for the fifth time in four years. All the teaching centers, from Montefiore in the Bronx to Long Island Jewish, which straddles the Queens-Long Island border, have been loudly complaining about the difficulties of recruiting enough prestigious attending physicians and American-trained house staff to retain their reputations as regional, if not worldwide, tertiary referral centers. Several of New York City’s once impervious medical centers have taken to advertising campaigns that set them little apart from the patent medicine huskers that once crowded the pages of early 20th century magazines and newspapers.

The change in the status of the medical empires, financially and politically vulnerable in ways that were unimaginable 16 years ago, has a bright side. No longer simply able to call the shots and have obedient public officials respond, their weakness has opened up the possibility for change.

Among the first beneficiaries were the members of 1199. We were humbled and almost destroyed by a 47-day strike in 1984 and a 1986 contract that gave us almost nothing. Many were predicting 1199’s ultimate demise. Yet by 1989 we had pulled ourselves together well enough to successfully challenge the employers of 50,000 New York hospital workers. Last summer we managed to negotiate a favorable contract 20 days before the expiration of the previous agreement.

Just this spring, New York State Governor Mario Cuomo proposed a new hospital reimbursement system that would shift upwards of $800 million over three years from inpatient payments to outpatient and primary care services. Neither the health care industry nor the members of the legislature were willing to move so far so fast, and the legislative session ended in deadlock.

But with change in relative power comes enormous
risk. New York's health care system is literally tottering on the edge. While there are no longer the great barons of medicine who can command public officials to dance to their waltz, there is also no powerful center of influence to demand adequate public financing of health care services.

The unthinkable undermining of New York City's health care infrastructure is now not only thinkable, but likely. That the public hospitals have been seriously wounded by budget cuts is no accident. There is no one powerful enough to keep the public troughs running fast enough to guarantee even an adequate supply of dollars and patients on which to train new physicians and develop new techniques.

The Dinosaur-Hospitals

These are dangerous times. Hospitals may be great dinosaurs, ill-equipped to serve the needs of their patients and managed by people with such limited vision that they often cannot distinguish between a man waxing the floor and the machine he uses to do the job. Still, dinosaur-hospitals are functionally key to the only health system we have. Without them, we have no health system at all.

We cannot prevent the ice age and the extinction of the species. Nor do we want to see them preserved in their present form. But I believe we can come up with ideas compelling enough and political strategies broad enough to ensure an evolutionary process of change for hospitals. Unlike Jurassic Park, we cannot abandon the island and hope that some hokey enzyme will do the work for us.

Taking stock of the 1960s from the vantage of outraged middle-class sensibility, in 1969 Life magazine ran an article subtitled: "That Slum of a Decade." Not all of us saw the sixties (or slums, for that matter) that way and, I suspect, the same is true of the eighties. To my mind, the 1980s seem best characterized as a gorge-and-purge period.\(^1\) Trouble was, the peristaltic link between the two was cut: the rich gorged; the poor were purged. Nowhere was that clearer than in the frank dispossession of the homeless poor. At that masked ball of false prosperity, they were the gate-crashers, insistent reminders of the unruly night outside. To be sure, most of the damage done to the poor in that decade took the form of a quiet, unobtrusive violence.\(^2\) But owing to the visibility of the street-dwelling poor, unwitting witness though it was, they screamed the truth home.

When it came to homelessness, Reaganbush and company never mastered the art of a credible lie. As an administration confronting a reality that everyone except them found unsettling, they were done in—not by incompetence—but by stupidity: a bullheaded preference for circuses over bread. Instead of policy, they offered wrist-flicks of dismissal. At a time of widely reversed fortunes and mounting hardship, official pronouncements about the homeless poor were marked by a distant, algebraic quality, the sort of thing you'd expect from someone describing exotic flora—a debilitating parasite, say, in some far-off river valley. Privation was treated as a kind of abstract, contextual variable.

But as the decade wore on and quiet prevailed even among those struggling at the margins, contempt for the poor slipped the leash of restraint and took on an open, unashamed quality.

In the slim space of 12 years, an almost wholesale transformation in the symbolics of poverty took place. Examples range from the reckless ("No one is living on the streets," an assistant secretary at the Department of Housing and Urban Development told a Boston audience in 1982\(^3\)); to the arcane and preposterous (in 1988, the U.S. Mission to the United Nations objected to film footage of homeless "street people" in the United States as part of...
the UN's "International Year of Shelter" because it ignored "the individual rights element" of the problem; the footage was cut); to the stupidly glib (asked what the Bush administration's poverty policy would look like, a White House official said the plan was to "keep playing with the same toys, only paint them shinier")

Dare to Struggle, Dare to Grin

Bit by bit—isn't that the way evil always works its mischief?—the face staring back at me in the mirror each morning acquired the lines of a double agent. Distasteful as the task was, when I took the trouble to reflect, I found myself housing "internal contradictions" that a few years earlier would have been laughable. Friends and strangers alike assured me that I was not alone. Midway through the decade, for example, readers of Time were treated to (Columbia '68 veteran) James S. Kunen's list of "Things to do today." It read: "Call insurance broker; add to IRA; smash the State." If ambivalence is the tribute that waffling pays to conviction, humor is the balm that eases the sting.

The 1980s seem best characterized as a gorge-and-purge period: the rich gorged; the poor were purged.

So, what have I learned? Or, rather, doggedly slow on the uptake as I have found myself to be, what lessons have even I been unable to dodge in the course of these last 12 years? Briefly, I want to discuss six.

1. Culture Redux. The first would have to be a new appreciation of the "relative autonomy" (to resurrect a phrase from the past) of culture—long overdue (I can hear the catcalls from the back of the class) in one who professes to be an anthropologist. Specifically, I mean those framing compulsions apparent in family practice. What I find impressive is not only the resilience of family-based supports, but (as growing evidence of ethnic differences in kinship patterns attests) the degree to which they are not strictly determined by class position and their adaptability in the face of changing demands. (The African-American record here is especially rich.) Whether one turns to the evidence of widespread "doubling up" as a solution to housing scarcity, or looks instead to the historical record of extended kin coming to the aid of distressed households and individuals, the importance of informal sources of sustenance is unmistakable. No doubt, families and households today look very different from their counterparts of a century or more ago. But they remain vital sources of cultural tradition and practical support. Over the years, what we learn and lean on at home not only has buttressed the flimsy scaffolding of parish assistance (and, later, the welfare state), but has also provided an indispensable fulcrum for popular resistance.

Without the help provided by even badly frayed networks of kin and friends, neither the "free market" nor the welfare state could function, let alone be called to task. It is one of the ideological triumphs of the right that this fact has been so effectively buried. Instead, we saw a renewed strain of moralism join forces with a once-upon-a-time version of domestic life in an attack on the poor for having succumbed to the subversion of "family values." Indignant cries ensued for "the restoration of moral order," for "taking the poverty out of the poor," instead of the other way around. You had to admire the sheer gall of the charge: after a decade of injury in which income differentials widened even further—as decent work opportunities shrank, AFDC benefits were badly eroded, unemployment insurance was cut back—and extended households were sorely stressed, why not add insult to the list? The "new Gradgrinds" (as Michael Harrington called them) remained steadfastly blind to the fact that, in good measure, it was the unheralded work of the much-despised "dysfunctional" families, who, "bound by kinship and neighborhood...engage[d] in time-honored forms of resourcefulness" that effectively enabled them to survive.

This is not to deny that poverty—and racism—can have (what economists call) "scarring effects" on the poor; that the scourge of the drug trade in poor neighborhoods continues to be horrific; or that irregular households face unusual obstacles in culling together a livelihood. Nor is it to ignore the fact that for the bonds of kinship to offer
sustenance in times of trouble, real work is required—work that typically falls to the women in the network. Rather, it is to insist that, for all their difficulties, were it not for the support of extended kin, the scale of homelessness would be far greater.

2. Racism's Resilience. If the injuries of inequality are secured by class and ratified by culture, they are amplified by racism. For too long, advocates have dodged—where we have not, in effect even if unconsciously, denied—the relevance of race in the discussion of homelessness. This is not, as any number of observers have also argued, to suggest that race should be the definitive trope for understanding poverty or dispossession. Rather, it is to say that margins, not a restructuring at the core. The dilemma is inherent in any reform that relies heavily on the courts and subjects itself, in consequence, to the attendant judicial simplification (or partitioning) of complicated social issues. In the event, the legal process "leaves many aspects of the underlying problems not only untouched but also unacknowledged." 17

4. Reenfranchising Popular Discontent—Even When it Runs Against You. In repeated meetings with neighborhood groups in New York City and Westchester County, I have been struck by the fervor and good sense of some of the opponents of relocation projects. Not all opposition to these good-faith projects, it was readily apparent, was stupid, self-centered, and/or motivated by irrational fears of pollution. Some of it reflected long-festering convictions that control over the quality of everyday life was spinning away from those who had to live it. Some of it stemmed from deeply felt (and not unreasonable) fears of defining a given neighborhood's only value as that of a repository for otherwise unwelcome (but collectively necessary) projects. It was as much the project as sign—that the area had been given up on for purposes of industrial development, normal residential development, or community amenities—as it was any specific configuration of program or collection of residents that was feared. Nor, it turns out, are facilities for the homeless especially targeted; the phenomenon extends well beyond issues of relocating suspect or stigmatized populations.

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a good deal of overlap has gone unexamined for the past decade; that the civil rights potential of homelessness (which seemed promising as recently as the March for the Homeless in Atlanta in February 1988) has been poorly developed; and that both causes—homelessness and racism—would benefit from being linked in a thoroughgoing analysis to underlying structured inequality grounded in economic class and political power. 15 The bridework necessary to do that, to write what would amount to a political economy of "the underclass" or "homelessness," is just now under way.

3. The Limits of Rights Talk. Facing a tradition of state relief founded on exclusion, advocates for the homeless mounted a campaign premised upon its opposite. For the most part, it has remained a fairly refined affair. 16 Public interest litigation claimed pride of place in the advocacy efforts of the 1980s, and litigation speaks the language of rights. After some stunning initial victories, the limitations of litigation are becoming apparent. Neither the transparent quality of the "needs of strangers," nor the self-evidence of the means to alleviate them, are quite so unproblematic today as they once seemed. The enforcement power of even vigilant courts is bounded; judicial decrees have proven subject to myriad compromises in practice. Attending solely to "shelter" is tantamount to assuming that the distress is transitory, that somehow both pre-homeless conditions and post-homeless precariousness will be resolved without recourse either to the courts or to the bracing rhetoric of individual rights. It has become clear, to put it simply, that what has been achieved is a minor (if terribly costly) adjustment at the margins, not a restructuring at the core. The dilemma is inherent in any reform that relies heavily on the courts and subjects itself, in consequence, to the attendant judicial simplification (or partitioning) of complicated social issues. In the event, the legal process "leaves many aspects of the underlying problems not only untouched but also unacknowledged." 17

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Increasing popular resistance to the nostrums of experts, at an increasingly sophisticated level of challenge, opens the possibility for democratizing the decision-making process. An obvious question presents itself: How might we best capitalize (if that's the right verb) on such an opportunity in linking rehousing to neighborhood development?

5. The Depths of Official Resistance. If events of the 1980s forced one to reexamine prejudices about popular opposition to rehousing efforts, they also produced soundings of the hidden depths of much official resistance. 19 Like none-too-bright novice psychoanalysts learning that it is not enough to have the correct "interpretation"—one must also work through the resistance to
insight on the patient’s part—we advocates often underestimated the limits of a campaign built on (to retrieve an even cruder phrase) “transitional demands.” We failed to appreciate how difficult it would be to convert the watered stock of popular compassion into the hard currency of lasting material gain.

Early wins were misleading because they were registered in two insulated domains: the courts and the voluntary sector. Significant inroads were made, but they were largely of an emergency nature—chiefly, acknowledgment of a right to shelter; increasingly, extensions of special protections to subgroups within the homeless poor. If progress in the legal arena cannot be checked by the usual measures employed to gut public assistance programs, it is nonetheless subject to all the instabilities of makeshift remedies as well as those of judicial reform.20

Advances in the voluntary domain—the mobilization of informal resources symbolized by the celebrated revivals of neighborhood-based (usually religious) private shelter—couldn’t have been more welcomed by the state. For government to be offered a chance to “reprivatize” some of the burden of support (if only for the duration of the “crisis”) was almost too good to be true. But as the crisis wore on, the ruse wore thin.

6. The Recovery of Complexity. In New York City, advocates won concessions because they simplified. Again and again, the dimensions of demand were reduced to elementals: “housing, housing, housing.” This was not, as some born-again service providers now claim, because advocates cynically chose to misrepresent the homeless poor in the interest of marketing a more appealing product; rather, it was intended as a corrective to more than a decade of obsessive attention to services that was stubbornly maintained while such vital material resources as low-cost dwellings were being plundered.22 No service package, no matter how refined, can work effectively if the intended “consumer” has no place to live.

That said, it is still the case that the spoils of victory (such as they are) reflect that fact of strategic simplification. As Joan Minieri argued recently in these pages, both the “immensity” of homelessness and its “institutionalization” as a “social problem” have dumped wind from the sails of advocacy.23 Although there were clear and immediate gains to be won by arguing for “targeted” programs for specific “exceptional” populations, the days of special pleading may be over. “Advocacy” in that guise takes the form of queue-jumping, predicated upon someone being designated an exception, while the prior and more basic questions—like the implications of applying the principle of equity to federal housing assistance—go unaddressed. Might it not be time now to shift the definition of the problem, the focus of advocacy efforts and the scope of analysis to more encompassing, more “universal” themes? Among these may well be a reconsideration of housing as a basic social good, rather than as a limited perk for the poor or vehicle for their improvement.

Such a deliberate redirection would have the added advantages of moving from remedial programs to preventive measures, of departing from a narrow (and increasingly troublesome) “individual rights” approach, of engaging a potentially much larger constituency of support, and of avoiding the affront to “fairness” that queue-jumping can represent. It would mean redefining both neighborhood vitality and adult skills as part of the nation’s social infrastructure, and arguing that an inflow of resources there would well repay the investment.

The Limits of Solidarity

Ever since I began this work, I have been haunted by the story of a tramp’s death that occurs early in Nadine Gordimer’s Burger’s Daughter. He had passed quietly away in a park one afternoon, while others nearby ate their lunch, slept, courted, or simply luxuriated in time off from work. The narrator is stunned: the tramp had “carried through the unspeakable act in our presence” — and no one had noticed. Not that noticing would have made a difference. He was a homeless ex-miner, a man who “drank methyalted spirits and slept in bus shelters.” But in the narrator’s family, it was believed that “the revolution we lived for” would change everything. That day in the park she slowly comes to see that the revolution wouldn’t have changed that unmarked death.

Advocates won concessions because they simplified.
The dimensions of demand were reduced to “housing, housing, housing.”

There are times when we need to distinguish between essential suffering and the needless, gratuitous sort—as Virchow urged us to distinguish genuine from “artificial” (i.e., preventable) epidemics. Call it the limits of politics. There are those for whom life at the margins can be a kind of calling, the place where misfits, defiance, and the unassimilable thrive. Call that the limits of solidarity. But for ordinary work, it suffices to see such limits as ever receding before us.

6. Time, May 19, 1986, p. 41. Kunen was author of the briefly infamous Strawberry Statement in 1970. The list is less whimsical than first ap-
Letting Their Voices Be Heard

The Role of Legal Advocacy in Working for Social Justice

Virginia Shubert

As a lawyer working for the past five years with and on behalf of homeless New Yorkers living with HIV and AIDS, I have been constantly reminded of the limits of legal advocacy as a means of attaining individual and social justice for politically disenfranchised people. It has been my responsibility to assist clients to assert their rights under existing law, and to advocate for changes in the law where existing rules fail to protect basic human rights. What I have found is that forcing the system to work for one client rarely helps

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to bring about the changes necessary to make it work better for others; that establishing policy can be meaningless in the absence of funding for mandated housing or services; and that "law" is often used to strip away the basic human rights of homeless people, addicts, and other marginalized people, rather than to protect those rights.

And yet, my experience as an advocate has also taught me what an important role lawyers can play in addressing issues of social justice simply by ensuring that the voices, experiences, and demands of affected people are heard. It is not a lawyer's job to attempt to control their client's choices, or to impose upon the client what the lawyer believes the client may need or deserve. The lawyer's responsibility is to offer advice when asked, but then to be directed solely by the wishes of the client. This professional responsibility to respect and support the client's self-determination is, in many ways, the lawyer's most significant contribution—both to the individuals represented and to efforts to bring about systemic changes.

Many attempts to improve the health and welfare of homeless individuals fail because they are designed to undermine rather than promote self-determination. A lack of respect for basic rights results in a focus on social control rather than on providing the means necessary for individuals and communities to regain control of their own lives. We have refused to acknowledge a basic human right to the fundamentals of healthy living—safe housing, basic income, and competent health care. What is worse, many well-intentioned "systems" created to extend those fundamentals to underserved individuals and communities have operated instead to legitimize substandard conditions. Rather than a right-to-housing movement, we have created a homelessness industry that perpetuates the institutionalization of homeless people in supposedly temporary "emergency" settings. Likewise, specialized health care, mental health, and drug treatment interventions, created to provide triage for homeless individuals, threaten instead to become a permanent second- or third-tier medical care system for people without homes. Indeed, arguments have been made recently that certain particularly vulnerable groups, such as homeless people with HIV or tuberculosis are actually "best served" by institutionalization in such substandard settings, because government can "keep an eye on them" there.

Recognizing the basic rights of individuals and communities will require us to reject these substandard systems that we know do not bring about significant or permanent improvements in health and welfare. In my experience, the clients who have lived the longest and most successfully are those who have refused to accept their categorization as a homeless person, a mentally ill person, or a drug user and have resisted being relegated to a shelter or institution. These clients have flourished because they have sought and received the best care available from the best hospitals and doctors. They have reestablished stability in their lives, finding permanent homes in their communities. With this stability, many have also found the means to reduce, or even end, the harmful use of drugs. Many have reestablished ties to family, friends, and community. Some have been able to return to employment, and many have become advocates for themselves and their peers. In short, they have been able to regain control of their lives.

**Forcing the system to work for one client rarely helps to bring about the changes necessary to make it work better for others.**

**Struggling With Systems**

These accomplishments on the part of clients have involved struggles with "systems of care," struggles that have been as challenging as their battles with illness or addiction. They have been forced to work against a public welfare system whose chief response to the problem of
homelessness is the institutionalization of homeless individuals in congregate settings that separate them from caring family and community and place them at risk of life-threatening infectious illness. They have been prevented from returning to work during periods of good health by an inflexible entitlements system that ties basic income support and access to health care to continued poverty. And those who suffer from the harmful use of drugs have confronted a health and social service system that has criminalized this health problem, excluding them from housing, separating them from their children, denying them access to clean needles, primary health care, or other means to preserve health, and incarcerating rather than treating them.

Rather than a right-to-housing movement, we have created a homelessness industry.

Many homeless people with HIV/AIDS have been able to overcome these barriers, however, because they have had access to a program of “enhanced” benefits created to meet the needs of the middle-class men who were first affected by the epidemic. While still minimal, these benefits are explicitly designed to foster independence by enabling people who are impoverished as a result of having AIDS to retain private housing in their communities, to gain access to good medical care, and to pay for necessary nutrition and transportation. Tragically, the changing demographics of the epidemic are being used as a justification for arguments to strip away these benefits. As more poor women, people of color, and injection drug users are affected, people with AIDS are no longer seen as “deserving” of such entitlements, or their lives are viewed as too unmanageable for them to benefit from such a program.

The chief argument offered to justify withdrawing benefits from poor persons with HIV/AIDS is the toll taken by the use of drugs. No one can deny that the harmful use of drugs and the associated mental and physical problems pose difficult challenges for drug users, their loved ones, and systems of care. But simplistic solutions based on denying basic human rights to people who use drugs do not work. More sophisticated approaches are needed: approaches grounded in the reality of the lives of addicted people as they experience them; approaches that acknowledge the reality of relapse and recognize the validity of goals other than abstinence; approaches that reflect the value of people’s lives by respecting their right to housing, health care, and other fundamental necessities.

The challenge for advocates is to ensure the creation of systems that further the health and well-being of all people without sacrificing the basic human rights of any person. Of course, no individual’s behavior can be allowed to place others at risk. But none of us are served by a system that refuses safe housing to a person with HIV because he or she is not ready to stop using drugs, or denies that person voluntary treatment for tuberculosis because he or she will not enter a drug treatment program, or has nothing to offer the person who wants help simply to begin to consider sobriety as a goal.

Housing As Advocacy

Two years ago I participated in the creation of Housing Works. This not-for-profit membership organization was designed to turn the provision of housing and services for homeless persons with HIV and AIDS into advocacy by demonstrating the fallacy of the assumption that homeless persons could not or would not take advantage of opportunities to establish homes and community. Our goal is to prove that housing can provide the stability to enable people to regain control of their lives. Safe housing and related support services are the first step, not the last, in confronting harmful drug use or other barriers to health. Housing Works has housed over 400 people in private apartments in their communities in just two years. At least 80 percent of these formerly homeless people still struggle with chronic drug use, mental health problems, or both. These individuals have formed a strong community among themselves and become a force in their larger communities.

I believe that we will continue to pay a high price in individual and social well-being as long as the rights of individuals are considered at odds with those of the larger community. The TB epidemic of the 1990s is becoming another striking example of the failure of public health approaches to address fundamental prerequisites for taking control of one’s health, such as housing, primary health care, and income to meet basic needs. Without these basics, many people with TB are unable to complete treatment, creating a situation in New York City where drug-resistant strains of TB threaten to make antibiotics ineffective in treating the disease. Yet, despite the demonstrated failure of coercive measures in the past, plans for the institutionalization or even detention of persons with TB are going forward, while fundamental barriers to treatment such as lack of housing and drug treatment interventions have not been addressed.

Effective reform to improve health and well-being will require that the individual’s responsibility be matched by a responsive health and social support system. There is much we can do to move toward this goal. We can facilitate direct advocacy by affected individuals. We can work to ensure that the systems that are supposed to assist people have been informed and directed by the needs of the affected individuals. We can constantly reexamine these systems to assess their validity and fairness and to determine if they protect the basic rights of all. And most important, we must always remember that our first responsibility is to adequately represent the interests of the client in front of us.
What Have I Learned? 
Patience, But Time is Running Out for Me

Frances Klafter

The time was 1960 and I was helping my high school son do research for a debate. The subject: “Shall the United States Adopt a National Health Insurance Plan?” My son was resolutely arguing in the affirmative. His side won the debate, but the United States still lacks a system of universal, comprehensive health insurance. And that was 33 years ago.

Within a few years of that debate, however, we did get Medicare and Medicaid—health insurance for the elderly and the poor—programs the reactionaries have been trying to scuttle ever since. But they can’t. The people won’t let them. The people are on our side. Let us not forget these two great victories, and the way the people have defended them, so that no pressures from the right have been able to undo them.

I am 84 years old, and I could not have survived without Medicare. But I am not content to have health care just for myself. I want to live long enough to see the day when universal, comprehensive health care is recognized as a right for all people. I am tired of seeing my country standing with South Africa as the only two industrialized countries without a national health care system.

So after I retired, I started a new career—working for national health care for all people. For some years I headed the Coalition for a National Health Service, working tirelessly for the Delums Bill for a National Health Service, which I still think is the best proposal, but not achievable in the climate of the 1990s.

So we learned to compromise. The forces that have struggled for decades for a national health plan, joined by many newcomers who have grown up since we started the fight, are now wholeheartedly working for the American Health Security Act (HR 1200/S 491). Maybe we will have to give something here and there to get some kind of a bill passed. But I for one know we can’t support any proposal that does not take care of everybody; include comprehensive care; provide affordable care; allow us to choose our providers; provide for public accountability.

I am 84 years old, and I could not have survived without Medicare. But I am not content to have health care just for myself.

We are going to have to work hard to make their proposal look more like ours. But if Medicaid and Medicare can still stand all these years (somewhat battered, it’s true), despite the onslaught of the reactionaries, we can certainly hold out for a national health plan that will stand the test of time.

I just want to see the day when we leave South Africa standing all alone as the only industrial nation without a national health care plan. Or who knows? South Africa might join us in adopting a national health insurance plan, but we don’t want to wait for them.

Frances Klafter is Vice-President of the New York Statewide Senior Action Council.

1965 demonstration for Medicare.
The Rise of the Health Care Consumer

Cynthia Rudder

As the director of a New York statewide coalition of consumers and their advocates, I have been advocating for 14 years for a better quality of life and care for our nursing home residents. Although in my darkest moments I believe that no one out there is listening, in my brighter moments I can see the changes we have wrought.

Two of the most significant changes have been a gradual, though reluctant, acceptance of consumers and their advocates in the health care policymaking process and a gradual acceptance of the fact that consumers of health care services have a right to know about and make decisions about their care.

Consumers as Policymakers

Accomplishing the first has, at times, taken media pressure to convince state policymakers that they need our expertise. For example, a front-page Village Voice article in 1985 or 1986 on the disarray in New York State’s surveillance systems led to the creation of a joint work group with the Department of Health. But it has finally become acceptable to include representatives of organized consumer advocacy groups on crucial policymaking bodies.

Our success in getting consumers included in the health care decision-making process in New York State has been the result of a combination of ceaseless fighting by advocates, who proved their ability to both protect consumers’ rights and to be an indispensable part of health care policymaking, and the responsiveness of New York State’s past health commissioner, Dr. David Axelrod, to consumer participation. Although there have been issues on which consumers disagreed with Dr. Axelrod, I was impressed with his understanding of the role of an advocate and his willingness to bring us to the table.

Yet I worry that our presence on these bodies may be used merely to demonstrate that consumers are involved in making decisions that are, in fact, really being made by government and health care providers. Although every different type of health care provider—voluntary, proprietary, public, upstate, downstate, etc.—is seen as being entitled to a place on these policymaking bodies, one consumer is thought to be able to represent the entire diverse consumer community. I sit on a number of policymaking bodies as the only consumer, facing 20 or 30 providers. In addition, there is little understanding of the fact that this one consumer has little of the financial support and resources taken for granted by the providers. We must continue to fight for more than a token number of consumers on any policymaking body. We must continue to fight for a large number of consumers representing the wide variety of health care issues that we all deal with, and we must be ready to write and promote minority reports when necessary.

Consumers’ Right to Decide

The second significant change I have seen over the past 14 years has been the movement away from full control and power by physicians and other care providers to more decision-making power by the consumer. This has been seen in a number of different laws passed in New York State in recent years, allowing consumers, for example, to have access to their medical records and to create advance directives expressing their preference regarding important health care decisions such as the withdrawal of life-sustaining treatment. It wasn’t too long ago that we had to sneak a look at our own records if we wanted to know what the physician had written and that the only way to have our wishes relating to life-sustaining treatment honored was to take health care providers to court. Although we clearly have a long way to go in implementing these laws, the momentum has begun and will not be stopped.

In my darkest moments, I believe that no one out there is listening; in my brighter moments I can see the changes we have wrought.

These victories are clearly seen in the major new thinking about nursing home residents that has swept the nation. After many years of struggle by advocates all across the country, Congress finally mandated many new rights to allow nursing home residents to participate in decisions about their care and to have access to information about themselves and their facilities. Nothing typifies the movement for individual consumer control and authority more than the emphasis on better quality of life in nursing homes, with its focus on the autonomy of residents and restraint-free facilities. Of all of our accomplishments over the last 14 years, I count among our greatest the fight to “untie” our elderly and to free them of restraints—devices (physical) or drugs (chemical) that control their movement or behavior or mood. It has been a long, hard fight, and here, too, we have faced intransigent providers and problems of implementation, but the end is in sight.

Cynthia Rudder is Director of the Nursing Home Community Coalition of New York State, based in New York City.
From Transplant Recipient to Health Care Access Advocate

Robert Fasano

However, we still face many hardships. Government regulators do not have the resources or staff to adequately monitor the standards we have fought so hard to win, and health care providers are not willingly or easily giving up full authority and control over decision-making. There are major confrontations ahead in both implementation of what we have already won and in winning new rights.

In addition, just at the time when advocates are needed more than ever, we face less and less financial support. The numbers of advocates are dwindling and our individual workloads are becoming overwhelming. Yet providers seem to have an unlimited supply of financial support—perhaps because most of their lobbying and litigation against the state is Medicaid reimbursable.

Coalition Building

What of the future? For me, the answer is more and more coalition building. We need to work together for a common cause. We not only have strength in numbers, but we need to have other people around who think like we do, to bounce around ideas with or just to cry with when things get tough.

We cannot use the excuse that we are too busy with our own priorities, too busy to work with other advocates. We must find the time. The elderly and their advocates must work with children and their advocates. Long-term care advocates must work with acute care advocates. Elderly long-term care advocates must work with the young disabled and the AIDS advocates. We must coordinate the work done by advocates on all the health policymaking groups and councils. We must support each other on all of these bodies.

My personal salvation has been the relationships I have formed with various other advocates. I have never met a more generous, altruistic, or caring group of people than the health care advocates I work with in New York State. With these people there is no question of protecting “turf”; there is just a question of how to get the job done. I am not sure I would still be here without them.

I have always believed that access to health care is a human right. As a social worker, I have long been an advocate for community empowerment. But I became a health care reform advocate the hard way.

In December 1990, after five years of life-threatening illness, my life was saved by a liver transplant. My experience represents the best as well as the worst of the U.S. health care system. As a result of a pioneering medical therapy and the generosity of a donor family, I have been brought back from the brink of death.

Health Crisis—Insurance Nightmare

When my health crisis and insurance nightmare began in 1986, I was a social worker for a small nonprofit agency. I thought I had adequate medical coverage. As a result of

I am insurance disabled, but I refuse to give in and be destroyed by my ongoing insurance crisis.

my deteriorating health, caused by a genetic disorder, I was physically unable to work anymore. My insurance company dropped me. My life-threatening health crisis caused the bills to mount to an astronomical level. Impoverished, I qualified for Medicaid. Out of work, isolated at home, and facing death, I felt marginalized by my illness. Even worse, gaining access to the basic health care

Robert Fasano is a social worker and co-founder of the National Transplant Support Network.
I needed was a constant struggle because of the insurance bureaucracy. I wanted to connect with a community that understood these issues.

During my nine-month wait for a transplant, I participated in support groups. I was helped by many generous transplant candidates and recipients (heart, liver, kidney, and lung) who listened, comforted, and shared their own experiences. We educated each other about living with life-threatening illness and about transplant. The conversation always turned to coping with problems with private insurance, Medicare, and Medicaid.

We talked about the fierce daily struggle for access to health care. Our discussions were about exclusions for pre-existing conditions, rejection by insurance companies because of a chronic health condition, out-of-pocket expenses that exceeded 10 percent of family income, exceeding annual caps on insurance policies, exclusion of coverage for essential benefits, higher premiums because of a chronic health condition, cancellation of benefits because of health condition, unaffordable premiums. Even those with good insurance coverage knew that their coverage could change tomorrow. The odds are that it will.

A successful transplant isn't over at the end of the operation. Like Americans with cancer, AIDS, and other conditions, I have to manage my health. Like them, I face a protracted and intense struggle to obtain the care I need every day to stay alive. Every decision my wife and I make about family life, employment, or education must be weighed against my need for life-sustaining drugs, tests, and treatment.

Like others with chronic health problems, I am stalled in my recovery due to the limitations of employer-based insurance coverage. I want to return to the work force but can't find an employer who can cover me. Recently, I applied for a position in my field, but the employer is self-insured, and that means I would be subject to the insecurity that I could face an arbitrary loss of benefits due to the U.S. Supreme Court's ruling in Greenberg v. H & H Music Co. So, I am insurance disabled, but I refuse to give in and be destroyed by my ongoing insurance crisis.

The Health Care Debate

After my transplant, I began gathering the stories of other transplant recipients and talking with them about health care reform. I met them in support groups at hospital clinics, in the community, through national newsletters published by transplant recipients, and on computer bulletin boards. I offered assistance to others negotiating for their care, analyzed proposed legislation, surveyed and gathered insurance horror stories, publicized our experiences with health care, informed elected representatives of our experiences, and educated the public. I did this through a national grassroots network of transplant support groups, the National Transplant Support Network (NTSN).

I also studied the options in the health care debate. Like most Americans, I had heard the myths that Canadians can't get access to high-quality care and that their system would put my life at risk. In fact, Canadians have higher rates of heart and/or lung and liver and bone-marrow transplants than do Americans, although the rate of kidney transplant is about the same. Within the last decade, it was Canadian doctors who pioneered lung transplant and bone-marrow transplant procedures.

As a social worker, I contacted transplant social workers in Canada. I was told that while the United States and Canada have similar problems in finding enough organ donors, transplant candidates in Canada do not have to worry about insurance coverage for the procedure. Even the life-sustaining drugs that are part of the life-long transplant therapy are covered. No one loses access to care because they change jobs or become unemployed or disabled.

**My personal salvation has been the relationships I have formed with other advocates.**

Some people from all sides of the health care debate believe that to halt the rise in health care costs, we must deny medically necessary care to some people. They pit health care consumers against each other, saying that the choice is between, say, prenatal care and kidney transplant. They say that we can't afford to provide primary and preventive care and still have high-quality, pioneering care. But the Canadians have shown that it is possible to provide high-quality health care to everyone by eliminating unnecessary administrative costs, excess capacity, and excess profits. We must ration the bureaucracy, not health care.

People with disabilities and chronic conditions can make an important contribution to the health care reform debate. We can point out the gaps in the system. We can tell about the harm to people, their families, and their communities when the system fails to provide health care access. We can point out that discrimination against people with disabilities will not end until we remove the barriers to health care access. Because during our lives everyone may need services ranging from primary and preventive care to chronic and acute care to home care and long-term care, the experiences of people with disabilities can be instructive.

**Joining the Movement**

In 1990, the National Transplant Support Network joined the New York State Health Care Campaign, working with consumer groups, seniors, unions, and progressive health care providers. Together, we fought Medicaid cuts and other health care access battles. Guided by common principles, we proposed universal access to health care through a single-payer system in New York. We are now at work on broadening our organizational base so that it fully reflects the racial and ethnic diversity of our community; fighting for media attention to the consumer.
The Personal and the Political

Medical Attitudes Toward Disability

Lisa Blumberg

A few years ago, in a medical journal article critical of federal regulations designed to guarantee food and basic hospital care for babies with disabilities, a physician remarked that if there was one thing these so-called Baby Doe regulations had done, it was to focus attention on the way "we" treat "the handicapped." Implicit in this off-hand comment was the assumption that the medical establishment treats people who are deemed handicapped differently than "normal" individuals.

This assumption has not escaped the attention of people with disabilities. The woman with spina bifida who as a child never saw her doctor alone, but was always examined in front of a group of professionals and students knows that she was regarded as exempt from ordinary rules of privacy. The man in a wheelchair who calls an ophthalmologist for an appointment, only to be told that her office is inaccessible, is aware that many doctors prefer to see able-bodied patients. The teacher with a congenital joint condition who finds that there is a dearth of medical literature on how people born with disabilities can best manage the disabilities naturally caused by age recognizes that there are certain issues that the medical community does not find very important. The deaf man with a malignancy who realizes too late that the treatment he received was not quite state of the art perceives that his life may have been valued slightly differently from that of a hearing person.

Two events precipitated my decision to focus my disability rights activities on trying to change medical attitudes and practices. One was personal and one was political, but the personal can be political and vice versa.

The Personal

When I was a teenager, my right adductor muscle was surgically severed. The operation was not performed in response to an acute problem I was having—I was in fact

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walking faster and more steadily than I ever had, despite my having cerebral palsy. It came about because I changed doctors when my family moved to Boston, the medical capital of the world.

My previous doctor had been associated with an unpretentious Easter Seal rehabilitation center. He preached the value of exercise and was mainly interested in helping people with permanent disabilities lead rewarding lives.

My new doctor was on the staff of Boston Children’s Hospital and had 2,000 patients. His approach was aggressive. “She will never be normal,” he told my parents, “but what can be done must be done.” He advocated surgery, casts, and crutches for me. When I objected, he mimicked my speech. When my mother asked if I would have problems with the operation, he did not respond, except to say that I had problems already.

My parents agreed to surgery, over my vigorous opposition, because of the reputation of the doctor and of the hospital. They felt that since he was a specialist in cerebral palsy, he was interested in the well-being of people with cerebral palsy. In reality, the doctor, who never fully disclosed to us that his background was entirely in surgery, was a technician who liked to see if he could make limbs that turned in turn out.

Disability disturbed him. He shuddered when describing the physical characteristics of some patients. He felt that risks in the name of fighting handicaps were justified. I was just one more “CP” to him, and he was more successful with some “CPs” than with others.

The end result of my surgery was that my once brisk, if ungracefully, walk was changed into an unbalanced slow-motion stagger. All this did not prevent me from getting a law degree and from finally learning to make my own decisions. Nevertheless, the tenor of my life was changed in fundamental ways because this doctor had not respected my view that my imperfect gait did not crimp my life-style so much that I wanted to buy the lottery ticket that he had to sell.

The Political

For years I thought my experience was unique and reflected just a personal problem I had had with a medical professional. Then, in the late 1970s, I joined the disability rights movement, came in contact with an appreciable number of other people with disabilities, and began to notice a pattern.

I met many people with mobility impairments whose childhood (and education) had evaporated in a blur of invasive procedures, some of which were successful but many of which were not. Few had been in environments where a range of alternatives had been offered to them. Few had felt any rapport with the specialists they had seen. I learned that what had happened to me—and more—tended to come with the territory.

My perceptions were further heightened when a baby boy was born in Indiana in 1982. His doctors told the boy’s parents that the baby had Down’s syndrome and so would always be a “blob” whose life would be traumatic to himself, his family, and society. They recommended that the baby not be given the simple operation that would have allowed him to eat like an ordinary baby. The parents, having no independent knowledge of people with Down’s syndrome, accepted this recommendation. So did the Indiana Supreme Court. The baby, not thought worthy of even a name—a Baby Doe—died of malnutrition and dehydration.

The medical decision that was made about this baby could not have been made about any “normal” child with the same type of digestive problem. Some doctors did
express misgivings, especially since the intervention the child needed was minimal. There was no widespread outcry from the medical community, however, no general sense that the profession should take steps on its own, before the government became involved, to eliminate medical prejudice based on disability. Instead, many in the medical establishment took the stance that concerns about a “defective” child’s potential could justify the withholding of care.

Slowly, people with disabilities began to challenge medical attitudes about infants with physical or mental limitations. Unlike right-to-life groups, we did not assert that everything medically possible had to be done to save every baby, no matter how slim his or her survival prospects. What we argued was simply that a viable child with a functional disability had the right to the same type of health care that he or she would be entitled to if he or she was not disabled and that to refuse him or her that care is discriminatory.

As long as we are seen as less than full-fledged people in medical settings, anatomy will needlessly be destiny.

Since then, my writing about disability rights has centered on medical attitudes toward disability and how these attitudes can influence both the care disabled persons receive and their status in society. For if a person can be defined solely in terms of his or her disability, he or she can be subjected to both overtreatment and undertreatment. He or she can be treated as a medical subject and teaching tool. Ordinary medical problems such as back pain, nicotine addiction, and low sperm count can be ignored. If an individual cannot be cured, he or she can be rejected by doctors and by society as a tragedy.

What is at stake is our ability to live full, long, and healthy lives as individuals with disabilities. As long as we are seen as less than full-fledged people in medical settings, anatomy will needlessly be destiny.


WHAM!

Anne Savarese

Founded in response to the Supreme Court’s Webster decision, WHAM! (Women’s Health Action and Mobilization) is one of several feminist groups formed within the past five years in what the media have called a new wave of women’s activism. WHAM!, which grew out of the direct action committee of the former Reproductive Rights Coalition, has remained a direct action group that advocates for absolute reproductive freedom and quality health care for all women. Because some of WHAM!’s actions are illegal and most use confrontational tactics, some people think of us as one of the more radical women’s groups in New York.

Consciously or not, WHAM! draws on a long tradition of grassroots political activism in planning its activities and deciding where to focus its energy. But WHAM! also tries to supplement the efforts of larger, more established feminist groups—to extend the boundaries of the issues they focus on and the demands they make.

Consciously or not, WHAM! draws on a long tradition of grassroots political activism.

Although WHAM!’s active membership is predominantly under 30, many members have been politically active for years in campus groups, NARAL, NOW, ACT UP, and others. Many join WHAM! because

Anne Savarese is an editor of Frontlines, a WHAM! newsletter.
they're interested in direct action, or because other direct-action groups they belong to don't focus on women's issues. As part of an organization with no paid staff, no officers or board of directors, and a budget funded mainly through benefit parties, t-shirt sales, and donations, all WHAM! members have a say in setting the group's agenda and changing the emphasis as needed. Actions generally develop within small committees devoted to one issue.

Over the past four years, WHAM! has organized or participated in activities large and small, one-time and continuing—from hanging pro-choice banners from the Statue of Liberty to monitoring rape trials, from taking over the offices of pharmaceutical companies to demanding research on women's illnesses to escorting clients past anti-abortion harassers at clinics every Saturday. In recent months, members of WHAM! have advocated for the release of Haitian refugees at Guantanamo Bay; helped defend clinics in Philadelphia during an Operation Rescue campaign; sponsored a "weed walk" with an expert on herbal healing; urged Congress to restore federal funding for abortion; worked with ACT UP and other groups to monitor right-wing, anti-gay activity; and begun researching how potential changes in the national health care system will affect women.

Other people join WHAM! because they have a broader conception of health care and reproductive freedom than they find in more mainstream or single-issue groups. Instead of working for change within the system, they want to challenge the system itself and refuse to compromise on long-term demands. Thinking of reproductive freedom solely as the legal right to abortion, for example, ignores women who have no access to abortion because there is no licensed provider in their county or state, or because they can't afford the procedure, or because their state's parental consent laws are too forbidding an obstacle. It also ignores women who wouldn't become pregnant if they had access to safe, affordable birth control and women who are not able to have children as a result of forced sterilization, court-ordered implantation of a birth-control device, punitive welfare "reform" laws, and other factors. In a similar way, WHAM! works on a variety of issues that threaten women's physical or emotional health and freedom, including racism, sexism, homophobia, and economic discrimination.

Self-Education

Of course, to be effective activists, we need to educate ourselves, and self-education is an important part of WHAM!'s continuing work. Weekly meetings often include teach-ins on such subjects as the politics of breast cancer and the plight of political prisoners in the United States.

As much as some WHAM! members fault more established feminist groups for concentrating on the concerns of white, middle-class women and alienating women of color, tension within WHAM! led many members to develop and participate in a series of workshops on resisting racism. With a broad agenda and limited resources, WHAM! is also recognizing that strong coalitions with other activist groups, large and small, are vital for mutual exchanges of information and support as we work toward related goals.

Members of WHAM! and similar groups generally take a political position to the left of women's organizations that have been around for the last two decades, but they also know that there is room for—in fact a need for—a variety of approaches to women's health care activism. Small grassroots groups like WHAM! attract a young membership interested in actions that bring urgent, immediate concerns to the attention of the general public and the media. Meanwhile, the larger, more powerful organizations work to enact legislation and provide services that address women's needs.

Direct action can be frustrating, because the more we do, the more clearly we see how much needs to be done.

As a member of WHAM! for nearly two years, I've learned that direct action can be exciting and effective. It can also be time-consuming and frustrating, because the more we do, the more clearly we see how much needs to be done. But, as Health/PAC and other long-standing advocacy groups have documented, health care activism works. WHAM! and other relative newcomers to the network of advocates for women's health may differ in strategy and priorities, but we seem to have a common message: Don't wait for someone else to protect your rights. Do something now.
Random Thoughts of a Health Activist

Ellen R. Shaffer

Random thoughts after 20 years as, at various times, a women's self-health educator; survivor of secretarial fusillades; hospital union organizer and negotiator; community advocate for San Francisco's public health services; health benefits consultant; congressional advisor; and, generally, organizer, writer, and thinker about better living through a humane national health care system:

General lessons: (1) You can't control everything. (2) You never know how far you can get until you try. (3) Never underestimate the forces of darkness.

Specific lessons: For a number of reasons, the health care system was a magnet for many in my generation of activists and analysts who first became involved with the broader movements—civil rights, anti-war, women, labor. Put most simply, it was such a mess on every level that it incorporated and exemplified almost every apparent malady of the American social fabric (as we used to refer to it). A quick scan of the public and private systems of paying for and delivering health care revealed institutional sexism, racism, homophobia, and class bias; involved big business, big academia, big money, and the public sector at its best and worst; incorporated antediluvian labor practices; and—talk about a system where the economic structure just got right up and stood smack in the path of a better way of doing the job—well, you couldn't ask for a clearer example.

It was also a system that embodied many of the most humane values of society. It did care for people and heal them, sometimes, and many people of conscience found that the health care sector provided a place to do good things for people and still make a comfortable living. (I did not aspire to that happy state myself until very recently; I would never wittingly put myself in a position to take care of someone who was bleeding unless I knew them personally, thereby precluding some of the more remunerative trades.)

An Arena for Social Change

Perhaps most important, and because of the first two characteristics noted, health care was an arena for social change. The fact that health status is a prism for other measures of well-being has given health care as an issue a role in overall efforts for equality, from environmental justice to occupational safety and health, encompassing race, class, and gender. Part of every community struggle against urban redevelopment and the wholesale dislocation of communities of color included fights to hold on to a local health center or hospital. Mobile health vans became part of the political landscape. Women's groups, having assimilated that knowledge was power, revived an American tradition of people's medicine and set up alternative health centers that educated women and fought to take back control over critical life decisions, including but not limited to the decision to bear children.

The magical cross-class alliance on behalf of national health care reform seems to have jelled during the last two years.

Hospitals were the last bastion of the explicitly hierarchical, industrially organized workplace, and as such were ripe for union organizing drives. As a participant in one such drive, I could have predicted on any given day in San Francisco in the late 1970s that the majority of workers in the kitchen would be Filipino; in the laundry, black; in housekeeping, black and Latino; among nonprofessional patient care workers, multiracial; and, up the very clearly demarcated ladder to clericals and professionals, increasingly white. And I also observed that these consciously drawn divisions dissolved surprisingly easily when workers took the opportunity to come together to address common workplace issues.

Most recently, gay and lesbian groups and other organizations responding to the AIDS epidemic have focused attention on the shortcomings of the health research establishment, the pharmaceutical industry, and the long-term care system, presenting new models for activism in the face of devastating obstacles, and changing the system irreversibly.

Health Reform in the Spotlight

National reform of the health care system—its financing, its delivery, its very definition—has woken in and out among other issues in the public spotlight during the last 25 years, in most ways dependent on the prevailing political winds, at times independently. (It must be true that the phrase "The health care system does not exist in a vacuum" was among the five most repeated in leaflets and political analyses at some time during the 1970s, trailing somewhere behind "It is no accident that...")

During the breathtaking decline of the American standard of living that began in 1981, it became clear that access to health care was a more pressing issue for low-
The author (center), marching in San Francisco on Solidarity Day in 1982, as President of ASCME Local 1650.

income people than quality, but also that in a period of political conservatism and broad repression of political and economic rights, it was difficult to muster the necessary activity to secure that access. While there was progress in some areas—increasing numbers of women and, to a lesser extent, people of color in medical school, the social and legal marginalization of tobacco smoking, alternative birth centers for women of means—struggles to maintain public health services were hard fought.

The magical cross-class alliance on behalf of national health care reform seems to have jelled during the last two years. If, in the new configuration of forces, only the enfranchised will be heard and heeded, then the moment for change is now. The critical margin of voting Americans is sufficiently panicked that they or a loved one could suffer real physical harm—or, equally frighteningly, bankruptcy—due to a very statistically possible loss of health insurance and/or a catastrophic illness. They are willing to agree to an overhaul of the health care system, though how actively they are willing to fight for it remains to be seen.

Simultaneously, but less important to the prospect of getting anything done, the cost of health insurance is becoming a problem for big business (though many have succeeded in shifting much of the cost to workers through wage decreases and to the public through price increases), and an even more binding problem for local, state, and federal budgets. (One health economist has been heard to predict that there will inevitably be national health care reform when the system consumes somewhere between 15 percent and 100 percent of the GDP.)

Reactions to the Public Advocate

In this heady if perhaps short-lived atmosphere, I find that many people react to me in my role as health care staff member to Senator Paul Wellstone, sponsor of the American Health Security Act (S 491)—and hence a public advocate of national legislation that would create a single-payer system—much as I imagine they might respond to a new acquaintance who turns out to be a sex therapist.

Progressives and many liberals find my point of view quite legitimate, of course. What is astonishing is the number of people of, well, other persuasions who routine-ly draw me aside after a public presentation, and tell me how much they agree now and have always agreed with my position, that they hope the bill enjoys some success, and generally press a business card in my hand and ask me to stay in touch. Mostly they let on a little nervously that this is just between them and me, although often enough someone will pipe up right in the middle of a meeting and tell me they disagree with their trade or health care provider association and support the American Health Security Act. Sometimes we talk about how they can bring it up with their boards.

This response I find interesting and encouraging. Another reaction, which goes far beyond discussions of the legislation, is, "How come nobody is talking about—?" prevention, quality, the special needs of poor people, health care instead of medical care, rural health care, reproductive rights, etc. From my vantage point, there's not much that hasn't been talked about regarding health care reform, either somewhere in the White House Health Care Task Force or somewhere in Congress between January of this year and now, if not over the last 20 years. Rather, these remarks reflect two things: First, there are thoughtful people doing important work all over the country who still feel left out of the policy effort to shape a proposal for national health care reform. There need to be better links. Second, the speaker doesn't think his or her subject of interest will be included in the president's proposal for national health care reform. (Mental health and substance abuse benefits have also been on the ropes, but people—meaning people at the White House and people who talk to the White House clearly are talking about them.) I think these concerns are legitimate. It will take some creative activity on the part of those concerned to see to it that these issues are addressed, and addressed soon. These expressions of dismay to those of us who are already convinced is an important first step; such expressions are most productive when coupled with a plan of action to involve others in winning over the unconvinced.

Sufficient Conditions

It is my own view that a single-payer system is a necessary but not sufficient condition for an equitable...
health care system that is responsive to a broad range of provider and consumer needs. We have to change the perverse economic incentives that are sending the health care bill into orbit, and at the same time figuratively casting adrift in space close to 75 million people who can’t get care as a result. We have to redefine and improve public health and our health care system. Both of these objectives will take the rest of our lives, and neither will be achieved without fierce battles. (A Minnesota sage said recently, “If you don’t think changing the system is going to be hard, you don’t understand how much money a trillion dollars is.”)

The question for advocates of a single-payer system is not, as some ask us, whether we’ve sold out yet on a single-payer system, nor, as others would phrase it, when we’re going to get out of the president’s way with this theological belief in a single-payer solution. The real question is how close we can come at this historical moment to reshaping a system that encompasses one-seventh of our economy in the interests of people rather than the special interests. And the answer depends not only on rigorous analysis of the proposals as they develop, but also on vigorous advocacy and mobilization by everyone with access to a journal, a newsletter, a newspaper letters column or editorial board, a membership, a member of Congress.

The question is not whether we’ve sold out yet on a single-payer system, but how close we can come to reshaping the system in the interests of the people.

The system must be universal, affordable, progressively financed, publicly accountable. It must include all employers and employees in one system, and it must cover comprehensive benefits. Not because we like these things, but because that’s the only way to make it work.

There’s plenty of reason to be discouraged. There always is. I have to admit that one of the most thrilling moments of my three years in Washington came during the inauguration festivities, when the Air Force jets flew over the mall precisely on time. A tear came to my eye, though I have no warm feelings for the military, because at that moment I had hopes that things could really work, in the most operational sense of the term. There have been few days like that since. But a great deal hinges on our success in the next two years, before the 1994 elections. If we don’t do well enough by 1994, the alternative is not likely to be another bite at the apple in 1996, but another eight years or more of social decline and chaos.

What We’ve Learned About Containing Health Care Costs

Alan Sager

In the past years of struggle for health and social justice, we’ve learned not to be surprised by how hungry a parasite health care has been in sucking so much money from society without covering everyone. U.S. defense spending was about double spending on health when John F. Kennedy was inaugurated, but health spending will be quadruple defense spending this year or next—an eightfold shift in eight presidential elections.

We’ve learned how well U.S. health care can ignore or absorb pressures for cost control and universal coverage. Grave problems have demanded some responses, but these have typically been limited to hopes and promises—like competition, managed care, and incentives for primary care training. Few interventions have been strategic, and no desired outcomes have been guaranteed. Health care continues to manipulate incentives instead of accepting boundaries and responsibilities.

We’ve learned not to be surprised that most technological change continues to raise costs, that few researchers work with an eye toward downstream affordability, or that few doctors are educated about the efficacy and costs of diagnostic and therapeutic interventions.

Persisting inequality is certainly, in part, a consequence of high spending. But rapid cost increases just as certainly persist partly because of inequality. This is no accident. Perhaps our nation has not worked very aggressively to overcome inequality so that it will serve as a persisting argument for ever-higher spending. (Recall war’s main function in George Orwell’s 1984.)

Inequity makes everyone nervous. Will I get care? Must I not, therefore, continue to pay through the nose to buy some marginal security? By contrast, guarantees of equity, at sensible and robust spending levels, help all citizens feel secure. People know they will be served.

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If we were to commit ourselves to equitable health care for all, we would have to contain costs. We have seen worldwide that no industrial democracy has contained health spending without assuring universal coverage.

Affordable equity requires putting in place concrete guarantees: a ceiling on spending, an effective budget for each hospital, a card assuring coverage in everyone’s pocket, and a family doctor for each person. Then the books are balanced by weeding out the care that does not work or is of marginal value.

The right types of cost controls—along with the right configurations of hospitals and doctors—work to reassure citizens. Constrained budgets discipline and protect everyone. All can see that if money is wasted by giving one patient care that is not needed, others will be denied vital services. People can relax when they perceive that resources are finite and that immortality is not a feasible goal.

**Containing Costs**

It appears that the current reform efforts will lead to a combination of managed competition, global budgeting, possible short-term price controls, higher taxes and business mandates to finance improved coverage, and state initiatives. These won’t do good jobs of containing cost or improving affordability. The result will be much stronger pressures for effective reform in a few years.

Managed competition might contain costs, but probably at the price of disrupting doctor-patient relationships and denying needed services to patients who can afford only basic benefits. Any savings achieved through managed competition could not be recaptured directly to finance care for previously underserved citizens. Also, having finally understood the folly of giving hospitals and doctors financial incentives to provide more care, do we really want to reverse these incentives by relying on HMOs that have sharp financial motivations to withhold care? To do so would make many patients even more mistrustful and demanding.

A competing possibility is that managed competition among machinelike health plans may inadvertently reduce health spending by making services less valuable and caring. Perhaps one reason health care has absorbed so large a share of the nation’s resources is that it has given many people personal attention as personal, familial, and communal bonds have loosened in recent decades.

We’ve learned not to be surprised by how hungry a parasite health care has been.

How can global spending ceilings be made compatible with managed competition? They will prove impossible to administer. We are now unable even to measure spending contemporaneously, so how will we enforce limits? Who would be responsible for containing costs where they inevitably exceed global ceilings? HIPCs? HMOs, PPOs, Hospitals? Doctors? Drug companies? The IRS?

In the absence of mechanisms to capture all health spending, pool it in one reservoir, and thereby make it fungible, higher taxes are required to finance care for uninsured people who are unemployed and to subsidize low-wage employers. But higher taxes, of course, are not popular.

There is no national consensus on reform, and the Clinton team’s approach has done nothing to build one. So state initiatives are required to balance the books since there is no agreement on what will work to contain cost and cover all Americans, states must be given wide latitude.
Steps Toward Universal Coverage

Most likely, any bill Congress will pass over the next year or two will do little to contain cost or ensure affordable universal coverage. But it will do much to sunder the physician-patient relationship, exacerbate patients' fears, doctors' and HMOs' motives, increase medical insecurity and generally elevate the public's mistrust of government.

Starting about 1995, the public should begin to recognize the recently contemplated reforms either will not be implemented or, if passed, are not adequate to limit spending by the millennium, then, should be possible to act responsibly to contain and then roll back costs and cover everyone.

We should start by recognizing that single-payer tax-financed schemes are only one method of raising and spending money; it is a goal in itself. It is probably the simplest and most direct method, but it is not yet available to this nation. Jerry Brown figured that out in ten minutes: why is it taking the rest of us so many years? There is no necessity now for converting $600 billion in non-tax payments (insurance or out-of-pocket spending) into tax-financed health care, and there won't be one soon. There would be too many massive winners and losers. The winners would say thanks and forget us. The losers would remember forever. Abraham Lincoln said that he hated appointing any office seekers to actual jobs because each time he ended up with ten alienated former friends and one grateful.

I believe as strongly as I did 22 years ago that we already spend enough to pay for health care that works for the people who need it.

The most important single step we can take toward more universal coverage and cost containment is to cut off all the financial reservoirs of money that finance health care. (Once collected, it can be spent like all other taxes raised through a simple tax.) How to do that? Through a combination of sustained payment—at real, sustained, and squeezing out-of-pocket payments, and financing of new real spending with public funds. Together, these steps permit greater equity and make cost increases dramatically visible. William Glaser's analyses and descriptions of European financing methods show how retaining multiple payment can be made consistent with the goals we all seek.

My estimate of what we are willing to tolerate rises annually, but reform is inevitable because health care costs rise even faster.

Special populations demand special action. Long-term care for frail or disabled Americans poses enormous problems. It took human society and psychology a few million years to adapt to the realities of prolonged childhood dependence (adaptations we are recklessly forgetting), but we have had only a few decades to begin to reconcile ourselves to the realities of widespread and prolonged adult dependence. We should spur cultural and personal evolution to cope successfully with these facts. More public money is needed, but it won't be available until nervous legislators are assured that public programs won't develop into bottomless pits. In the meantime, people must contribute more voluntary time, partly because the true medium of exchange in long-term care is time, not money. To mobilize more unpaid time, we need new social technologies such as time banking. These will have to be developed incrementally, like the automobile, but quickly, like a space program. Since the lure of loot is lacking, public investment is required to spur experimentation.

Reform is Inevitable

I believe as strongly and recklessly as I did 22 years ago that we already spent enough to pay for the health care that works for the people who need it, and that this should make health care the easiest problem to solve in the United States. When this problem gets bad enough, we will fix it. The only thing that changes: my estimate of what we are willing to tolerate rises annually. But reform is inevitable because health care costs rise even faster. We can advance reform by finding ways to articulate the link among rising costs, insecurity, and inequality.
The Health Care Reform Two-Step
One Forward, Two Back

H. Jack Geiger

Health/PAC began in a watershed year. 1968 saw the assassinations of Martin Luther King and Robert Kennedy; the police riots at the Democratic convention in Chicago; Woodstock; and the cresting of the absurd belief in some quarters that the counterculture, the occasional bomb at a Bank of America branch, and even the growing wave of protest against the Vietnam War, represented a serious “revolutionary” threat to the American political and economic establishment.

It was also a year that saw the continued expansion of community health centers funded by the Office of Economic Opportunity into a national network; an expansion of the National Health Service Corps; the growth of Medicaid to cover significant fractions of populations in poverty; and—despite the political emasculation of community action programs in the so-called War on Poverty—a significant reduction, ultimately to reach almost 50 percent, in the number of children in poverty.

It was the year Richard Nixon was elected President, signaling a resistance to social change and economic redistribution; a resurgent and deliberately fostered racism; and the flowering of a corrupt military-industrial complex and government of the rich, by the rich, and for the rich, which were to continue with only brief interrup-

H. Jack Geiger, a physician and the Arthur Logan Professor of Community Medicine at the City University of New York Medical School, is also President of Physicians for Human Rights, vice-president of the Committee for Health in Southern Africa, and a founding member and past president of Physicians for Social Responsibility.

We have not argued forcefully enough that the right to health care flows inevitably from other rights, political and economic.

Geiger (left) in 1967 with Dr. John W. Hatch, Director of Community Organization at the Delta Health Center (under construction) in Mound Bayou, Mississippi.

The pendulum had begun its swing. Nonetheless, a quarter-century later, there is a significant residue of change in health care for the poor. Community health centers, for example, though battered, have survived—and there are even some, like the Delta Health Center in Mound Bayou, Mississippi, that after years of struggle are truly governed by their communities. The shells—mere skeletons—of Medicaid, the National Health Service Corps, and other programs almost abandoned or seriously perverted in the last decade, remain available for restoration and expansion. There is more mainstream talk than there has ever been of health care reform, but that observation is very different from the statement in Health/PAC’s invitation to make these com-

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Yes, we have a health care system that is collapsing under the accumulating weight of its costs, its profit-driven distortion of priorities, its technological absurdity, and its social inutility. But we also face a political process in which the power of vested interests (read: insurance companies and the AMA) is greater than it has ever been. We confront a social landscape in which there is more poverty, more homelessness, more racist segregation, and more social disintegration than in 1968—and far less national belief in the ability, let alone the responsibility, of government to provide solutions.

The Illusion of Reform

What was best in the upheavals of 1968 was the attempt, implicit in many of the specific reform efforts of the Great Society and the voices of protest but not often spelled out beyond the level of rhetoric—to rewrite the social contract, to establish a new set of understandings about the responsibilities of government, the principle of equity, and the meaning of community (as Ronald Reagan did so spectacularly and viciously in the 1980s). If there was a flaw in the work of some of us in health care reform in the 1960s, it was in health care in the absence of real change in the social contract.

Reports from inside the Health Care Task Force are best described as Managed Contradiction or Mangled Competition.

Nothing in the limp, let’s-cut-a-deal political behavior of the present administration suggests any real interest in such fundamental social change, and reports from inside the Health Care Task Force are best described as Managed Contradiction or Mangled Competition—take your pick. Therefore, I think hopes for real health care reform in the near term are an illusion. We are most likely to get expenditure reductions and a new level of organizational complexity designed to obscure the continuation of a three-tiered system in which the sick poor and minorities, as always, get the least and suffer the most, and insurance conglomerates, hospital corporations and subspecialists fare best.

That grim expectation is emphatically not a reason to quit fighting for real reform. Rather, it is the impetus for trying health care explicitly to a broader social agenda; making it clear that our health care system is at once an illustration of and a metaphor for most of what is wrong with our political economy; and arguing that the way to begin the approach to a new society is to deconstruct and then reconstruct its health care system.

A nurse making a home visit to a diabetic woman in Rosedale, Mississippi, 1967.

The Right to Health Care

We have yet to establish a real national belief in a universal right to comprehensive and effective health care. The national debate instead has been set in terms of who can lobby most effectively for the biggest share in some new system of maldistribution, an argument in which “rationing” is used as a bogeyman rather than as a description of present reality. But this failure is linked to a larger difficulty. We have not argued forcefully enough that the right to health care and a just and equitable health care system flows inevitably from other rights, political and economic, whose realization would require more sweeping economic and social change. To say this is, in effect, yet again to bemoan the absence of an effective American left to forge unity of class across the deepening racial fault line in American society, the single greatest barrier to justice. (It is a measure of the one-step-forward, two-steps-back nature of the past quarter-century that we talk less, these days, of the left; now we are required to defend “liberal.”)

There is another residue of the 1960s, a personal effect that does not have to be explained to the Freedom Riders, the civil rights workers, the contemporaries of people like Fannie Lou Hamer and Amzie Moore and those fortunate enough to work with them. For a while, then, there was a real vision of a better society, expressed in action rather than mere quadrennial campaign slogans, and the direct experience of the potential strength of communities and the empowerment that came with direct involvement. Health/PAC was one manifestation of that vision. Maybe there was naive optimism, but we were right in 1968. We still are. It is the reason for continuing the struggle.
Sifting the ashes of a burned-out left these days, there are no sparks of hope for a progressive turn, save one. Suddenly, the elements of a movement come into focus, a national consensus, urgent and potentially decisive, to reform the finances of health services. The source of this surge is, of course, the unraveling system of medical care. Its deficiencies, its cruelties, its destabilization of the economy, and its ravaging of government budgets are documented daily, thereby fueling a broad coalescence about the imperative for action.

There are no sparks of hope for a progressive turn, save one. Suddenly the elements of a movement come into focus.

The choices have been reduced to two conflicting paths: managed competition, which would complete the corporatization of the health industry, and single-payer or Canadian-style reform, which offers a consumer-friendly model of remarkable promise. Crucial to the politics of this development is the cast of players, winners and losers, bad guys and good guys. The stakes are very high, as the health care industry zooms toward a trillion dollar annual cost in 1994. The health insurance consortium has committed totally to a massive propaganda blitz for the public and blitzkrieg lobbying for the legislators—whatever it takes to protect its hold on a $94 billion annual creaming, which will abruptly come to an end the first day single-payer insurance is implemented. Meanwhile, no independent constituency supporting managed competition, the position of the insurance giants, is anywhere in sight.

The pharmaceutical giants, arguably the highest rollers in this game, position themselves nervously against the perception that their awesome profits all too often are the source of intensified impoverishment of those cursed with both poverty and sickness. The drug companies are also mobilized to protect their high returns as well as they can. Public opinion is running against them as the alarming ubiquity of drug expense-induced penury too alarms the elderly and the middle-class.

The hospital empires, deeply penetrated and defined by the behavior of for-profit chains, are in a "feeding frenzy" of vertical and horizontal consolidation in anticipation of the mammoth health alliances that the Clinton proposal would herald the public into. Predictably they see a post-reform world ever more hospital-based than the present one, already steeped in high-tech and bereft of community-based services. Politically, hospitals are powerful!

The other providers of care, the work force, offer a more complex picture. By and large, the unions of health workers support a single-payer system, though other considerations in their close political alliance with President Clinton cause concern about their tenacity once the administration's proposal is actually revealed. (This oft-postponed event led one cynic to assert that the date for the release of the President's bill has been definitely scheduled; they are now working on the year!)

Professional organizations of nurses and social workers have endorsed progressive plans. Physicians, remarkably, are no longer a solid reactionary bloc. Even the American Medical Association has floated a tepid package, paying obeisance to universal access. This otherwise modest shift does, however, reflect a fresh diversity in the house of medicine. The American College of Physicians—with 80,000 internist members, the second largest grouping of doctors—has an elaborate, generally positive proposal, considerably different from (and superior to) that of the AMA. The fledgling Physicians for a National Health Program has some 6,000 members firmly committed to the complete single-payer package. These fresh winds offer serious possibilities for a vital consumer-provider alliance that could favorably shape the national effort (and the local one as well, since state option seems to be a likely feature in the reform package).

The Surge Toward Single Payer

Most important is the remarkable popular surge toward single-payer reform. A valid movement must have several features to be authentic and to prevail. It must have a goal around which its various constituencies rally. It must be large and steadily growing. It must cross the established political barriers: overcoming traditional regional, gender, racial, and even class differences. All this is happening in the health reform movement at this time. Finally, the coalition must have skilled, courageous, and incorruptible leadership.

While this movement is clearly burgeoning, it has not yet achieved critical dimension and effectiveness. And, certainly, its powerful opponents have great fire power in
their political armory, ready to be detonated. Indeed, the configuration of the fray is already apparent. The vested interests have unmatched media and lobbying strength. The movement, if it is to win, will have to do so district by district, representative by representative and state by state, senator by senator. There is no other, nor any better, strategy.

The hospital empires are in a feeding frenzy of consolidation in anticipation of the mammoth health alliances.

Health insurance reform hardly ushers in the New Jerusalem in health care. It does not confront the array of social determinants of health status—occupational hazards, the ravages of slum housing, race and gender discrimination, to name but a few from a very long list. The McDermott-Conyers American Health Security Act obviously is not the Dellums bill. It also differs from its precursor, the 1991 Conyers bill, in several significant ways. The American Health Security Act’s handlers inexplicably have weakened it in important areas. Some of these defects, fortunately, are corrected in Paul Wellstone’s Senate legislation. Nevertheless, enacting this progressive insurance reform will move us toward the vision of the health-enhancing, consumer-led, socially based system contemplated in the Dellums bill. Simply put, getting our national arms around the destabilizing issues of cost, access, quality, and profiteering allows us to then address the basic challenges to health care and social justice. In the most optimistic script, successes in the domain of health care could significantly assist us through the national morasses in education, the environment, housing, and even the economy itself.

The Clinton alternative—the health care of the entire population controlled by corporate giants seeking maximum profit behind a facade of competition—will not work. But if enacted, it will in the meantime scourch the earth for ten precious years or more, inflicting incalculable further harm on the public as patients, on the economy, and, perhaps not least, it will engender more pessimism about the ability of our troubled society to recognize and address necessity.

Can the growing strength of the popular movement for a single-payer system prevail? In a classical manner, battle lines are being formed for a major struggle. Its outcome will define in large measure the social and political landscape of the United States in the next century. ☑
Are You On the Bus or Off?

Patricia Moccia

The possibility of abandoning the struggle—personal and political—is always with us: blatant and explicit at times, subtle and just below the surface at others, but always there. In every choice, at every decision point, with every alliance, pact, or compromise solution, the political question, after 25 years is still the same as when Ken Kesey first audaciously dared us: Are you on the bus or off?

As we did 25 years ago, we still march and rally and protest for peace and freedom. Today, as we move to act from within the privileged positions of our professions—whether in classrooms, clinics, or communities—we also question authority, as we did then. But this time it is our own.

Audre Lorde was certain and clear in her understanding that "the war against dehumanization is ceaseless." So, therefore, is the need for our attention and vigilance to where and how the battles are fought. For those of us who create our life projects within health care or education, the challenge is to situate these projects as the practice of freedom—to sustain and nurture all aspects of these projects as our praxis.

Do the actions we choose advance the cause of peace, freedom, and social justice? As we decide where to commit the precious resources of our energies, does the decision open the way for others? Does it move against forces of domination? Is it in the interest of transforming society? Will our energies be joined with others of similar visions and similar values? Are we clear about our loyalties to the process of liberation or distracted from the totality by the moment? Are we—moment to moment, decision to decision, and finally at the end of day—on the bus or off?

The Temptation to Give Up

The temptation to give up in the United States is strong. Over the past 25 years, we have often come achingly close to the point of accepting the notion that despite the best efforts and the best intentions of some of the best and the brightest, certain ideals might never be realized in our lifetime. We have lived with the tragic reality that whatever battles we thought we had won in the War on Poverty, babies and children were and are still starving in this country. Whatever strides we thought we had taken in our march against racism, we cannot now ignore the growing incidence and prevalence of this pernicious disease.

Today we also question authority, as we did 25 years ago. But this time it is our own.

 Entire communities of our people are abandoned to drugs and violence, as our nation moves to the destiny of its moment in history described by the poet Maya Angelou as "bloody days and frightful nights when an urban warrior can find no face more despicable than his own, no ammunition more deadly than self-hate and no target more deserving of his true aim than his brother."

But the spirit of freedom and the spirit of our humanity are not entirely quelled. Thankfully, thankfully, this spirit and its energizing potential are not to be denied, as they have not been denied over time.

The Spirit That Sustains and Nurtures

The spirit that sustains us after these years of struggle can be traced by examples from across time and from around the world: The spirit that nurtured and is nurtured by our sister, Assata Shakur who told us from her prison cell here in the United States, "Don't worry. These people

San Francisco, September 1981.

Patricia Moccia, a registered nurse, is the Chief Operating Officer of the National League for Nursing in New York City and was formerly President of Health/PAC.
can lock us up—but they can’t stop freedom.” This is the same spirit that sustained Rigoberta Menchu of Guatemala, the mothers of the disappeared in Argentina, Archbishop Desmond Tutu and Nelson Mandela in South Africa, and Daw Aung San Suu Kyi, the Burmese opposition leader. The spirit that America could not kill in El Salvador, no matter how many they shot and massacred. The spirit of South Africa. The spirit of Malcolm and that of Reverend Dr. King. The spirit of our poets, our musicians, and our artists. Of our women. The spirit of our international trade unionists. For me also, the spirit of the nurses—Dock, Ashley, Wheeler, and the many who today march in their footsteps, who heal and care where healing and caring is most needed.

Over the past 25 years we have often come achingly close to accepting the notion that certain ideals might never be realized in our lifetime.

Each of these people made or make choices in their lives. They challenged the status quo, challenged the positions to which they were relegated by the prevailing order in their country. Those who continue in this glorious tradition question authority, even today, 25 years later, when they are, more usually than not, the authority. They choose certain connections over others, certain relationships over others. The choices these men and women make expose questions of loyalty and alliances. They chose over and over to be on the bus rather than off.

For How Much Longer?

Those on the bus are often asked, How long is the ride? Most of Health/PAC’s first generation boarded the bus with baggage, much of it from the civil rights movement of the early 1960s. Langston Hughes does not make it easy to forget that time, 30 years ago this September, on a “Birmingham Sunday” when

Four little girls  
Who went to Sunday school that day  
And never came back at all  
But left instead  
Their blood upon the wall.

Many of us boarded this bus with that image forever a part of our consciousness. We have spent our days and nights since then like Lady Macbeth. And until those four little girls who left their blood upon that wall have four tiny girls of their own, we’re on the bus. Our struggle is their struggle, until those children have their own children. Until then, we’re on the bus.

Time to Think About Winning

Linda Lowe

Twenty-five years of Health/PAC! It is an honor to join in thanking you with hundreds of other activists who have relied on you as a “gyroscope” staying on the people’s course. The invitation to offer a personal viewpoint on the struggle for health care justice is a welcome chance to reflect on what we’re doing here, what we’ve learned, and why it is time to think about winning.

Ironic as it seems, it may be harder than ever to keep on track now, with the White House friendlier to our ideals than it has been in a long time. For those of us who are accustomed to being the speakers the conference organizers invite to present the iconoclastic view on health care, it may be a little difficult to accept that we have to keep doing it. As a local minister and civil rights leader said recently, “Bill Clinton is a good person and he can do a lot, but he ain’t our savior.”

Anger absorbed will give us ulcers.  
Anger pointed in the right direction can give the ulcers to the profiteers who deserve them.

From here in the steamy South, with its contrasts of filthy-rich hospital corporations, locked-out uninsured people, and long stretches where you can’t find a doctor no matter who you are, it seems to me that those of us who’ve seen the vision of a universal, comprehensive, single-payer system have to press on. When, after 14 years of trying to help low-income people get even shabby treatment, I walked into a Vancouver emergency room where the only pamphlet on the counter offered helpful hints to the patient without a word of harangue about paying, I thought I’d been to the mountaintop! Not to ride

Linda Lowe is a consumer health advocate in Atlanta, former health planner, and a member of Georgians for a Common Sense Health Plan.
the pre-inauguration Health Care-a-Van to Little Rock after that would have been unthinkable.

Reasons to Keep Going

One reason to keep going is that we’ve learned too much about what works and what doesn’t to go back. For another thing, we’re not just a band of renegades anymore, when most Americans from all walks of real life (that is, life outside the Washington Beltway) tell pollsters they would prefer a national health plan along the lines of Canada’s. We may owe it to them, and we certainly owe it to ourselves, to keep the faith. Maybe our best role is as the people’s health policy wonks.

The more managed competitors talk about their plan, the better ours looks.

Managed competition, as Health/PACers know, will ignore decades of experience to keep health care cumbersome, expensive, and segregated based on ability to pay. My own early-1970s’ beginning in health policy was as a staffer in a regional planning agency. Our plan for limiting cost-fueling hospital expansion, entitled “Empty Beds and Needy People,” provoked salacious jokes (one wag suggested we admit patients only to occupied beds), but did not convince politicians to limit growth. Nothing tried before or since to address overall cost or access—HSAs, DRGs, HMOs, PPOs, METs—has had much salutary effect beyond full employment for accountants and actuaries who game the systems. Coming from Arkansas, President Clinton must know the expression, “When you find you’re digging yourself into a hole, the first thing to do is quit digging.”

Some of our colleagues argue we should be “Friends of Bill’s,” agreeing to whatever he proposes, so he’ll have a base of support for reform. It seems to me that what he needs is ballast against pressure from the other side—“tough love,” or whatever you want to call it. Compromise, in my book, is overrated, especially when the deal is lopsided. Besides, the more managed competitors talk about their plan, the better ours looks.

The public needs to see that managed competition just doesn’t square with the facts. Having embarked on reform with assumptions that reflect a health industry bias and a conviction that big insurance companies must be appeased, the Clinton administration has driven into a conceptual cul-de-sac. Showing the way out requires shining a bright light on everything that is said and done to expose the misdirection, while pointing out the guideposts that will get us where we want to go.

Here’s an example. An often-cited reason for hanging on to the notion of employment-based health benefits is the belief that businesses pay for most health care now (“Employers are the major purchasers of health care, so we should build on that system”). The truth is, it isn’t so. In Georgia, employment-based coverage pays for only 22 percent of all personal health services, even giving management credit for the share of the premiums workers pay. The vast majority of health care dollars already come from taxes and out-of-pocket payments. Our local legislators are amazed when they hear this fact and start to ask good questions about what it means for reform.

Another whopper the AMA uses its expensive media campaigns to tell (and we should all say out loud that they do it with money taken from patients), is that a health plan like Canada’s would mean rationing high-technology care such as organ transplants. The fact is, Canadians get
as many or more transplants per hundred thousand people than we do, and they can get them in centers of excellence instead of profit centers. Surveys show

**How many people get a chance in life to contend with adversaries as rich and powerful as ours?**

Americans endure more inconvenience, even for non-financial reasons, than Canadians do, much of it caused by our failure to train enough primary care providers, allocating our dollars to paper pushers instead. We also enjoy less choice of doctors and hospitals. Arming people with such facts keeps them from reflexively discounting their own experience when bombarded with industry hype.

**Using Anger**

We need to use our anger effectively. Anger absorbed will give us ulcers. Anger pointed in the right direction can give the ulcers to profiteers who deserve them if they don't back off their opposition to real reform. It can help to "put the cookies on the bottom shelf where everyone can reach them," as our friend Gordon Bonynym, health advocate from Tennessee, admonishes us to do when framing our arguments. It is one thing to publish a study that will be forgotten before the press release is issued. It is another to use it to mend the media "disconnect" between health policy debate and everyday reportage.

Example: When the evening news shows us another family reduced to panhandling to pay for a loved one's expensive medical treatment, we should insist on talking about the "price," which sounds like you can haggle over it, instead of about the "cost," which sounds like it has been calculated by some exact and unchallengeable process. A recent study of transplants shows that procurement charges for hearts range from $390 to $60,000. How many people have died trying to raise the last third of the high-end sticker price? Suitable organs for a particular patient may be scarce; funds to treat the patient are not, when we spend at least a third more per capita than any other country. Another model of research turned to practical use is the expose by the Metro New York Spring Mobilization for National Health Insurance on the health industry connections of the New York Times' Board of Directors, which has held forth (until now, inexplicably) in a rapture over managed competition.

Maybe we should give the people who have survived our system recognition for "originality and aptness of thought" (to borrow a tagline from the 1950s send-your-entry-with-three-boxtops contests). I've been privileged to know some of the most resourceful. In the mid-80s, I was winding down my training for a community group on their rights under the new hospital anti-dumping law. After waiting patiently through my explanation of how to use the wallet card we'd distributed, this lady carefully smoothed her crisp, tailored dress as she stood up to speak, "The way to keep the hospital from turning you away is to go wearing your pajamas," she said. "They're afraid to send you home if they think you're sick enough to go out in your bed clothes." Maybe we should have memorial services for the ones who didn't make it—like the child whose mother told me matter of factly in her kitchen how he had died in her arms of a burst appendix while she tried to get him past the admissions clerk. Maybe we should have a defense league for the Louisianans who, as a result of a hiking accident, are serving time in prison for their life-saving, but illegal, transfer of an identity and an insurance card.

**How Much Fun!**

National columnist Molly Ivins likes to tell about the time an aged civil libertarian, too ill to receive his own award at a banquet in his honor, was asked by his "second" what to say in the acceptance speech about the struggle he'd lived. Thinking for a minute, the warrior for unpopular causes smiled reflectively and said, "Tell them how much fun it was!" How many people get a chance in life to contend with adversaries as rich and powerful as ours? Surely we can carry on this high-stakes adventure as long as we have to.

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**THIRD ANNUAL U.S.-El Salvador Colloquium on Health**

**NOVEMBER 18 - 20, 1993 EL SALVADOR**

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A cooperative effort of the National Central America Health Rights Network and the University of El Salvador, the U.S.-El Salvador Colloquium on Health gives health providers and others interested in health and development an in-depth, experiential understanding of El Salvador's health care situation. Participants may present during a week of conferences at the University and major public hospitals, direct hands-on training sessions for Salvadorian health workers, or just observe. Fluency in Spanish is not required. The cost of the program, not including airfare, is $745 for NCAHRN members, $795 for non-members.

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New York City’s largest public employees union, congratulates the Health Policy Advisory Center (Health/PAC) on the occasion of its 25th anniversary.

Health/PAC’s advocacy for universally accessible, high quality health care for all New Yorkers has been an important source of support for the more than 30,000 municipal workers DC 37 represents who work in public hospitals and the public health department. The members and supporters of Health/PAC have always been part of the ongoing coalition of unions, community groups and advocacy organizations fighting for decent health care in New York City.

The Health/PAC Bulletin continues to offer perceptive analysis of health care issues from the perspective of both the community and the health care worker.

Best Wishes for 25 more productive years!

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We are proud to count ourselves among Health/PAC's earliest supporters, and look forward to the next 25 years of achievement.

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Please continue to champion the health care cause with integrity, honesty, and purpose as you have in the past. Best of luck from a charter member of the Student Health Organization.

Jack Leary, MD
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We would like to extend a warm thanks to the Health/PAC staff and Board for the ideas, hard work, humanism and for your commitment to health care and social justice that you have embraced over the last 25 years. Bravo.

Center for Visual Arts in the Public Interest
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The progressive forces in the U.S. have benefited from having Health/PAC as a resource. We need a bloom of thousands of Health/PACs around!

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Beyond Crisis
Confronting Health Care in the United States

A Health/PAC Book
Edited by Nancy F. McKenzie, Ph.D.
Foreword by Barbara Ehrenreich

Penguin USA
ISBN 045201108-6

Designed to fill the gap in discussion of the “real deal” with our health care system, Beyond Crisis gives an unflinching and comprehensive analysis of the current state of American health care delivery through a wide-ranging gathering of essays, articles and studies by Health/PAC-ers: activists, economists, providers, and individuals. Beginning with analyses of the devastating policies of the Reagan/Bush years, it treats access, cost, public health and health care (or the lack of it) to the communities whose health is at greatest risk—the poor, homeless individuals, the mentally ill, the unemployed, women, children, people with AIDS, the aged, and others who look in vain for the “safety net.” There are detailed critiques of the continuing “medical-industrial complex,” as well as treatments of health and social justice and the crisis in democracy that health care delivery in the United States represents. Finally, there are full examinations of the array of proposals for reform now on the table, including an in-depth look at the Clinton administration’s promise of reform through “managed competition,” treatments of the single-payer alternative, as well as two sections on community activism and innovation in health care delivery.

“This book illustrates a fine old radical principle: Things are often simpler than they seem....The solution Health/PAC points us toward is conceptually simple and politically daunting: Take the profit out of health care.”
—Barbara Ehrenreich, from the Foreword